Editorial

Welcome! Debate on Alzheimer’s disease and the issues which surround it has been kept alive these last two months at a European level.

At the Swedish Presidency conference on health and dignified ageing we were given a poignant personal testimony by H.M Queen Silvia of Sweden (whose mother had Alzheimer’s disease) on how important attitudes are if we are to ensure people are cared for with dignity. We were reminded of the challenges we face, with an ageing population, in providing high quality services which respect the dignity and wishes of people. As our understanding of these challenges increases, it is clear that huge differences exist between Member States regarding the scope and quality of those services. We heard that some best practices have been identified and as these are communicated it is hoped that such disparities will be reduced.

In this issue, we also bring news of our members’ hard work to make sure World Alzheimer’s Day was commemorated throughout Europe. We are delighted to be able to report on the activities in over 20 European countries.

In September, aside from our Board meeting, we organised our 6th lunch debate in the European Parliament on European Action taken on Alzheimer’s disease. Hosted by the Vice-President of the European Alzheimer’s Alliance, Frieda Brepoels, (MEP, Belgium) the debate was attended by nearly 60 participants, who enjoyed presentations from Commission representatives, Antoni Montserrat and Maria Vidal-Ragout. Many of the audience expressed their delight, myself included, at the speed in which action has been taken at a European level.

In October we launched our brand new website. In addition to integrating the information of our previous three sites (Alzheimer Europe, Dementia in Europe and our conference site) into one, we have included new information on Ethics and Policy developments. We are extremely pleased with this new site and all of us at Alzheimer Europe sincerely hope that you will find it very useful and user-friendly.

We have also been working on our 2009 Yearbook, which will include the results from the Lawnet project and this, as well as our 4th Dementia in Europe magazine, will be published in early December.

Jean Georges
Executive Director
European Alzheimer’s Alliance

29 September 2009: Frieda Brepoels, MEP (Belgium) hosts Alzheimer Europe’s sixth European Parliament lunch debate on “European action on dementia”

Frieda Brepoels, MEP, (Belgium), Vice-Chairperson of the European Alzheimer’s Alliance, hosted Alzheimer Europe’s sixth lunch debate in the European Parliament which was entitled “European Action on Alzheimer’s Disease”. She welcomed her fellow MEPs, who were among the audience of nearly 60 participants. She spoke of her delight that calls for action by policy makers and Alzheimer Europe had been heard and she said that the European Alzheimer’s Alliance had been a prime partner in triggering initiatives.

Antoni Montserrat, Policy Officer for rare diseases, neurological and neurodevelopmental disorders, Directorate of Public Health, European Commission, explained that when there is no specific mandate on a disease, it is necessary for the Commission to use the existing measures. He cited Article 152 of the EC Treaty, as it confers a duty to improve health and prevent disease, as does the second Health Programme. However, it was the combination of the political force arising from the French Presidency, which resulted in two Council recommendations and the message from the European Parliament (in form of Written Declaration 80/2008), which has resulted in action from the Commission.

He also acknowledged the role played by Alzheimer Europe and said that other instruments may also prove useful (the Directive from the European Parliament and Council on the application of patients’ rights and cross-border health border care, the adoption of the 2008 European Pact for Mental Health and the best practices identified in the recent Peer Review in France on Alzheimer’s and other related diseases).

Mr Montserrat concluded by speaking of his delight that the Commission could now continue to work to help address the challenges dementia creates and was grateful that momentum to act had been built by the Council, European Parliament, Commission and NGOs all working in the same direction.

Maria-José Vidal-Ragout, Deputy Head of Unit “Medical & Public Health Research”, Directorate for Health Research, European Commission, then presented the Commission’s plans for joint programming for research into Alzheimer’s disease and other neurodegenerative diseases, which resulted from the Commission’s adoption of a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer’s through joint programming of research activities (COM 2009, 379/3).

To date, there are some 20 countries participating in the Joint Programming initiative. If this initiative is successful, the pooling of information and resources should enable the EU to make very practical advances, for example by developing an assessment of the effectiveness of treatments, early diagnostic tests, large, cross-border population studies, standardised diagnostic criteria and the sharing of knowledge.

Lively discussion ensued and Ms Brepoels closed the lunch debate by saying that the Commission proposals had raised many expectations for people with dementia and that the Parliament would remain vigilant to ensure that the work proceeds. She went on to ask all MEPs to act as mentors of the Alliance by asking their fellow MEPs to support and join the European Alzheimer’s Alliance.
3 September 2009: European Commission publishes EuroCoDe results on their website

The final report of the Alzheimer Europe “European Collaboration on Dementia – EuroCoDe” project was published on the Commission website.

23 September 2009: German Health Ministry announces support to European Dementia Ethics Network

At a meeting of the European Dementia Ethics Network held in Berlin on 23 September 2009, Ulla Schmidt, Federal Minister for Health, announced the support of her ministry to this initiative and the allocation of a grant of EUR 60,000. Minister Schmidt stressed: “In a social Europe, we need common answers and solutions to improve the situation of people with dementia and their carers. The ethical approaches towards people with dementia will be supported through this project and the findings will be a good building block for improving care in Germany and promoting the necessary societal debate on the future of care.”

The members of the network’s steering committee welcomed this support and identified the key priorities for the network in the coming months:

- Establishment of a web presence on the project
- Setting up of an Advisory Board
- Identification of national ethics correspondents
- Carrying out a literature review of the ethical issues linked to the use of assistive technologies
- Organisation of a meeting of the Advisory Board and the working group on assistive technologies in 2009.

The participants of the meeting were: Prof François Blanchard (University of Reims and Coordinator of the French Ethics Network), Christian Berringer (German Ministry of Health), Jean Georges (Alzheimer Europe), Dianne Gove (Project Manager, Alzheimer Europe), Sabine Jansen (German Alzheimer Association), Cornelia Reitberger (German Ministry of Health), Matthias von Schwanenflügel (German Ministry of Health) and Sigurd Sparr (Norwegian Alzheimer Association).

28 September 2009: Alzheimer Europe Board reviews organisation’s activities and plans for 2010

The Alzheimer Europe Board met in Brussels, Belgium on 28 September. The Board discussed:

1) European developments including
   a) The Commission initiatives (joint programming of research on neurodegenerative diseases and European collaboration). The Executive Director, Jean Georges, explained that Alzheimer Europe had been invited by both the European Parliament and the European Economic and Social Committee to submit its views on the Commission initiative;
   b) The successful European project application for core funding from the European Commission, which will enable the previously agreed work plan to be executed.

2) Alzheimer Europe projects including the
   a) Evaluation of the success of the 2009 Alzheimer Europe Conference, which had been held in Brussels in May. It was widely acknowledged that the Conference had been interesting with a great programme and variety of speakers and that the new “conference concept” had now been set.
   b) Alzheimer Europe website which is due to be launched imminently. The new site combines three sites (Alzheimer Europe, Dementia in Europe and the Alzheimer Europe Conference sites), has a stronger corporate identity and hopes to be more user-friendly.
   c) Progress of the Dementia Ethics Network. The first meetings now need to be organised as well as setting up an expert group on new technologies.
   d) Dementia Research Observatory project. A draft document was presented which aims to help lay people to understand what kind of research is being carried out, the advantages and disadvantages of participation and why research is important. Once checked, this will be made available on the new website.
   e) Preparations to include the Lawnet project in the 2009 Dementia in Europe Yearbook.
f) 4th issue of the Dementia in Europe magazine.

g) Current status of the European Alzheimer’s Alliance and the importance of encouraging MEPs to join.

3) Sponsorship. The Board unanimously adopted the sponsorship opportunities document which was presented by the Executive Director.

4) Elections of new Boards in 2010. The Board discussed the process of elections as per Alzheimer Europe’s statutes, rules and regulations and decided that the deadline for receipt of nominees would be 30 August 2010.

5) Rules for membership applications, potential participation in future projects and partnership agreements were also discussed during “any other business”.

The next Board meeting will be in December 2009.

15 October 2009: European Commission adopts decision to provide an operating grant to the activities of Alzheimer Europe in 2010

Alzheimer Europe was informed by the Executive Agency for Health and Consumers that the European Commission had adopted a decision on the projects to be financed under the 2009 call for proposals under the second programme of Community action in the field of health (2008-2013) and that the application of Alzheimer Europe had been evaluated positively and that an operating grant of EUR 250,000 would be awarded to Alzheimer Europe for its activities in 2010 pending a successful negotiation of the contract.

The support of the European Commission would cover the core activities of the organisation, including the continuation of the European Dementia Ethics Network, the 2010 Alzheimer Europe Conference in Luxembourg and the Alzheimer Europe projects on guardianship systems and the involvement of people with dementia.

Other organisations selected for operating grants are BKK Nundersverband GbR, the European Health Management Association, the European Organisation for Rare Diseases, the European Public Health Alliance, Nationaal Instituut vor Gezondheidsbevordering en Ziektepreventie and Stichting Aids Fonds – Soa Aids Nederland.

27 October 2009: Alzheimer Europe launches new website

The new Alzheimer Europe website (www.alzheimer-europe.org) has been launched. With a stronger corporate identity, this comprehensive website combines all Alzheimer Europe’s previous sites (Alzheimer Europe, Dementia in Europe and our conference website) into one. The highly user-friendly site includes new navigational aids (including a more comprehensive search function) to assist users to find appropriate information quickly. Information can be found on:

- Alzheimer Europe – who, what and where we are
- Dementia – the different types of dementia as well as easy to use A to Z list
- Living with dementia – tips for living with dementia from a carer’s or person with dementia’s perspective
- Policy in practice - the work of the European Alzheimer’s Alliance, developments on European action on dementia, Alzheimer Europe’s opinions on different issues as well as country comparisons
- Ethics – discussions on some of the ethical issues which are at the core of caring for, and treating people with dementia. In addition, there is information on the newly-formed Ethics Network
- Our Research – the results from our latest European Collaboration on Dementia project are available as are details of the Dementia Research Observatory which Alzheimer Europe is developing
- Conferences – details of past, future and the forthcoming 20th Alzheimer Europe conference which will be held in Luxembourg
- News – the most up to date information on Alzheimer’s disease and dementia as reported in the news
Alzheimer Europe Networking

On 1 September (London, United Kingdom), Jean attended a meeting of the GSK Health Advisory Board.

On 1 September (Brussels, Belgium), Annette attended the Parliament Magazine Reception for the Swedish Presidency of the European Union.

On 2 September (Brussels, Belgium), Annette attended the meetings of the European Parliament Environment Committee and of the European Parliament Employment and Social Affairs Committee.

On 3 September (Brussels, Belgium), Annette attended the meeting of the European Parliament Industry and Research Committee.

On 7 September (Luxembourg, Luxembourg), Alzheimer organised its internal staff meeting.

On 8 September (Luxembourg, Luxembourg), Jean met with a Luxembourg conference organiser for the preparations of the 2010 AE Conference.

On 9 September (Luxembourg, Luxembourg), Julie and Jean met with Visual Online to discuss the finalisation of the new AE website.

From 14-16 September (York, United Kingdom), Dianne attended the conference “Facing the future” of the Dementia Services Development Centre.

From 15-16 September (Stockholm, Sweden), Jean participated in the EU Presidency Conference on Healthy and Dignified Ageing.

On 22 September (Brussels, Belgium), Annette attended the think tank of the European Federation of Pharmaceutical Industries and Associations (EFPIA).

On 23 September (Berlin, Germany), Sigurd, Dianne and Jean attended a meeting of the steering committee for the European Dementia Ethics Network.

On 24 September (Luxembourg, Luxembourg), Gwladys and Jean met with Luxembourg Congrès for the preparations of the 2010 AE Conference.

On 28 September (Brussels, Belgium), the AE Board met.

On 29 September (Brussels, Belgium), the AE Board had a meeting with the sponsors of the organisation.

On 29 September (Brussels, Belgium), Annette attended the meeting of the European Parliament Industry and Research Committee.

On 29 September (Brussels, Belgium), Alzheimer Europe and the European Alzheimer’s Alliance organised their sixth lunch debate in the European Parliament.

On 30 September (Brussels, Belgium), Pekka and Annette met with Liisa Jaakonsaari, MEP (Finland).

On 30 September (Brussels, Belgium), Annette met with Philippe Lambert, MEP (Belgium) and Rapporteur of the Industry Committee for the Commission’s Joint Programming Initiative.

On 2 October (Luxembourg, Luxembourg), Jean met with Malou Kapgen from the Luxembourg Ministry of Family for an exchange of views on the organisation’s activities and the 2010 AE Conference.

On 6 October (Brussels, Belgium), Annette attended the meeting “Towards a new ageing vision: the role of ICT in business and industry”.

On 7 October (Brussels, Belgium), Annette attended the launch of the AGE publication on how to promote ageing well in the European Union.

On 13 October (Brussels, Belgium), Annette attended a meeting of the “Alliance for MRI”.

On 14 October (Brussels, Belgium), Annette represented Alzheimer Europe at the drafting group meeting of the European Economic and Social Committee on the European Commission Alzheimer’s Initiative.

On 15 October (Brussels, Belgium), Jean met with representatives of Eli Lilly for an exchange of views on the organisation’s activities.

On 29 and 30 October (Lisbon, Portugal), Maurice and Jean participated in a meeting of Alzheimer Portugal on the necessity of a Portuguese Alzheimer’s Plan.
European developments

15-16 September 2009: Swedish Presidency Conference held on health and dignified ageing

Maria Larsson, Swedish Minister for Elderly Care and Public Health opened the Swedish Presidency Conference on health and dignified ageing, which took place in Stockholm. Ms Larsson said that all European healthcare systems face the challenges of how best to promote health, whilst at the same time providing high quality services respecting the dignity and individual wishes of people in poor health but added that “Europe can deal with the challenges of an ageing population”.

Jérôme Vignon, Director, DG Employment, Social Affairs and Equal Opportunities, European Commission, reminded the audience of previous EU Presidencies which had highlighted similar themes, such as the Luxembourg Presidency’s focus on the economic, social and ethical aspects of long-term care, the Slovenian residency Conference on intergenerational solidarity or the French Presidency initiatives in the field of Alzheimer’s disease and related disorders.

Mr Bernd Marin, the Executive Director of the European Centre for Social Welfare Policy and Research, presented the key findings of the “Who cares?” report, giving recognition that the provision of elderly care and long-term care are relatively new areas of interest that are only now emerging and that huge differences exist between Member States as to the scope and quality of services. Mr Marin questioned the sustainability of the allocation of resources regarding residential care and highlighted the important role which informal carers play. Raising the issue of disparities which exist between Member States in regard to workers’ rights, Mr Marin concluded by acknowledging that we can all learn a lot from each other.

Quoting the recently released prevalence figures of the “European Collaboration on Dementia – EuroCoDe” project, Prof. Bengt Winblad, Director of the Alzheimer’s Disease Research Center of the Karolinska Institutet, highlighted the need to include the 7.3 million Europeans living with a form of dementia in our discussions on dignified ageing. He highlighted the recently adopted national guideline for good dementia care in Sweden and concluded by calling for more European investment into dementia research.

A number of parallel workshops were organised during the conference with one focusing specifically on Alzheimer’s disease. This workshop was chaired by Florence Lustman, the coordinator of the French Alzheimer’s Plan who reminded the audience that the true number of people affected by dementia in the European Union was 19 million, when one included the carers and family members of people with dementia. Nick Fahy, Head of Unit for Health Information at the European Commission, presented the four pillars of future European action on dementia. Sylvie Legrain, Professor of geriatrics at Hôpital Bretonneau, provided a report on the peer-review organised by the European Commission and hosted by France on the subject of how best to deal with behavioural problems at home. Jean Georges, Executive Director of Alzheimer Europe, outlined some of the findings of Alzheimer Europe’s Lawnet and Eurocode projects which had highlighted differences between European countries in social support systems or the legal protection of people with dementia and had identified some existing best practices in this field.

H.M. Queen Silvia of Sweden, whose mother had Alzheimer’s disease, emphasized that dignity should not be just about treatment, but also about attitudes. She gave a highly personal testimony, explaining how her mother had turned to her complaining that “I forgot my life”.

Maria Larsson highlighted that as elderly care already represents over 50% of healthcare budgets, all European societies face the challenge of how to expand this sector whilst improving the quality of care at the same time. Her aspiration was to “put elderly issues permanently on the EU agenda”.

Further challenges and opportunities were identified by the other participants in the round table. Mr Marian Hosek, Deputy Minister of Labour and Social Affairs of the Czech Republic, focused on the growth of the labour market in the social care field with an increasing demand for skilled staff. Ms Melinda Medgyaszai, Hungarian Secretary of State for Health, emphasised the lack of communication...
between health and social sectors and called for a social care knowledge to be included in medical education. Ms Lenia Samuel, Deputy Director-General of DG Employment, social affairs and equal opportunities of the European Commission, described the care sector as an important growth factor for employment with 82% of new jobs in this sector having been taken by women and jobs being less dependent on the fluctuations of the economy. Ms Pilar Rodríguez, Director General of the Institute for the Elderly and Social Services (IMSERSO), promised a continuation of a focus on elderly issues at a European level during the forthcoming Spanish EU Presidency. Mr Fabrice Heyriès, Director General at the French Ministry of Health, presented some of the key innovations introduced through the French Alzheimer’s Plan.

Maria Larsson concluded the conference with the statement that “there is a need for strengthened collaboration.”

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

21 September 2009: Council of Europe’s Human Rights Commissioner calls for respect of fundamental rights of people with mental disabilities

Thomas Hammarberg, the Human Rights Commissioner of the Council of Europe, chose the fundamental rights of people with human disabilities as the subject of his Viewpoint (a fortnightly publication in English, French and Russian) released on 21 September.

In his article, the Commissioner takes a critical look at national laws on legal capacity and guardianship and regrets that some countries still allow for total deprivation of one’s capacity and the possibility of guardians to take all decisions without the need to consult or involve the person under guardianship.

Recalling the UN Convention on the Rights of Persons with Disabilities which asks countries to recognise “that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”, the Commissioner calls for the development of supported decision-making by providing a network of support and advice for an adult to make decisions.

According to him, a number of European countries have failed to fully implement these UN recommendations in that “there has been a tendency to declare almost routinely people with mental health and intellectual disabilities legally incapable and put them under legal guardianship”. Similarly, the right to vote or to be elected is withdrawn from people in some European countries when declared legally incapable, a practice which the Commissioner disapproves of.

21 September 2009: EU Commissioner for Health releases video message for World Alzheimer’s Day

For the occasion of World Alzheimer’s Day, Androulla Vassiliou, the EU Commissioner for Health, recorded a special video message.

In her message, she highlights the growing numbers of people with Alzheimer’s disease and other forms of dementia in the European Union. Currently, there are 7.3 million Europeans living with a form of dementia, but the true number of people affected by the disease is considerably higher, as the disease equally impacts on family members and carers.

The Commissioner underlined the EU’s determination to tackle Alzheimer’s disease and other dementias and reminded her audience of the recent adoption by the Commission of an Initiative in this field whereby collaboration between Member States would be strengthened through:

- the promotion of preventive measures and the development of tools for early diagnosis,
- the development of a common research agenda into the causes and treatment of dementia,
- the exchange of best practices for the care of people with Alzheimer’s disease and other dementias and
- a common reflection on how best to promote the rights of people with dementia.
9 October 2009: European Commission launches public consultation on the functioning of the Clinical Trials Directive

The assessment of the application of Directive 2001/20EC on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practices in the conduct of clinical trials on medicinal products for human use has been launched by the European Commission (the ‘Clinical Trials Directive’).

In particular, the assessment will consider various options for further improving the functioning of the Clinical Trials Directive with a view to remedy shortcomings and unintended negative consequences while taking the global dimension of clinical trials into account.

Deadline: 8 January 2010.

20 October 2009: European Commission presents its Communication on Solidarity in Health: Reducing Health Inequalities in the EU

To address the health inequalities between the regions and populations of the EU, the European Commission (DG Health and DG Employment, Social Affairs and Equal Opportunities) has announced a series of actions to help Member States and stakeholders make faster improvements in order to catch up.

The EU actions will include: helping the national authorities, regions and other bodies to address health inequalities; regular statistics and reporting on the size of the inequalities in the EU and successful strategies to reduce them; impact assessment of the EU policies on health inequalities; better information on possible EU funding to help national authorities and other bodies address the inequalities.

The beneficiaries will be the social groups most in need.

The EU’s role will facilitate the collection of data and the exchange of best practices. The Member States have committed to use the Open Method of Coordination on Social Protection and Social Inclusion to reduce health inequalities in access to healthcare and health outcomes.

10 September 2009: New mental health bill announced in Northern Ireland

Following on from the public consultation on “A legislative framework for mental capacity and mental health legislation in Northern Ireland” which was carried out earlier this year, Michael Mc Gimpsey, the Minister for Health, has announced that the laws regarding these two areas will be combined. He hopes that this “single piece of legislation will bring innovative long-term legislative change to Northern Ireland and will make a real difference to people’s lives.”

The finalised legislation is expected to be ready for introduction to the Assembly not before 2011.

Members’ News

7 September 2009: Alzheimer Society of Finland welcomes Susann Mörck as new Executive Director

Susann Mörck (Master of Economics) started her work as the Executive Director of the Alzheimer Society of Finland (Muistiliitto ry) on 7 September 2009 and replaced the outgoing Executive Director, Varpu Kettunen.

Previous to her current position, Susann worked as the Executive Director of the Neurological Foundation from 2002 to 2007. She has also been the initiator of the Brain Foundation in Finland and worked as a Financial and Development Consultant.
7 September 2009: Alzheimer’s Society is looking for volunteers for its clinical trial into the benefits of mind training

The Alzheimer’s Society is working with the BBC and researchers at King’s College to carry out the first large-scale clinical trial into the benefits of brain training and the Society hopes to establish whether brain training might be developed as a preventative treatment against the onset of dementia.

The trial was launched by the BBC on 7 September and is open to anyone over the age of 18. Nevertheless, the Society is particularly interested in recruiting people over 60, as it is hoped that these people will answer important questions about whether brain training can help improve or stabilise brain function in older adults.

8 October 2009: Charter of rights of people with dementia and their carers launched in Scotland

Scotland’s first charter of rights for people with dementia and their carers was launched on 8 October 2009 by Irene Oldfather, Member of the Scottish Parliament and Convenor of the Cross-Party Group on Alzheimer’s. Support from other MSPs and the public was

At the launch, Irene Oldfather stressed that “the publication of a Charter of rights for people with dementia and their carers is long overdue. In recent years, numerous reports have demonstrated that levels of care for people with dementia are simply not at a high enough standard. This Charter should be used both as an empowering tool for service users, and also serve as a framework for care homes, hospitals and other organisations when developing services for people with dementia.” At the same time, she asked other MSPs and the public to register their support for the Charter at the Alzheimer Scotland Charter site: http://www.dementiarights.org

The Charter reflects the standards already set by the United Nations and other international instruments by recognising:

- the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support
- that persons with disabilities must be guaranteed the fullest possible realisation of their human rights including an opportunity to participate in and contribute to society, and where necessary, with the highest attainable standard of care
- that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person.

15 October 2009: Alzheimer’s Society welcomes Angela Rippon and John Hughes as new Ambassadors

Business man John Hughes and broadcaster and journalist Angela Rippon have been named new ambassadors for the Alzheimer’s Society.

John Hughes has more than 30 years of global business experience, which includes holding senior executive positions at Thales Group, Lucent Technologies and Hewlett-Packard. As a new ambassador, John Hughes hopes to use his business experience to help fund raise for the society.

Angela Rippon has personal experience of the condition, with her mother Edna being diagnosed with dementia in 2004. She will be supporting the society in improving hospital care. On her appointment, she said: “Dementia is the curse of the 21st century. We are an ageing population and this is going to touch us all. Alzheimer’s Society campaigning and support makes a huge difference to those affected by this cruel condition.”

26 October 2009: easyJet passengers raise over £420,000 for Alzheimer’s Society

The Alzheimer’s Society announced that easyJet and its passengers have raised over £420,000 to help the charity fight dementia. The funds were raised from inflight collection of passengers’ left over currency between July and September 2009.

Neil Hunt, Chief Executive of the Alzheimer’s Society said: “I am delighted that easyJet and their passengers have raised over £420,000. This will help people live well with dementia today and fund research to find a cure for tomorrow.”

29-30 October 2009: Portuguese MPs pledge support to development of Portuguese Alzheimer’s Plan

Alzheimer Portugal organised a conference entitled “Alzheimer Disease and other Forms of Dementia: Which politics?” at the Fundação Calouste Gulbenkian.

The conference addressed the need for a comprehensive "National Dementia Plan", discussing some existing National Dementia Plans already in the European Community. Speakers included Maurice O’Connell and Jean Georges from Alzheimer Europe, as well as
Charles Scerri from the Malta Dementia Society and Andrew Chidgey from the UK Alzheimer’s Society.

On the second day of the conference, Portuguese MPs from all political parties (Maria Antónia Almeida Santos, Teresa Caeiro, Fernanda Negrão, João Semedo and Bernardino Soares), discussed the need for Portuguese action on dementia and jointly called for the setting up of a working group in the Portuguese Parliament. This working group would be charged to make recommendations on how to improve research, prevention, early diagnosis, treatment as well as the access to care services and the quality of life of people with Alzheimer’s disease and their carers.

**World Alzheimer’s Day**

On 21 September each year, people with dementia, their carers and Alzheimer associations all over the world come together to raise awareness amongst all about the realities and effects of dementia on individuals, families and societies. Here we report on events around Europe.

**Bulgaria: 21 September 2009: Alzheimer Bulgaria raises awareness with a media campaign**

To raise awareness of Alzheimer’s disease, Alzheimer Bulgaria organised a press conference in Sofia on World Alzheimer’s Day as well as organised a week-long media campaign which resulted in debates about Alzheimer’s disease on two national television stations and two national radio stations. For the first time ever, family members participated in these broadcasts and a spokesperson from Alzheimer Bulgaria said, "I'm so happy that family members participated. That's a real success. Since 2004 we have worked very hard for the carers to be heard.” In addition to the broadcasts, Alzheimer Bulgaria organised for articles and adverts to be placed in daily newspapers and magazines and was covered on 28 internet sites.

**Czech Republic: 21 September – 1 October 2009: The Czech Alzheimer Society carries out events to mark World Alzheimer’s Day**

The Czech Alzheimer Society seized the opportunity on World Alzheimer’s Day to highlight the importance of early diagnosis. In a press release they referred to their earlier project “Days of memory” which focused on early diagnosis and has now offered free memory tests to some 2000 people since 2008, Dr Holmerová, President of the Czech Alzheimer Society, said “the project showed that monitoring memory is important… Correct diagnosis, when you identify the causes of the problem with memory, is a necessary step to then initiate treatment, which at that stage can yield positive results.”

In addition to the press release, the Society commenced an international programme to educate children about ageing and Alzheimer’s disease. The programme includes a book “The Magic Tape Recorder” which was written by Joyce Simard (who has worked in the field of dementia for over 35 years) and illustrated by the Czech artist, Inka Delevová, for elementary school children and on 1 October, the Society launched the Czech version of the book at the American Embassy.

Iva Holmerova said "The Magic Tape Recorder is a textbook that teaches children about Alzheimer’s disease and other diseases causing dementia. It helps them not to be frightened of someone with a memory problem but how they can be “helpers”. So, it is not just another children’s book; it differs from existing books for children that tell stories of people (especially grandparents) who suffer from dementia. This book teaches and familiarises children with this problem and explains how they can continue to have a happy relationship with grandparents in spite of their memory loss. The “Magic Tape Recorder” simply explains with examples how dementia develops, what the symptoms are (that is the main contribution), how even a small child can help people suffering from dementia, and how should they behave with them.”
Croatia: 21 September 2009: The Croatian Alzheimer association holds several events to mark World Alzheimer’s Day

As in previous years, Alzheimer Disease Societies Croatia (ADSC) had a stand on the very popular square in the centre of Zagreb on World Alzheimer’s Day from 10am until 7pm. Volunteers raised awareness of Alzheimer’s disease by handing out brochures, leaflets and information about the disease. They also sold roses under the motto “Autumn rose for the autumn of life”, the proceeds of which went to ADSC. This year, ADSC also encouraged people to sign the petition to support a Global Charter for Alzheimer’s disease (from ADI but translated into Croatian by ADSC). The organisation was successful in securing 221 signatures, including those of local celebrities such as Milan Bandic (Major of Zagreb), Zdravko Mamic (President of football club Dinamo from Zagreb) and Ljubo Jurcic (local politician).

ADSC also held a press conference at their office, which people from newspapers and TV stations attended. This resulted in coverage of Alzheimer’s disease on some TV and radio stations as well as several articles being written.

Cyprus: 21–27 September 2009: The Pancyprian Alzheimer’s Association holds various events to raise awareness of Alzheimer’s disease

The Pancyprian Alzheimer’s Association held awareness-raising events on World Alzheimer’s Day in the large cities in Cyprus where balloons were released and free flyers and caps were distributed. These events enjoyed the support of the mayor of Nicosia, Ms Helen Mavrou, as well as a representative of the Minister of Health, Dr. Yiannis Kalakoutas.

On 27 September the Minister of Health, Dr. Christos Patsalides, inaugurated the second Alzheimer Day Care Centre (which was set up by the Pancyprian Alzheimer’s Association) in a village called Lythrodontas. A recently-elected Member of the European Parliament, Ms Antigoni Papadopoulou, attended as well as another two Cypriot MPs from the Health Committee (Ms Michaouli and Mrs Kyriakidou). All events were supported by the Ministry of Health and the Nicosia Rotarian clubs.

Finally, the Association had a gala dinner organised under the auspices of the Minister of Health.


The Estonian Alzheimer Association organised various events on World Alzheimer’s Day. Information leaflets were handed out, and Mark Braschinsky, one of their sponsors, released balloons to raise awareness of the disease. Every balloon had the account number of the Estonian’s Alzheimer organisation on it and the organisation asked for help to allow people with dementia to organise their activities.

A press conference was held by political leaders, a psychiatrist and a neurologist in the newest church in Tallinn. Also, the Estonian association organised a boat trip on the EMAJÖGI “mother river” which had over 100 participants from the Estonian university city of Tartu.

The association also organised chess games, with Estonia’s best lady chess player participating. This was to show participants how to increase brain reserve.


Almost all of the Finnish Alzheimer Association’s (Muistiliitto) 43 regional Alzheimer associations took part in the World Alzheimer’s Days activities. Regional associations arranged lectures, seminars, Memory Walks and Memory Cafes. Their active volunteers distributed information about dementia, prevention, brains and memory. Media coverage was gained especially in the regional radio programs and in the internet.

France: 21 September 2009: Clotilde Courau, actress, presents the film “Words of love” on World Alzheimer’s Day

The fictional film, “Words of love” was presented at the L'Arlequin cinema, Paris, by actress Clotilde Courau on World Alzheimer’s Day. The film tells the story of Eric (Michel Vuillermoz), who has Alzheimer’s disease but...
hides this fact from Alice (Clotilde Courau). Organised by France Alzheimer, the presentation was supported by the attendance of many personalities. A discussion was also organised.


The German Alzheimer Association (Deutsche Alzheimer Gesellschaft e.V.) held a press conference to commemorate World Alzheimer’s Day. During this event, the Association took the opportunity to talk of the launch, with the support of the Federal Ministry for Senior Citizens, Women and Youth, of several projects that aim to deal with the problems of living alone with dementia and also to raise awareness of dementia in schools. Heike von Lützau-Hohlbein, Chairperson of the Association and Honorary Treasurer of Alzheimer Europe, said, "these projects are very important to us. In addition to good medical and nursing care, we need to encourage citizens of all ages to reach out to people with dementia and their families and support them so that this great task is not insurmountable."

Furthermore, some of the regional organisations (e.g. In Soest and Ingolstadt) are collecting wishes for people with dementia and their carers. These wishes will be collected until the end of November then presented to the public on 2 December 2009 (the 20th anniversary of the organisation). Wishes include, for example, “more respect”, “better understanding”, “more financial support for caregivers” and “more personnel in nursing homes.” For World Alzheimer’s Day, the regional organisation in Soest displayed all of the wishes collected to date and posted them on a tree for all to see.

**Greece: 21 September 2009: A Memory Walk is organised by the Greek Association of Alzheimer’s disease and related disorders**

For the celebration of World Alzheimer’s Day 2009, the Greek Association of Alzheimer Disease and Related Disorders organised for the first time a “Memory Walk”. The walk took place on Sunday, 20 September 2009, at 11.00 a.m. The walk began in the waterfront of the city and ended in the 4th Coastal Park. The walk was accompanied by the band of the Municipality of Thessaloniki and many citizens.

All participants received T-shirts and hats with the logo of the event “Step by Step together”. Furthermore, magazines, leaflets, snacks and refreshments along with gifts from lottery tickets were given to every participant.

The event and the speeches that were made by the Chairman of the Pan-Hellenic Federation of Alzheimer’s Disease, Ms Magda Tsolaki, and local authorities were covered by television channels.

The Association’s aim and objective was to encourage the citizens of Thessaloniki to participate in the walk in order to honour people that have been affected by Alzheimer's disease and their caregivers and convey the message that no one confronts the disease alone.

In the meantime, at many cities all over Greece, like Chalkida, Edessa, Volos, Mitilini, Chios, Rhodes, Athens and Iraklion, Ms. Tsolaki made speeches in view of the celebration of World Alzheimer’s Day.

**Hungary: 21 September 2009: A “Memory Bridge” event organised by the Hungarian Alzheimer Society**

The Hungarian Academy of Sciences was the venue of the press conference held by the Hungarian Alzheimer Society on World Alzheimer’s Day. In conjunction with the press conference a “Live Chain” event, entitled “Memory Bridge” was also held on the near-by Chain Bridge in Budapest, with wide media coverage. The Memory Bridge awareness campaign symbolised the Association’s wish to connect people with Alzheimer’s disease with their family members and friends, locally and around the world.

The hundreds of children, who formed the Live-Chain, demonstrated the Association’s efforts to join the generations and avoid the isolation of people with dementia. As the evening set in, the flood-lights on Chain Bridge were switched off (for an hour) to symbolise the fading of memory, associated with the illness. The Live-Chain was held with two main participating partners, the Red Cross and the Rotaract Club Budapest-City.
The 11th Alzheimer Conference was held this year in Szeged (Hungary) on 21-22 September, to promote research on the disease and other dementias. The Conference was joined and reinforced by the five-member professional team of the Association of Hungarian Neurologists/Alzheimer section and the Hungarian Alzheimer Society was also invited to join its management.

**Italy: 21 September 2009: Federazione Alzheimer Italia helps to organise a conference (Biography, not only biology) on Alzheimer’s disease**

On the occasion of the XVI World Alzheimer’s Day the Italian Alzheimer Federation and the Golgi Cenci Foundation organised the conference “Biography, not only biology” in Milan. Enjoying the patronage of the Ministry of Labour, of Health and of Social Policy and of the Lombard section of the Italian Society of Gerontology and Geriatrics this event also had the support of the councillorship of Health of the municipality of Milan, the province of Milan and the Lombard region.

Participants included Ferruccio Fazio, Deputy Minister of Health; Antonio Guaita, gerontologist and director of the Golgi Cenci Foundation; Gabriella Salvini Porro, President of Federazione Alzheimer Italia; Peter J. Whitehouse, Professor of neurology of the Case Western Reserve University of Cleveland; Gianluigi Forloni, Head of the department of Neuroscience of the Institute of Research Pharmacology Mario Negri; Alberto Spagnoli, Psychotherapist and director of the department of Psycho-geriatrics at the Center of S.Ambrogio Fatebenefratelli of Cernusco sul Naviglio, and Giovanni B. Frisoni, Neurologist and scientific vice-director at l’IRCCS Fatebenefratelli di Brescia.

Numerous issues came under discussion: the necessity of studies across the board that highlight the risk factors and the protection of the loss of cognitive functions; the inadequacy of medical models based purely on reductionist genetic biology and the necessity of integrating them with the personal biographies of the victims; the importance of research on biological markers with which to monitor patients in pre-clinical phases; the communication with the person with dementia to bring out his subjectivity and the importance of the policy of inclusion that maintains a link between the victim, his or her family and the community in which they belong; the new ethical challenges linked to the communication of the diagnosis; the necessity of a strong collaboration between the family and health professionals in order to create a care philosophy based on the victim considering him or her a person with a history, an identity and a personality.

**Luxembourg: 19 September 2009: Memory Walk held in Luxembourg**

On 19 September 2009, the "Association Luxembourg Alzheimer" organised its 8th Memory Walk, in Esch-sur-Alzette which is in the south of Luxembourg.

The day’s events kicked off at 8.00 a.m. and included information-stands, animation for children, musical entertainment from the “Harmonie municipale d’Esch-sur-Alzette”, as well as lots of delicious food and drink. The “Memory Walk” started at 2.00 p.m. with this year’s theme being “an architectural walk through Esch-sur-Alzette”.

**Malta: 27 September 2009: Malta celebrates World Alzheimer’s Day with a Memory Walk**

The World Alzheimer’s Day in Malta was celebrated with a Memory Walk on Saturday, 27 October.

During the activity, which was organised in Valletta, the capital city of Malta, information was presented to those individuals that were interested in increasing their knowledge on dementia and related disorders. The activity was publicised in national media channels and received substantial coverage on daily news programmes and newspapers. Members of the Malta Dementia Society, together with other interested parties, attended the event. The Hon. Secretary for the Department of Health, Elderly and Community Care, Mr Mario Galea, attended the activity and gave a short speech on the importance of having dementia at the top of the local health agenda and of having a strategy which should enhance high-quality care in Malta.

**Netherlands: 21 September 2009: Memory walks held throughout the Netherlands on World Alzheimer’s Day**

Since 1989, Alzheimer Nederland have organised Memory Walks, to draw attention to dementia, each year around World Alzheimer’s Day and this year was no exception. This year, for the first time, a Memory Walk was held in
Leek (near the city of Groningen). It was a great success, with 230 walkers, including 23 people with electrical scooters, participating. The walks varied from 2.5 to 15km. In addition to the walk, a fair, music and quiz were also organised.

Norway: 21 September 2009: Norwegian Alzheimer’s Associations host lectures to raise awareness of dementia and give awards to people for their work in the field of dementia on World Alzheimer’s Day

The local Alzheimer’s Association in Sandnes (west of Norway) arranged an open meeting where Professor Knut Engedal discussed; “Dementia, what is dementia, what treatment is available, and what will the future bring?” There were nearly 100 participants, ranging from employers of the council’s health and social services, health care from home-based services and dementia and carers of persons with dementia. “This was fantastic - and so easy to recognise ourselves,” were comments from the participants afterwards.

The Dementia Prize in Rogaland County was awarded at the same meeting. This year, it was given to Dr Per T Haaland, who was awarded for his work by Carerschool, which he has contributed to from the opening in 1996 – and still is. He provides information on symptoms, development and treatment of dementia in a professional and educational way. Dr Haaland is an important representative of the general practitioner service, which is often the first contact next of kin, carers and persons with dementia have with the health services.

In Arendal (south of Norway) a meeting was held in Philadelphia’s premises. The lecturer was Liv Wergeland Sørbye PhD from the Diakonhjemmet College. Her topic for the evening was “No good life without food and drink for persons with dementia.” In addition, Anne Gry Bleie from a local care home told some stories about the daily life with patients with dementia.

The Dementia prize in Hedmark County (central Norway) was awarded to the singing teacher Ingrid Sløgedal, who has sung and played with people with dementia, next of kin, carers and health professionals for several years. Ingrid believes that singing helps persons with dementia to recall memories and words, even if the language and memory are impaired. The background for this recognition is her commitment to her work. She is an outstanding supporter and a good guide for families with people with dementia and employees at dementia wards. Her project “Music in the oblivion forests,” marked a new direction in the local therapy for people with dementia. She is constantly searching for new ways to reach her main objective; to improve the lives of persons with dementia through songs and music.


The Polish Alzheimer Association organised a picnic on 18 September for people with dementia, their relatives, members of their association together with local government politicians. This is a regular event, which is organised each year in the garden of a nursing home in Warsaw, which will house the first Alzheimer’s Centre with a day care centre (building has just commenced). The annual picnic is held to mark World Alzheimer’s Day, raise awareness and to give people with dementia and their carers an opportunity to relax, have fun, sing, dance and meet friends. A church mass was also held in memory of the people with dementia and their relatives.

On 21 September the Polish Alzheimer Association held an open day at their office. Many people either called or attended in person and the Association was able to distribute a lot of information, including their publications. It was also an opportunity to promote the Polish Association and, most importantly, offer help to those in need.

Portugal: 20-21 September 2009: Alzheimer Portugal mark World Alzheimer’s Day by organising “A Walk To Not Forget” and by launching their new website

On 20 September, the North Branch team of Alzheimer Portugal organized a walk which was held by the seaside, for people with Alzheimer’s disease, carers and the general public, gathering more than one hundred participants. This activity was entitled “A Walk To Not Forget” and was very successful. A fitness session was also conducted making
everyone feel involved and happy on a sunny morning.

On 21 September, Alzheimer Portugal launched its new website as well as presented new communications materials: an institutional brochure and an information leaflet about Alzheimer’s disease and the services and aims of the Association.

The website has been reformulated with a new design and contents, increased functionality, offering a better browsing experience, special pages for its branches among other functionalities.

All these improvements were made to unify the institutional image of Alzheimer Portugal in both the Headquarter and Branches, providing better information to people with dementia, carers, Association Members, professionals and all those who have an interest in Alzheimer’s disease.

Slovenia: September 2009: The Slovenian Alzheimer’s association organise talk on pet therapy

In honour of the 2009 World Alzheimer’s Day, the Slovenian Association of the Western Styrian Region for the Help at Dementia “Forget-me-not” Šentjur organised a public lecture about pets which offer emotional, cognitive, and social benefits for elder people. The picture shows, Lun, a certified therapy dog, which loves bringing light to the lives of people with Alzheimer's disease and other dementias.

Spain: 16 September 2009: The Spanish Alzheimer association (CEAFA) presents award for dementia work and highlight World Alzheimer’s Day

The Spanish Alzheimer association, La Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), organised their third annual award ceremony which gives recognition to different work in the field of dementia. Awards were given to (i) Mr Manuel Sarasa whose work has been devoted for many years to finding bio-markers for early diagnosis (ii) the newspaper “Entre mayores hablamos de ti” which has focused on Alzheimer’s disease (iii) The European Parliament for its adoption of Written Declaration 80/2008 on Alzheimer’s disease and to the organisation “ConFEAFA” in Andalucía.

Switzerland: 21 September 2009: Alzheimer Switzerland holds award ceremonies and raises awareness of Alzheimer’s disease

World Alzheimer’s Day was highlighted by Association Alzheimer Suisse (Switzerland) by holding several events. Award ceremonies were organised by some of its regional associations, to distribute prizes in recognition of a specific person or group of people who have improved the quality of life of people with dementia and/or their carers. The Association sent out communications to various media organisations who reported on Alzheimer’s disease. Last year’s campaign to collect signatures in order to further raise awareness of the disease and make it a Swiss public health priority was continued and can be seen on the Swiss Association’s website. Finally parliamentarians passed motions to the government asking for a monitoring of dementia politics and the development of a common strategy between the confederation and the cantons.

UK: 21 September 2009: Memory walks held across the UK to celebrate World Alzheimer’s Day

Memory Walk is the Alzheimer's Society's flagship fundraiser with hundreds of walks taking place across England, Wales and Northern Ireland in 2009. The fundraiser started out in 2002, raising just £15,000, and has grown enormously since then with last year's Memory Walk raising over £420,000. This year has been even bigger and better and the Alzheimer's Society hopes to smash last year’s total.

Walkers turned out in force, thanks in part to a number of partnerships with high profile British media titles, the generous sponsorship of SimplyHealth and the support of local celebrities. The money raised by Memory Walk
will help provide people with dementia and their carers with access to vital services. Better still, the money raised at each local walk will go towards helping people in that area.

Memory Walk is fast becoming a well-recognised event and the Alzheimer's Society is now looking forward to next year's walks. The hope is to make the targets even more ambitious but, whatever happens, the Alzheimer’s Society will continue to offer people the chance to have fun, raise money and fight dementia every step of the way.

UK (Scotland): 21 September 2009: World Alzheimer’s Day celebrated in Scotland with a lecture and launch of a Dementia Manifesto

Alzheimer Scotland organised a lecture on World Alzheimer's Day in Glasgow by Richard Taylor PhD, a retired psychologist from Texas, who has been diagnosed with Alzheimer's disease. Richard also gave a series of talks in different parts of Scotland (Dundee, Perth, Dunblane). His mission in life is to influence decision-makers and professionals, by speaking out as widely as possible and encouraging others to do the same. Alzheimer Scotland said that Richard made a powerful impact on everyone who came to hear him speak and that he was also interviewed for BBC Scotland's Reporting Scotland on WAD, thus fulfilling one of Richard's lifelong ambitions to appear on the BBC!

In addition to the lecture, Alzheimer Scotland marked World Alzheimer’s Day by the launch of their Dementia Manifesto, entitled “Words into Action on Dementia”, which calls for an overhaul of Scotland’s dementia services.

Science Watch

1 September 2009: Study examines the relationship between the subtype of HIV and dementia

The predominant human immunodeficiency virus (HIV) subtype is clade B in the US, but clades A, C and D in sub Saharan Africa. A study of sixty people with HIV who were at risk of HIV associated cognitive impairment underwent neurological, neuropsychological and functional assessments. The results suggest that “in untreated HIV infected individuals with advanced immunosuppression who are at risk of developing HIV associated cognitive impairment, HIV dementia may be more common among patients infected with subtype D virus that amount those infected with subtype A virus.” The researchers concluded that the study may demonstrate that HIV subtypes may have a pathological factor with respect to their capacity to cause cognitive impairment and called for further research to be carried out.

The study is published in the journal of Clinical Infectious Diseases.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

1 September 2009: Study investigates the effect of the drug memantine on language in people with moderate to severe Alzheimer's disease

A symptom of Alzheimer's disease can be language impairment. Researchers, led by Steven Ferris of the Alzheimer's Disease, New York School of Medicine, USA, analysed the effect that the drug memantine had on people with moderate to severe Alzheimer's disease. They found that memantine treatment resulted in "significant benefits for language function."


3 September 2009: Scientists discover new protein involved in the production of amyloid

In a research report published online in The FASEB Journal, a group of researchers from the United States, South Korea and France, describe how the N60 fragment of the RanBP9 protein increases the production of the amyloid beta protein, which is present in excessive amounts in the brains of people with Alzheimer’s disease.

David Kang, assistant professor of neurosciences at the University of California, San Diego and one of the researchers involved in the work stated: “Our study suggests that targeting RanBP9 expression and/or N60 fragment generation may lead to novel strategies to combat this devastating disease.”

6 September 2009: Study examines the genetic codes of people with and people without Alzheimer’s disease

The gene APOE4 has been associated with Alzheimer’s disease. A new study in which researchers studied the genetic codes of nearly 4,000 people with Alzheimer’s disease and nearly 8,000 people without the disease, found that “common non-protective versions of genes known as clusterin (CLU) and PICALM” might account for some of the Alzheimer’s cases.

The genetic study was led by Professor Julie Williams, Chief Scientific Adviser to the Alzheimer’s Research Trust and published in the journal Nature Genetics.

6 September 2009: Study suggests gene variant CLU and CR1 associated with Alzheimer’s disease

Findings from a recent study on some 2,000 people with Alzheimer’s disease in France and over 5,000 controls, as well as nearly 4,000 people with Alzheimer’s disease and over 3,000 controls from other European countries, suggest that the genetic variants clusterin (CLU) and Erythrocyte complement receptor 1 (CR1) may be associated with Alzheimer’s disease.

The research was conducted by scientists from France, Italy, Spain, Belgium, Finland and Australia and published in the journal Nature Genetics.

10 September 2009: Study considers incidence of dementia in ex-National Football League players

A study was commissioned by the National Football League (NFL), and conducted by the University of Michigan’s Institute for Social Research, in order to “learn more about retired professional football players and obtain an accurate portrait of the current health and well-being.” Over 1000 retired players were asked questions regarding their background characteristics, life in the NFL, work outside the NFL, relationships with others, health behaviours, health and disability, mental health, health insurance and care and financial well-being. Respondents were asked if they had ever been diagnosed with “dementia, Alzheimer’s disease, or other memory related disease”. The responses were noted to be particularly high for the older retirees.

The researchers have called for further studies to confirm these findings.

14 September 2009: Phase II clinical trial data released for potential Alzheimer’s drug

The drug EHT 0202 is a candidate for the treatment of Alzheimer’s disease. The phase Ila clinical trial data for EHT 0202 was released at the 13th Congress of the European Federation of Neurological Societies. Developed by ExonHit they announced the trial Ila findings as:

- Primary endpoints: Good safety and tolerability data supports moving into phase IIb trial
- Secondary exploratory endpoints: A trend for efficacy on cognition was observed on the Alzheimer’s disease
assessment scale- cognitive subscale (ADAS-Cog) scores and in ApoE positive population.

23 September 2009: Sleep loss linked to increase in Alzheimer’s plaques

Chronic sleep deprivation in a mouse model of Alzheimer’s disease makes Alzheimer’s brain plaques appear earlier and more often, researchers at Washington University School of Medicine in St. Louis report in Science Express.

The also found that orexin, a protein that helps regulate the sleep cycle, appears to be directly involved in the increase. “Orexin or compounds it interacts with may become new drug targets for treatment of Alzheimer’s disease,” says senior author David M. Holtzman, M.D. and chair of the Department of Neurology.

ExonHit are now seeking a partner for further development and commercialisation of EHT 0202.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

21 October 2009: Study investigates the retinal changes in mice and link with Alzheimer’s disease

Researchers found that the retinas in mice which were genetically altered to have Alzheimer’s disease “undergo changes similar to those that occur in the brain, most notably the accumulation of amyloid plaque lesions. In addition, when Alzheimer’s therapies are tested in such mice, retinal changes that result might predict how the treatments will work in humans better than changes in mouse brain tissue.”

The study, led by Zhiqun Tan, University of California, was republished in The American Journal of Pathology.

27 October 2009: Study on pneumonia and influenza finds that there are strong disparities in health care for people with dementia

A 5-year study of over 6 million health records compared the demographic and geographical patterns of pneumonia and influenza hospitalisations, length of stay in hospital and mortality rates among the elderly with dementia to national estimates. Researchers found that people with dementia “had a lower frequency of influenza diagnosis, a shorter length of hospital stay and a higher rate of death as the national average.”

The senior author of the study was Elena Naumova PhD, professor of public health and community medicine at Tufts University School of Medicine, Boston, USA.

Dementia in Society

September 2009: Laila Lanes, wife of former Norwegian Fisheries Minister Jan Henry T. Olsen, writes book about their life with Alzheimer’s disease

Laila Lanes has written a book about her life with her husband, the former Fishery Minister Jan Henry T. Olsen who was diagnosed with Alzheimer’s disease at the age of 51. The book is entitled, “Make haste with your love” (Skynd deg å elsker” – which refers to a well known love-song by Tove Jansson) and is a declaration of love with a description of the challenges which the couple have met.

Laila and Jan Henry met each other in 2005. A couple of years later, when they both turned fifty, they celebrated their birthdays by getting married. The following year, Jan Henry was sent from one specialist to another and finally diagnosed with Alzheimer’s disease. “It was a shock”, Laila describes in her book, “it was obvious that we would not get old together”.

It has been difficult, even for a couple such as Laila and Jan Henry, a journalist and a former politician, to get hold of the necessary information and find adequate support. They have been in contact with the social welfare system, GPs, specialists, municipalities and different organisations. “Everyone in this situation needs help, but the help being offered is insufficient and has been too difficult to find”,

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Laila says. She herself has found help and information at the local branch of the Norwegian Alzheimer Association in Tromsø.

Laila has considered quitting her job to help her husband. But after a prolonged battle with the social welfare system, a scheme was finally set up giving Jan Henry daily support from a personal assistant and the opportunity to participate in customized activities during the day. “It gives me energy to be at work. I have more to offer when I get home, and Jan Henry will be able to live at home longer” said Laila. “It is terribly exhausting, but at the same time it gives us so many good moments”.

“Make haste with your love” is a warm and personal book about love and how two people are coping with a life with Alzheimer's disease. The book's greatest strength is the author's willingness to share with the reader the painful and difficult emotions that all families struggle with when they face an illness there is no known cure for.

1 September 2009: Alzheimer's Research Trust launches campaign

The Alzheimer's Research Trust have invited members of the public to share their unforgettable moments as part of their new campaign to draw attention to the memory loss experienced by people who have Alzheimer's disease and other forms of dementia. These memories will be placed on the Alzheimer’s Research Trust’s Memory Wall.

Sir Terry Pratchett, Patron of the Alzheimer’s Research Trust, who lives with Posterior Cortical Atrophy posted “Deep down I know that one day my memories will go. The day my daughter was born. It was a dark and stormy night when she was in intensive care, but kind of OK. It was a long delivery. I thought that some celebration was in order. I found a piece of stewing steak in the fridge. It was the best damn steak I’d ever had. I cooked with lots of onions. It was very tough, but it tasted absolutely beautiful. I went off into the driveway and I fell flat on my face. I didn’t hurt myself. And the elation – I mean, nothing could’ve gone wrong that night. I think I’d hate to lose that memory.”

14-16 September: International conference on dementia held in York, England

The Dementia Services Development Centre (DSDC) held their 3rd conference in York, England, which had over 500 delegates attending. In light of the recently-launched dementia strategies, the theme of the conference was “Facing the future” with the programme containing some 70 presentations. The Conference welcome event included a performance of “The Woman from the North” which is a play about dementia. Awards were also presented for excellence in dementia care.

1 October 2009: Nuffield Council on Bioethics launches major report on ethical dilemmas in dementia

A report launched by the Nuffield Council on Bioethics on 1 October recommends that carers of people with dementia need more support and advice to tackle the difficult ethical dilemmas that they face on a daily basis.

This report was produced by a Working Party chaired by Professor Tony Hope, Professor of Medical Ethics at the University of Oxford and comprised of a number of leading dementia specialists.

Amongst the key recommendations, the report highlights the following:

- People with dementia can have a good quality of life with the good care and support set in place,
- Medical and social services should be available to people with dementia and carers not only in crisis moments,
- Good quality assessment and support should be available from the time people become concerned about symptoms of dementia,
- Families should be treated as “partners in care” by professionals,
- Protecting people from harm is important, but “risk assessments” should be replaced by “risk-benefit assessments” that also take into account the well-being of a person with dementia,
- Mental capacity legislation should ensure full involvement of people with dementia,
- More funding for research should be made available including for quality of life research.

Professor Hope commented at the launch that “Things are starting to change but dementia still carries a stigma. Dementia needs to become an accepted, visible part of our society, and people with dementia should be able to take part in the activities they enjoy.”
New resources and publications

14 September 2009: Carers of people with dementia share their experiences in new book

“Telling Tales About Dementia, Experiences of Caring” is a new book in which thirty carers share their experiences of caring for someone with dementia.

Their stories talk about diagnosis, treatment, care as well as the feelings of loss.


21 September 2009: National directory of dementia services available on line in France

An on-line national directory has been launched by Fondation Médéric in France. This easy-to-use website (http://www.fondation-mederic-alzheimer.org/) provides information on dementia services including:

- Places where you can get diagnosed
- Places for information and coordination
- Information for carers
- Day care centres
- Long-term care facilities

Information can be found by searching for a specific service or by region.

7 October 2009: Brochure launched to provide information on European instruments which may be used to promote active ageing and greater solidarity between generations

AGE - the European Older People's Platform - and the Committee of the Regions have launched a joint brochure to help local and regional actors make better use of the EU funding for innovative projects to promote ageing well in Europe.

The brochure is a toolkit addressing a series of challenges (promoting quality social and health services for the elderly and prevent elderly abuse, promote housing adapted to the needs of an ageing population, promoting healthy ageing, to name a few). It illustrates what can be done in each of these areas with examples of projects funded by EU programmes as well as the most relevant funding instruments.

Additional information on the most relevant EU programmes and methodological tools can also be found in the toolkit.

The document is not an exhaustive list. New examples can be shared with AGE and will be used to update the brochure in the future.

The brochure is available in English, French and German and can be downloaded in the three languages from the AGE website.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

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Marc Schaefer (Luxembourg)
Maria do Rösario Zincke dos Reis (Portugal)
## AE Calendar

The following meetings will be attended by representatives of Alzheimer Europe:

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tr>
<td>3 November</td>
<td>Parliament Magazine Hearing “Towards a healthier Europe” (Brussels, Belgium)</td>
<td>Annette</td>
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<td>10 November</td>
<td>Alzheimer’s in Europe – The opportunities of Joint Programming, European initiatives and Danish research (Brussels, Belgium)</td>
<td>Jean</td>
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<td>19 November</td>
<td>Recognition Programme Meeting (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>19 November</td>
<td>EFPIA Think Tank (Brussels, Belgium)</td>
<td>Annette</td>
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## Future Conferences

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>3-5 November 2009</td>
<td>4th UK Dementia Congress, <a href="http://www.ukdementiacongress.co.uk">www.ukdementiacongress.co.uk</a></td>
<td>Harrogate, UK</td>
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<tr>
<td>18-22 November 2009</td>
<td>62nd Gerontological Society of America Meeting, <a href="http://www.kenes.com/vascular">www.kenes.com/vascular</a></td>
<td>Atlanta, USA</td>
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<tr>
<td>19-22 November 2009</td>
<td>The 6th International Congress on vascular dementia, <a href="http://www.kenes.com/vascular">www.kenes.com/vascular</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>28-29 January 2010</td>
<td>Brains in dialogue on genetic testing, <a href="http://www.neuromedia.eu">www.neuromedia.eu</a></td>
<td>Trieste, Italy</td>
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<tr>
<td>27 February-2 March 2010</td>
<td>18th European congress of psychiatry, <a href="http://www.kenes.com/epa">www.kenes.com/epa</a></td>
<td>Munich, Germany</td>
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<tr>
<td>10 March 2010</td>
<td>25th International Conference of Alzheimer’s Disease, <a href="http://www.adi2010.org">www.adi2010.org</a></td>
<td>Thessaloniki, Greece</td>
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<tr>
<td>26 April 2010</td>
<td>25ème Colloque Médecine et recherche sur la maladie d’Alzheimer de la Fondation Ipsen</td>
<td>Paris, France</td>
</tr>
<tr>
<td>21-23 October 2010</td>
<td>18th Congress of European Society for Clinical Neuropharmacology, <a href="mailto:ivan.rektor@fmsa.cz">ivan.rektor@fmsa.cz</a></td>
<td>Zagreb, Croatia</td>
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