



NEWSLETTER

May 2010

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Editorial



I would like to extend a warm welcome to Elena Oana Antonescu, MEP from Romania and thank her for joining the other 46 MEPs who have become members of the European Alzheimer's Alliance from 16 European Union countries.

Raising awareness of the disease itself and the issues which surround it plays a fundamental part of our members' work. This month is no different and we report on our members' activities from Finland, Greece, Ireland, Portugal and the UK (both in England and in Scotland).

Greater understanding of the disease can also be gained by hearing people describe how it has affected their lives. This month we report on John Suchet's moving observations of caring for his wife, Bonnie, who has Alzheimer's. We also bring news of a play about the life of Rita Hayworth and her struggle with the disease. The contrast between her on screen life and battle with Alzheimer's disease provides a stark reminder of the fact that dementia can strike anyone at any time.

In the office we continue to prepare for our forthcoming conference in September and I take this opportunity to remind readers that our call for abstracts closes on 30 June. Early bird registration is also still available and you can register at a reduced rate until 31 July.

We have also started preparations for our lunch debate in the European Parliament on national

dementia plans, which will take place on 22 June.

Work is progressing well on our different projects, such as the literature review on the ethical implications of assistive technologies or the establishment of national reports on proxy-decision making in dementia.

In May, Annette and I attended an expert meeting convened by the Belgian Ministry of Health for the preparations of a Belgian Presidency Conference on the societal aspects of dementia and the research paper presented by Professor Murna Down highlighted a number of interesting policy approaches to destigmatise dementia and improve the quality of life of both people with dementia and their carers. This will definitely be a Conference to look forward to.

In this newsletter, we also report on two meetings organised by the European Patients' Forum. As a founding member of the Forum, Alzheimer Europe continues to believe in the need of a strong and united patients' voice in Europe and we are delighted to report on the organisation's continued good health both in its past activities, future plans and financing.

Finally, as always we bring you a selection of research news on the genetics, prevention and treatment of Alzheimer's disease and other forms of dementia. It is truly encouraging to see the amount of research that we can report on a weekly basis.

Jean Georges
Executive Director

European Alzheimer's Alliance



Antonescu Elena Oana
(Romania, EPP)

In April, Antonescu Elena Oana (Romania) joined the European Alzheimer's Alliance, which brings the total number of MEPs in the Alliance to 46, representing 16 Member States of the European Union and six of the seven political groups in the European Parliament.

The members of the European Alzheimer's Alliance are the following:

Belgium

Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Sterckx Dirk (ALDE)

Cyprus

Triantaphyllides Kyriacos (GUE-NGL)

Czech Republic

Cabrnock Milan (ECR), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP)

Denmark

Schallemose Christel (S&D)

Finland

Jaakonsaari Liisa (S&D), Jääteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP)

France

Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Morin-Chartier Elisabeth (EPP)

Germany

Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP)

Greece

Chountis Nikolaos (GUE-NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP)

Ireland

Aylward Liam (ALDE), Childers Nessa (S&D); Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP)

Italy

Panzeri Pier Antonio (S&D), Toia Patrizia (S&D)

Luxembourg

Lulling Astrid (EPP)

Netherlands

De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP)

Portugal

Coelho Carlos (EPP)

Romania

Antonescu Elena Oana (EPP)

Slovakia

Mikolasik Miroslav (EPP), Zaborska Anna (EPP)

United Kingdom

Hall Fiona (ALDE), Lynne Liz (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Watson Graham (ALDE), Willmott Glenis (S&D)

Alzheimer Europe Networking

On 4 May (Brussels, Belgium), Jean and Annette attended the **Belgian Presidency expert meeting on dementia**.

On 4 May (Brussels, Belgium), Annette attended the **European Parliament Environment and Health Committee** meeting to hear Commissioner Dalli's Work Plan for 2010.

On 5 May (Berlin, Germany), Jean attended a **Recognition Programme meeting** and gave a presentation on Alzheimer Europe's campaign to make dementia a European priority.

On 6 May (Brussels, Belgium), Annette attended the **Patients' Rights Day** organised by Active Citizenship in the European Parliament.

On 11 May (Brussels, Belgium), Annette attended the **STOA meeting on ageing research** in the European Parliament (FUTURAGE, a roadmap for ageing research).

On 13 May (Luxembourg, Luxembourg), Jean met with Ruth Bosworth from **Pfizer**.

On 18 May (Brussels, Belgium), Annette attended the **European Patients' Forum Health Technology Assessment seminar**.

On 19 May (Brussels, Belgium), Annette represented Alzheimer Europe at the **European Patients' Forum General Assembly meeting**.

On 25 May (Brussels, Belgium), Annette met with Roxana Radulescu (**European Patients' Forum Senior Policy Advisor**).

European developments

Here we report on developments from the European institutions which may impact people with dementia and/or their carers.

20 May 2010: European Commission launches second stage social partner consultation on electromagnetic field legislation

The European Commission launched a 2nd stage consultation with European social partners on 20 May 2010 to seek their views on the electromagnetic field legislation.

The aim is to improve Directive 2004/40/EC of 29 April 2004 on the minimum health and safety requirements regarding the exposure of workers to the risks arising from physical agents (electromagnetic fields).

Based on the outcomes of this consultation and other elements such as new scientific recommendations and studies, the Commission will prepare a comprehensive socio-economic impact assessment before adopting a new legislative proposal.

Consultation deadline : 5 July 2010.

Other European organisations

Here we cover the news from independent European organisations such as the European Patient's Forum, (rather than official bodies of the EU)

18 May 2010: Seminar on Health Technology Assessment held

The European Patients' Forum (EPF) seminar on Health Technology Assessment (HTA) took place in Brussels on 18 May 2010. The seminar's aim was to redress the limited knowledge and know-how the patient community has on the science and rationale behind HTA. With speakers from the European Commission, patient organisations, industry and health professionals, the event presented the science, methodologies, processes and policies behind HTA and how the patients could get involved.

Parallel workshops were organised on:

- the science and methodologies behind HTA
- the politics of HTA at EU and national level: how can patient groups best get involved?
- applying the Value+ model on patient involvement in the HTA process.

Annette Dumas attended on behalf of Alzheimer Europe.

19 May 2010: European Patients' Forum holds its AGM

The European Patients' Forum (EPF) General Assembly Meeting took place in Brussels on 19 May 2010. EPF received a warm welcome from its members for its work carried out in 2009, its 2010 work plan, its European policy work and the management of its funds.

Working groups were organised to focus on two questions 1) how can EPF membership best guide, strengthen and reinforce EPF to the benefit of all of its members and 2) where would the EPF be in 2020 as a European Patients' Movement ?

In a closing speech, Commissioner Dalli's representative reiterated the Commissioner's commitment to put patients high on the European Commission's agenda and work with patients. He touched upon the economic crisis and feared some difficult decisions would need to be made. It will be necessary to establish priorities in terms of limited budgets. Health promotion and prevention will empower people to make healthy choices. As a healthy population goes hand in hand with a healthy economy, it will be worthwhile investing in health.

On a question from the audience regarding the funding of patient groups, Commissioner Dalli said that it is very likely that the 25% level of industry funding for patient organisations being eligible to EU funding will be maintained. The way forward would be the setting up of a Foundation. In this respect, the Norwegian model was said to be an interesting model.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on:

www.alzheimer-europe.org

Policy Watch

In this section you can find articles on various national policies and initiatives which can have an impact on issues surrounding dementia.

7 May 2010: The state of California develops an Alzheimer's Plan

The Alzheimer's Association (US) and the State Alzheimer's Advisory Committee are leading the development of a State Alzheimer Plan, which is the first time that policy and practices regarding Alzheimer's disease have been addressed since 1987. It is being drafted by the Alzheimer's State Plan Task Force, which is composed of representatives from the health care and provider community, researchers, academics, family caregivers, local and state government, law experts for the elderly and Alzheimer's association staff and volunteers. The Plan be completed at the end of 2010 and will address:

- Care and Services for people with Alzheimer's disease and related dementias

- Support for family caregivers
- Public awareness and education
- Creation of a dementia capable workforce
- End of life care.

African-Americans are at higher risk for Alzheimer's disease, but less likely than whites to have a diagnosis and this can result in a delay of treatment. To address this, a special consultation meeting (at the Town Hall) was arranged. Online feedback was possible throughout May. The Task Force created a caregiver survey (in English, Chinese, Spanish, Vietnamese and Korean) with input being submitted before 31 May 2010.

27 May 2010: Alzheimer medication reimbursed if used in hospital treatment in Bulgaria

For the first time in Bulgaria, Alzheimer medication (Aricept and Exelon) is to be reimbursed by the state if it is used during hospital treatment. Irina Ilieva, the Executive Secretary of the Bulgarian Alzheimer society welcomed this decision, saying that the society likes to "think that our joint efforts, including the case we filed at the Commission for the Prevention of Discrimination, contributed to this." The Society will continue to campaign for the Alzheimer medication to be reimbursed for all treatment (not just in hospital).

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Members' News

In this section we report on our members' latest initiatives and work.

24 April 2010: Workshops for caregivers of people with dementia organised in Greece



The Athens Association of Alzheimer's Disease and Related Disorders organised educational workshops for relatives and caregivers of people with dementia on Saturday, April 24 2010, at the Athens War Museum, from 10:00-19:00 hours.

More than 250 caregivers attended and had the opportunity to talk with health care professionals about the problems and difficulties experienced trying to meet patients' needs.

Workshop titles were:

- 1) Treatment of Alzheimer's Disease
- 2) Alzheimer's Disease Progression
- 3) Behavioral and Psychological Problems
- 4) Practical issues of Caring.

Parallel to the workshop presentations on Alzheimer's disease were held repeatedly all through the day.

Brochures and booklets were distributed to 1,500 people while 150 new members enrolled with the Athens Alzheimer's Association.

30 April 2010: Alzheimer Scotland launches report on social care for dementia



Alzheimer Scotland's new report, *Let's Get Personal – personalisation and dementia*, was launched at the end of April and received significant Scottish media coverage. The report demonstrates what can be achieved when people with dementia and their carers are given control over their own social care support.

The Chief Executive of Alzheimer Scotland said, "This research shows that, when empowered to direct their own support, families effectively combine state resources around their own natural supports - creating truly personalised support. Our findings add weight to the Scottish Government's drive towards self-directed support and point to a new way forward for dementia services.

"Improving access to personalised support, so that people with dementia and their families can have genuine choice and control, is the key to achieving the best possible outcome from both state and personal resources. Scotland must change its methods of community-based dementia care – remaining static is not an option. We hope that this approach will be recognised by the forthcoming National Dementia Strategy and will be central to reshaping care in the future."

May 2010: "Kelembra has forgotten"- New Project of Alzheimer Portugal brings generations together



The Northern Branch of Alzheimer Portugal has embraced a new project, this time planned for children and the relationships established with their grandparents.

The main objective is to raise awareness in children regarding the importance of support for their grandparents helping them to overcome memory problems and some daily life difficulties. Promoting links between generations, reinforcing the role of the elderly in society/family, with children as key players in strengthening and nurturing these ties, are also part of the objectives.



Based on the book "Memo, the baby elephant", which was edited by Alzheimer Portugal, "The Storyteller - Kelembra has forgotten" is intended for children aged 6 to 10 years and is being presented in interact with children in a very creative and captivating way. Also involved are an Occupational Therapist and a Clinical Psychologist, from the Association, who answer the questions, which arise from the story, regarding Kelembra the grandmother and the attitudes of Memo comparing them with real life situations of children. These sessions stimulate their social interaction, patience,

affection, and provide a better understanding of the relations with grandparents.



The book "Memo, The Baby Elephant" is aimed at children from 5 years contributing to the demystification of Alzheimer's disease. It's available in a bilingual edition – Portuguese/English - and is illustrated with colorful designs that tell the adventures of Memo in Kenya. The book has the retail cost of EUR 12.50 and a special price of EUR 10 for members of Alzheimer Portugal.

10 May 2010: Regional helpline launched by the Alzheimer's Society

The Alzheimer's Society has launched a 24 hour helpline for people in Cornwall who are affected by Alzheimer's disease. The service offers information and support for people concerned about memory loss, confusion and dementia. The service is supported by Age Concern Cornwall.

10 May 2010: Workshop organised "Supporting the caregivers - An updated view on coping with dementia" in Greece

The Greek Association of Alzheimer's Disease and Related Disorders (GAADR) has participated in the 'Students Week', held at Aristotle University of Thessaloniki, organising a workshop entitled "Supporting the caregivers - An updated view on coping with dementia".



'Students Week' is an event that encompasses a series of student activities and events held each year for a period of 4-5 weeks mainly within the premises of the Aristotle University of Thessaloniki. This event aims at promoting student pursuits in many fields of science and culture, encouraging the expression of individual and collective creativity, and supporting human relations and social solidarity.

Within this framework, GAADR organized the aforementioned workshop on 10th May (17:00 - 20:00), at the Ceremony Hall in the old Faculty of Philosophy. Professor Magda Tsolaki and her staff, in close cooperation with students from the Medical faculty of the Aristotle University and other specialists, were able to create a multidisciplinary workshop. The event was open to all members of the academic community but also to the general public and was attended by almost 220 people.

Speakers covered a wide range of topics for caregivers. Areas covered included: family therapy, tackling social stigma, legal advice for caregivers, dealing with behavioural disorders, communication techniques with patients, coping with caring problems, satisfaction rising from the caregiving role, spirituality and the role of caring itself.

The event proved to be a unique opportunity, both for students who were able to make presentations and learn more about dementia, but also for caregivers, who were given updated information in order to deal with their strenuous role. It is the Greek Association's intention to continue organising these events and retain close cooperation with the academic community, in an effort to mobilize as many people

as possible, for the support of dementia patients and their caregivers.

12 May 2010: UK- Award ceremony recognises the work a carer of a person with dementia and also donates proceeds to the Alzheimer Society

The dementia carer of the year 2010, which is one of five awards given at the Daily Mail's National Carers of the Year Awards, was given to Michael Tuton, whose mother, Molly, is in the late stages of dementia. Following the death of his father in 2002, Mr Tuton moved back to Hull from Canada in order to care for his mother.

The event was sponsored by Bupa in support of Alzheimer's Society, which will receive all funds raised from the day. Celebrities supporting the event included Lynda Bellingham, Britt Ekland, Julian Fellowes and Angela Rippon.



Andrew Ketteringham, Director of External Affairs of the Alzheimer's Society, said "Every year we ask our patrons, vice-presidents, partners and ambassadors to meet together so that we can thank them for the enormous help they give us. This year, with the proceeds going to Alzheimer's Society, we came to the conclusion that this was the event to which we should invite them all. It couldn't have been a better decision; it was moving and inspirational and all of us came away feeling privileged to have been present at a very special occasion."

20 May 2010: Alzheimer's Society calls for advice to be given to doctors on palliative care

Following the publication of the General Medical Council's (GMC) end-of-life care guidance, the Alzheimer Society has called for doctors to receive advice on palliative care for people with dementia.

A spokesman for the Society said: "This guidance is a good start towards addressing the needs of people at the end of their lives but it does not go far enough to tackle the specific needs of people with dementia. It is good to see the GMC emphasising the need for doctors to weigh up the benefits of starting or withdrawing treatment; that clinicians should presume someone has the capacity to make decisions; and the importance of dealing with family members in a sensitive manner. However dementia is not adequately addressed in the report despite the fact that one in three people over 65 will die with the devastating condition. People with dementia have specific end-of-life care needs and too many are subjected to an undignified and unnecessarily painful death. We need dementia-specific guidance for clinicians if we are to ensure people with dementia get the dignity they deserve at the end of their lives."

24 May 2010: The Alzheimer Society of Ireland calls for action to be taken to develop a national dementia strategy, streamline dementia care and increase funds

A programme which focused on dementia care has been welcomed by the Alzheimer Society of Ireland

(ASI), which is the leading dementia specific service provider in Ireland. The programme on RTÉ News, 'Prime Time Investigates: Alzheimer's Disease' highlighted the issue of dementia care and the deepening crisis for carers due to difficulties in accessing information, support services and specialist care.

The Society is now making an urgent appeal for action to alleviate this hidden health crisis for carers and those affected by Alzheimer's disease or a related dementia but warns that it is struggling to cope with the growing demand for its services nationwide.



The Society has launched an online campaign for public support calling on the government to:

- recognise Dementia as a National Health Priority NOW and expedite its plans to develop a Dementia Strategy and implementation plan so that there can be better planning of services and policy as soon as possible. The Society has reaffirmed its commitment to working with all the relevant stakeholders to achieve this objective
- take immediate action to streamline dementia care so that current spending on vital services can be more effective for families
- increase the commitment of funding for community based services - such as those provided by the charity - in order to enable families to continue caring for their loved ones at home, with dignity, for longer.

Fundraising plays a vital role in providing Alzheimer Society of Ireland services. On average HSE funding represents only 68% of cost - with more than €5m to be raised through fundraising, donations and other grants annually. Despite funding constraints, demand for services is rising with more than 800 people on The Society's waiting list for services.

The Society is grateful for the tremendous outpouring of support it has received following the Primetime programme and the generous contribution of fundraisers and donors who help bridge the gap between funding received and cost of service provision.

Equitable and timely access to specialist information, diagnostic services, community services such as home care, day care and short term respite as well as quality residential services must be the benchmark towards which the state strives according to the Society.

The personal stories portrayed in the programme gave a snapshot of the complexity of issues families are dealing with, highlighting the lack of uniformity in delivery of services (the quality and availability of services can be very different in one area compared to another) and fragmentation of the system which can see

carers dealing with 12 different agencies at any one time.

Alzheimer's disease and related dementias affect more than 40,000 people in Ireland, impacting on the lives of 50,000 carers. The number of those affected is set to increase substantially due to population ageing.

30 May 2010: The Finnish Alzheimer Society poster awarded the title of the 'Best Health Promotion Material of the Year'



The Finnish Centre for Health Promotion has a tradition of electing the Best Health Promotion Material of the Year. This year the title was granted to a poster by the Alzheimer Society of Finland. The message of the poster is built on a play of words: The Finnish word MUISTA meaning both the imperative form of the verb to remember" and also the word "others". All in all, the message is to encourage people to care for others, to get inspired about others, to worry about others - and to remember it all.

The poster was designed by a small Finnish Advertising Agency called Maustamo.



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Science Watch

This section has highlights of the most recent published research on dementia, including research on the prevention, diagnosis and treatment of the disease.

1 May 2010: New brain research project launched

The UK's independent science academy, the Royal Society, has launched a new project, Brain Waves, which will investigate developments in neuroscience and their implications for society.

The project will be led by a Steering Group, chaired by Professor Colin Blakemore, who said "Our increasing understanding of the brain and associated advances in technologies to study the brain, including the human brain, are beginning to give us the tools to improve the treatments for neurodegenerative diseases, such as Parkinson's and Alzheimer's, and mental illnesses, including depression and schizophrenia. But these advances will also increase our insights into normal human behaviour and mental wellbeing, as well as giving the possibility of enhancement, manipulation and greater understanding of the degradation of brain function."

"Brain research is likely to have huge implications for society. We need to do something that scientists usually don't like to do - to speculate about the future. There's a lot to think about and we must begin

now the process of providing the best possible information in areas of public policy such as health, education, law, and security. Progress in neuroscience is going to throw up all sorts of questions about personality, identity, responsibility and liberty. We need to be prepared to answer and respond to those questions."

There will be five reports, the first of which is expected this Autumn and the last should be published in 2011:

1. The first module consists of an assessment of the relevance of neuroscience to the areas of public policy, addressing such issues as the ethics of neuroscience technologies and their commercialisation. It is expected that this report will be published in the Autumn.
2. Neuroscience, education and lifelong learning - How can neuroscience help explain (and potentially enhance) memory, creativity, attention, motivation and other brain processes that are essential for learning? The project will look at these issues as well as the challenges, opportunities and limitations of applying the lessons from neuroscience to learning in the classroom and beyond.
3. Neuroscience, conflict and arms control - Addressing concerns around the military and security applications of rapid advances in the neurosciences; the risks of 'militarisation' of neuroscience. These include indications that advances in neuropharmacology are stimulating new interest in the development of toxic chemical and biological agents as incapacitating weapons. These would target the central nervous system to degrade human cognition, performance, or consciousness.
4. Neuroscience, responsibility and the law – Assessing the possible future impact of brain research on the legal system. This could include such issues as the possible prediction of criminality, behaviour change, surveillance and mental privacy, as well as wider discussion about what neuroscience could mean for understandings of decision-making, intention, responsibility and free will.
5. Lessons for the governance of novel areas of science and new technologies - Bringing together lessons and common themes from the first 4 reports, this part will reflect on the governance, regulation and public accountability of science and technology, principally for neuroscience but also for other developing areas of science and technology, such as synthetic biology, genomics and nanotechnology.

3 May 2010: Researchers identify common protein structure in neurodegenerative diseases

Researchers have discovered that the proteins in neurodegenerative diseases such as Parkinson's,

Alzheimer's disease and Huntington's syndrome have a common 3D structural unit, which researchers have called "β-arcade". The researchers hope that their work will help to diagnose the risk of developing neurodegenerative diseases and also facilitate the identification of target sites in order to develop new treatments.

3 May 2010: Study examines the relationship between liver disease and memory loss

A study on 300 people who had cirrhosis of the liver found that over half of them also displayed symptoms of neurocognitive impairment. The study was part of a larger study looking at the effects of AST-120 on people who have liver disease and neurocognitive impairments.

Led by Christopher Randolph, Clinical Professor, Department of Neurology, Loyola University, Chicago, the study was reported at the Digestive Disease Week meeting, New Orleans, USA.

4 May 2010: Results from animal study on potential Alzheimer's disease released

A potential Alzheimer's drug, Anavex 2-73, which targets mitochondrial dysfunction, has been tested on rats, mice and dogs. Results showed that "when (the drug was) administered prior to amyloid-beta 25-35 peptide, ANAVEX 2-73 protected against the amyloid peptide-induced learning deficits, hippocampal lipid peroxidation and cell loss in the CA1 pyramidal layer and showed potent neuroprotective activity." Preparations are now underway to carry out Phase I trials.

Developed by the company Anavex, the research was carried out with the research organisation Forenap Pharma EURL.

5 May 2010: Study finds an increased risk of dementia for spouses of people who have dementia



A study published in the Journal of American Geriatrics Society has found an increased risk of dementia for spouses of people who have dementia.

The study, led by Dr Maria Norton, Utah State University USA, was conducted on over 2,000 people aged 65 and over who were monitored over a 12 year period. The results showed that "incident dementia was significantly associated with older age, and having a spouse with dementia, with participants with a spouse who developed dementia being at a six times increased risk of developing dementia."

5 May 2010: Study examines the relationship between the presence of AB protein and Alzheimer's disease

A study which examined 43 brains to investigate the relationship between biochemically distinct forms of amyloid-β protein and the presence of Alzheimer-type dementia found that "soluble amyloid β-protein is a major correlate of dementia associated with Alzheimer-type pathology and is likely to be intimately involved in the pathogenesis of cognitive failure."

The study was led by Dominic Walsh, University College Dublin, Ireland and reported in the journal Brain.

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5 May 2010: Study on mice examines the effect physical activity has on memory function

A study found that the regeneration of hippocampal neurons was greater in those mice which were physically active or which had seizures compared to those mice which were inactive.

The study was led by Dr Verdon Taylor, Max Planck Institute of Immunobiology, Freiburg, Germany, and published in the journal Stem Cell.

6 May 2010: Study on mice examines the relationship between 'histones', gene expression and memory function

German researchers who investigated the relationship between ageing and the function of tiny protein spools (which control gene expression known as histones) found that "by injecting a drug (some of which have been previously used for cancer treatment) into the hippocampus of older mice to restore acetylation, the gene expression of these mice looked similar to their younger counterparts. Moreover this treatment improved the ability of old mice to remember a foot shock."

The study, led by Andrew Fischer, laboratory for Aging and Cognitive Diseases, European Neuroscience institute, Göttingen, Germany, was published in Science.

7 May 2010: Study examines the relationship between music and recognition

A study which investigated the effect musical mnemonics had on verbal information recognition found that people with Alzheimer's disease demonstrated better recognition accuracy for sung lyrics than spoken lyrics. People without Alzheimer's disease showed no marked difference between the accompanying sung or spoken recording when recalling the information. Participants were presented visually with lyrics to 40 songs, 20 of which were accompanied by a sung recording and the other 20 by a spoken recording.

The study was carried out by scientists from Boston University School of Medicine (BUSM) and published in the journal Neuropsychologia.

10 May 2010: Study examines the relationship between flavour processing and semantic dementia



A study which investigated the processing of flavour information giving different flavoured jelly beans to

people found that those people with semantic dementia, whilst "able to discriminate between different flavours and indicate whether they found them pleasant or not, had difficulty in identifying individual flavours or assessing the appropriateness of particular flavour combinations (for example, vanilla and pickle)". Researchers believe that this loss of meaning for flavours links up with why people with semantic dementia develop a preference for unusual foods and food combinations.

The study was led by Katerine Piwnica-Worms, Washington University in St Louis, Missouri and Jason Warren, University College London, UK and published in the journal Cortex.

10 May 2010: Phase III trial commences for potential Alzheimer treatment

A Phase III clinical trial has begun which tests the ability of Intravenous Immune Globulin (IVIg) in slowing down the progression of Alzheimer's disease. For over 20 years IVIg has been used to treat primary immunodeficiency disorders.

The trial is being led by Michael Rafii, Assistant Professor of neurosciences, UC San Diego School of Medicine and Associate Director of the Alzheimer's Disease Cooperative Study (ADCS).

10 May 2010: Test which indicates propensity for various diseases, including Alzheimer's disease, to be sold over-the-counter in the US



A test called the "Insight test", which scans people's genes for a propensity for various diseases, including Alzheimer's disease, is to be made available in 6,000 Walgreens' drugstores in the US from 14 May 2010. This will be the first time that such testing be made available over-the counter.

The US Department of Food and Drug Administration has questioned whether the Pathway Genomics' test will be sold legally as it does not have the agency's approval. In addition, there have been various criticisms including those that the results will be too vague to provide much useful guidance.

12 May 2010: Study identifies two genes associated with the risk of Alzheimer's disease

A study suggests that there are two more genes (one gene near BIN1 and the other near to BLOC1S3 and MARK4) which are associated with the risk of Alzheimer's disease. The results also reinforced earlier results from 2009 which had identified the genes PICALM and CLU as being associated with Alzheimer's disease. This was a genome-wide association study (GWAS) on more than 35,000 people (the largest to date for Alzheimer's disease).

The study was led by Monique Breteler, Erasmus University, Rotterdam, the Netherlands and Sudha Seshadri, Boston University, USA.

12 May 2010: Study examines word recall in the elderly

A study which examined word recall in people between 75 and 90 found that people with few teeth scored lower than those with more teeth.

Participants' recall was tested periodically over a three year period by their being asked to recall 10 words they had been presented with five minutes earlier.



The study was carried out by researchers at the University of Kentucky, America.

13 May 2010: Studies examine the relationship between people with a trial fibrillation who are treated with catheter ablation and the risk of Alzheimer's disease

Research presented at the Annual Scientific Sessions of the Heart Rhythm Society suggests that people with a trial fibrillation treated with catheter ablation are less likely to develop Alzheimer's disease or other forms of dementia.

The on-going research has been carried out on over 37,000 people over a three year period by scientists from the Heart Institute at Intermountain Medical Center and led by John D May and T Jared Bunch.

17 May 2010: Experts explore the relationship of caffeine on the brain and Alzheimer's disease



A collection of original studies by experts offer various perspectives on the role caffeine may play including:

- Caffeine and Cognition in Functional Magnetic Resonance Imaging
- Is Caffeine a Cognitive Enhancer?
- Chronic Caffeine Consumption Prevents Memory Disturbance in Different Animal Models of Memory Decline
- Caffeine and Coffee as Therapeutics Against Alzheimer's Disease
- Caffeine Protects Against Disruptions of the Blood-Brain Barrier in Animal Models of Alzheimer's and Parkinson's Diseases
- Caffeine, Cognition, and Socioeconomic Status
- Caffeine, Cognitive Functioning, and White Matter Lesions in the Elderly: Establishing Causality from Epidemiological Evidence
- Caffeine as a Protective Factor in Dementia and Alzheimer's Disease
- Caffeine Intake is Associated with a Lower Risk of Cognitive Decline: A Cohort Study from Portugal
- Caffeine Intake and Dementia: Systematic Review and Meta-Analysis.

The experts were brought together by guest editors of the Journal of Alzheimer's disease, Alexandre de Mendonga, Institute of Molecular Medicine and Faculty of Medicine, University of Lisbon, Portugal, and Rodrigo A. Cunha, Center for Neuroscience and Cell Biology of Coimbra and Faculty of Medicine, University of Coimbra, Portugal.

20 May 2010: Study examines the relationship between the use of pesticides and risk of dementia



A study has found that pesticide exposure may increase the risk of dementia and Alzheimer's disease in late life. The study was carried out by inviting residents of the agricultural community of Cache county, UT, aged 65 years and older to participate. Over 3,000 people enrolled. Cognitive status was assessed at baseline then after 3, 7 and 10 years.

The study was led by KM Hayden, Departments of Psychiatry and Behavioural Sciences, Duke University Medical Center, Durham, USA and was published in the journal Neurology.

20 May 2010: Study examines obesity and dementia



An analysis of the relationship between various factors (body mass index (BMI), waist circumference (WC), waist to hip ratio (WHR), subcutaneous adipose tissue (SAT), visceral adipose tissue (VAT) with magnetic resonance imaging (MRI) markers of brain ageing) found that in middle-aged participants there was a stronger connection between central obesity and the risk of dementia and Alzheimer's disease.

The study, led by Sudha Seshadri, was carried out by researchers from the Boston University School of Medicine and published in the journals Annals of Neurology.

30 May 2010: Study highlights the role three proteins, Aβ, tau and α-synuclein, may play in cognitive decline

A study in which researchers developed a mouse model which exhibits the combined pathologies of Alzheimer's disease and dementia with Lewy bodies (DLB) found that, compared to other transgenic mice, the mice with AD/DLB exhibited "accelerated cognitive decline associated with a dramatic enhancement of Aβ, tau, and α-synuclein pathologies." The researchers believe this supported the theory that Aβ, tau, and α-synuclein interact in vivo to promote the aggregation and accumulation of each other and accelerate cognitive dysfunction. The study also revealed that the accumulation of α-synuclein alone could significantly disrupt cognition.

The study, led by Frank La Ferla, University of California, was published in the Journal of Neuroscience.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on:

www.alzheimer-europe.org

Dementia in Society

10 May 2010: USD 15 million donated to Alzheimer's research

A US couple, Charles F and Joanne Knight, have donated USD 15m to Washington University's Alzheimer's research centre. Joanne Knight's mother was diagnosed with Alzheimer's disease in the 1980s and she is a board member and former chairperson of the St Louis chapter of the Alzheimer's Association.

The Centre's director, John Morris, said, "The Knight funding of the Alzheimer's centre will provide us the wherewithal to retain faculty whom we'd like to keep and also to recruit faculty that we need to replace individuals or to go into a new direction that's been developed. We don't have to wait to develop a track record of preliminary findings and then a grant application process and then wait to see if the grant is awarded. We can immediately begin exciting and promising new studies with this wonderful gift."

The news was announced on the St Louis Public Radio Station.

10 May 2010: Song about Alzheimer's disease performed

Song writer and singer Loretta Hagen performed her song "Sundown Till Dawn" at the Connecticut Film Festival, USA. The song is written about her mother, Vera Tutini, who was diagnosed with Alzheimer's disease seven years ago. Hagen hopes that her song will raise awareness and funding for research into the disease.

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14 May 2010: Play performed about Rita Hayworth's life and struggle with Alzheimer's disease



"Me, myself and Rita" is a one-actress play depicting the life of 1940s film star, Rita Hayworth which was performed in many countries, the latest of which was, Malta, in May. Written and acted by Almog Pail, the play presents the contrast of Ms Hayworth's glamorous stage life with that of her real life, in which she lived with early onset Alzheimer's disease.

In an interview in the Malta Independent, Ms Pail described the impact Alzheimer's disease had on Rita Hayworth saying, "Alzheimer's disease struck Rita in her early forties, progressively ruining her life. She could barely memorise text, and it became impossible to work with her. The real tragedy was the lack of awareness of the disease at the time, leading people to confuse her condition with alcoholism and foolishness. She was thrown out of Hollywood, dying as a recluse in her New York apartment after a 20-year struggle. The power of this destructive disease

and its symptoms played a big role in my decision to write the play. I have personally experienced it through a close family member, and it is not easy to grasp the deterioration of a person with so much knowledge and vividness. It is one of the most absurd phenomena of human nature."



Charles Scerri, General Secretary of the Malta Dementia Society, who attended the play said, "I found the performance very refreshing and I believe it can be used as an educational tool in raising awareness. It was different and highly entertaining."

19 May 2010: Author talks of her mother's dementia

Author Catherine Horwood has described her experience having a mother with Alzheimer's disease. Ms Horwood had noticed over a two-year period that her mother, a former ballet dancer, found tasks increasingly difficult and witnessed her mother's frustration. For example, her mother found that she could no longer read because she couldn't remember what the proceeding text was about, nor could her once elegant mother remember how to button up a cardigan. Ms Horwood felt further confirmation that something was deeply wrong when her mother lost her passion for gardening, something which had been a common interest for them both. Her mother also recognised her changing condition, as Ms Horwood's grandma had also had dementia. Ms Horwood explained how the symptoms worsened and one day her mother, who rarely left the house, went outside into the street and told a neighbour "there's a man in the house. He wants to kill me. I can't go back in there." She refused for a long time to return to the house and a chair was brought out for her. The man, explained Ms Horwood, was her father who had been married to her mother for 50 years. Her mother died two months later.

Ms Horwood said "few other degenerative diseases strip someone of their personality quite so thoroughly as Alzheimer's. Watching someone you love become so diminished is agony. At the first signs, there is the denial that this can be happening. Then there is anger with the illness itself; and sometimes even anger with the person themselves for no longer being who they were. And finally there is the living bereavement: mourning someone who is still alive but no longer with you."

27 May 2010: British newscaster talks about his experience of his wife having dementia



British newscaster, John Suchet, has spoken about his experiences since announcing that his wife, Bonnie, has dementia. After some encouragement by specialist nurse, Ian Weatherhead, he kept a journal about this journey, which he has decided to publish, calling it "My Bonnie: How Dementia Stole The Love Of My Life".

Originally Mr Suchet thought not many people would take notice of his announcing his wife's dementia, but he explained his surprise as he "received hundreds of thousand of e-mails and letters from all across the world, all from carers saying that's what we're going through. Thank you for talking about it."

Since the announcement made last year of Bonnie Suchet's dementia, Mr Suchet has had to place her in a home. He said that "Bon went into full-time care last September and to say it was the most difficult decision I've ever had to take is a pathetic understatement."

He also described the day he took her into care and the fact he had to buy her a one way train ticket, saying "It's the little things that break you up."

Mr Suchet talked of his own struggle, having to adapt to his new life without his wife and said "I'm starting a new life. Am I happy? Of course not. Am I excited? God, no. It was never supposed to be like this."

New resources and publications

By reporting on recently published books, reports and information videos on dementia we hope to offer updates on the current resources available to anyone who is affected by dementia.

1 May 2010: Book published on dance for people with dementia

The guide "Invitation to the Dance" offers practical suggestions (such as dance ideas, themes, music and props) aimed to help carers organize simple dance sessions for people with dementia. It is not necessary that the carers have experience in dance as the book hopes to encourage lay people to run the sessions.

The guide includes chapters on:

- Where does dance fit in?
- Let's dance!
- Structure of the session
- The ethic of the dance session
- Materials for the dance session
- Dancing with people with dementia
- Sample dance sessions.

The author, Dr Heather Hill, who has run dance sessions for people with dementia explains "Dance sessions gave care staff the opportunity to see behind the mask of dementia, giving staff the time and space to relate to residents simply as human being to human being, joining with them in an activity which could be vigorous, could be relaxing, could allow for sharing of memories, self expression or social interaction. These practical experiences, together with my own research, have convinced me that dance has much to offer in terms of meeting not merely the physical but also the social and emotional needs of people with dementia."

Invitation to the Dance (48 pages) by Heather Hill and the accompanying music CD by Ian Cullen costs GBP 25.00 and is available from the Dementia Services Development Centre (DSDC) Stirling, Scotland.

5 May 2010: US Teenagers from Alzheimer organisation hope to expand content on their website

A part of the Alzheimer's Foundation of America's website is dedicated to helping teenagers who are affected by Alzheimer's disease. Written by a teenager the site is called AFATeens.org. and calls for teenagers to:

- Get connected – by gaining support from experts, sharing experiences and remembering loved ones with creative contributions
- Take action – by joining or starting AFA Teens chapters and
- Learn more.

The author wishes to develop this site, hoping to expand the education content by adding interactive online tools which explain disease progression, offer coping strategies and encourage teens to adopt healthy lifestyles that can lower risk factors. To fund this, a proposal has been posted on the Pepsi ideas website (refresheverything.com) where ideas are posted then voted on. The winner is awarded money from Pepsi for their project.

20 May 2010: The French Ministry of Health guidelines on Alzheimer's disease published in English

Recommendations by the Ministry of Health which were made within the framework of the French Alzheimer's Plan (2008-2013) have now been made available in English. Quick reference guides now available in English are:

- The management of behavioural disorders
- Diagnosis and treatment of Alzheimer's disease
- Alzheimer's disease and related conditions: Health monitoring for family carers.

And the Clinical Practice Guidelines now published in English is

- Alzheimer's disease and related conditions. Diagnosis and Treatment.

All of the above guides are available on the Ministry of Health's website.

AE Calendar

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

Date	Meeting	AE Representative
8-9 June 2010	200 th Anniversary Meeting of Karolinska Institutet (Stockholm, Sweden)	Jean
11-12 June 2010	European Memory Clinics Association (Basel, Switzerland)	Heike
21 June 2010	Alzheimer Europe Board (Brussels, Belgium)	AE Board and staff
21 June 2010	European Parliament lunch debate "Alzheimer's disease and dementia as a national priority: Contrasting approaches by France, Germany and the UK" (Brussels, Belgium)	AE Board and staff
28-29 June	EU Conference "Mental health and Well-being in older people" (Madrid, Spain)	Jean

Future Conferences

Date	Meeting	Place
9-11 June 2010	7th International Short Break Conference, www.isba2010.com	Galway, Ireland
21-23 June 2010	International elder care conference, Transforming care 2010, www.sfi.dk/transformingcare2010	Copenhagen, Denmark
21-23 June 2010	18 th European Social Services Conference, http://esn-conference.org/	Barcelona, Spain
24-27 June 2010	1st International Congress on controversies in longevity, health and aging (CoLONGY), www.comtecmed.com	Barcelona, Spain
28-29 June 2010	Mental Health and Well being in Older People- Making it Happen, http://ec.europa.eu/health/mental_health/events/ev_20100419_en.htm	Madrid, Spain
29-30 June 2010	Together for Health – a Strategy for the EU 2020, http://ec.europa.eu/health/interest_groups/eu_health_forum/open_forum/2010/index_en.htm#fullwidth	Brussels, Belgium
26-27 July 2010	2010 IANA (International Academy on Nutrition and Aging), www.healthandage.com/html/min/iananda	Albuquerque, New Mexico
2-5 September 2010	Dignity for the Frail Old: From dilemmas to solutions, www.dignity.no	Bergen, Norway
8-11 September 2010	International Conference on evidence-based policy in long-term care, Itconference2010@lse.ac.uk	London, UK
15-17 September 2010	26e Congrès de la Société de Psychogériatrie de Langue Française (SPLF), www.nexcom-events.com	Limoges, France
22-25 September 2010	5th Croatian Congress on Alzheimer's Disease with international participation, www.alzheimer2010.com	Zadar, Croatia
30 September – 2 October 2010	20th Alzheimer Europe Conference "Facing Dementia Together", www.alzheimer-europe.org/conferences	Luxembourg, Luxembourg
7-9 October 2010	Gemeinschaft leben, www.deutsche-alzheimer.de	Braunschweig, Germany
19-21 October 2010	Coming of Age: Dementia in the 21st Century, www.dementia.stir.ac.uk	London, UK
19-21 October 2010	9ème Congrès International Francophone de Gériatrie et Gériatologie 30èmes Journées Annuelles de la Société Française de Gériatrie et Gériatologie, www.cifgg2010.com	Nice, France
21-23 October 2010	10th Congress of European society for clinical neuropharmacology, http://www.esncp.org	Zagreb, Croatia
28-31 October 2010	The 4th World Congress on Controversies in Neurology (CONy), www.comtecmed.com	Barcelona, Spain
3-5 November 2010	Third Conference: Clinical Trials on Alzheimer's Disease (CTAD),	Toulouse, France

	http://www.ctad.fr	
9-13 March 2011	The 10th International Conference on Alzheimer's & Parkinson's Diseases (AD/PD 2011), www2.kenes.com/adpd/Pages/Home.aspx	Barcelona, Spain
14-17 April 2011	The VII International Association of Gerontology and Geriatrics (IAGG) – European Region Congress “ Healthy and Active Ageing for all Europeans II”, www.iaggbologna2011.com	Bologna, Italy



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