Editorial

In April, we were able to welcome MEPs Nikolaos Chountis and Liz Lynne as two new members of the European Alzheimer’s Alliance. I am delighted to see that our campaign to make dementia a European priority continues to receive the support of Members of the European Parliament regardless of nationality and political affiliation.

Our political priority to see greater collaboration between European countries on dementia research also received a significant boost this month, as the European Commission has adopted a contribution of nearly EUR 2 million to support the work of the Joint Programming Initiative (JPI) on Alzheimer’s disease and neurodegenerative diseases. This funding will help to ensure that this important initiative, which already has the commitment of 24 European countries, will succeed.

The Chair of the Management Board of the pilot JPI, Professor Philippe Amouyel, has given an in depth interview about the Initiative in issue 5 of the Dementia in Europe magazine, which we launched in April. This issue of the magazine also carries news on dementia from various European countries (including Malta, Cyprus, Portugal, Finland, Spain and Greece) as well as updates on Alzheimer Europe’s work. The magazine can of course be bought in the e-shop of the Alzheimer Europe website.

We had hoped to host our 8th lunch debate in the European Parliament but unfortunately due to the travel disruption caused by the volcano in Iceland, we had to cancel this event. We look forward to our next debate in the Parliament, scheduled for 22 June this year.

The Alzheimer Europe Board met up in April and was happy with the direction in which the organisation is going and satisfied with the accounts.

This month we report on our members’ work in Germany, Greece, Ireland, Portugal, Scotland and the UK. Both Ireland and Scotland have produced reports regarding carers of dementia, highlighting different ways in which they need support.

As the elections in the UK get underway, I am pleased that the Alzheimer’s Society (UK) reports that each of the main political parties in the UK has highlighted dementia research and care and support as issues which need to be addressed in any future government.

In this newsletter, we also report on the increasing number of clinical trials being conducted to identify new drugs for the treatment of Alzheimer’s disease, whilst a report from the National Institute of Health in the United States makes for sombre reading as to possible preventive approaches to reduce the risk of Alzheimer’s disease.

Finally, I am happy to report that registrations for our forthcoming 20th Alzheimer Europe Conference are now well underway and would take this opportunity to remind you of the early bird registration which is available until the end of July.

Jean Georges
Executive Director
European Alzheimer’s Alliance

In April, Nikołaj Chountis (Greece) and Liz Lynne (UK) joined the European Alzheimer’s Alliance, which brings the total number of MEPs in the Alliance to 45, 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:**
Cabrnoch Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP)

**Denmark:**
Schaldemose Christel (S&D)

**Finland:**
Jaakonsaari Liisa (S&D), Jääätteenmäki 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-Tsarapoulou 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)

**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

26 April 2010: Alzheimer Europe publishes issue 5 of the Dementia in Europe magazine

Issue 5 of the Dementia in Europe magazine has been published by Alzheimer Europe. As well as the regular features, highlights of this issue include:

- Interviews with the Executive of the European Alzheimer’s Alliance (MEPs Françoise Grossetête, Frieda Brepoels, Dagmar Roth-Behrendt and Brian Crowley)
- Updates on two of the Alzheimer Europe’s current projects that Alzheimer Europe is involved in (European Ethics Network and PharmaCog)
- A review of the 2009 Dementia in Europe Yearbook on healthcare decision making in Europe for people with dementia
- Updates on the development of national plans in Malta, Cyprus and Portugal
- MEP Sirpa Pietikäinen talks about the challenges faced by people with dementia in Finland
- An in-depth interview with the Chair of the Management Board of the Joint Programming Initiative of Neurodegenerative diseases, Prof. Philippe Amouyel
- A carer’s perspective of living with dementia in Spain
- The work of the Greek Association of Alzheimer’s disease and related disorders which celebrates its 15th anniversary.

The magazine costs EUR 2.50 (plus EUR 2.50 p&p) and can be purchased from Alzheimer Europe’s publications section of the website.
26 April 2010: Alzheimer Europe Board Meeting takes place in Brussels

The Alzheimer Europe Board met in Brussels, Belgium.

Discussions included:

- The 2009 financial accounts which were approved with an operating surplus of nearly EUR 16,000.
- The 2010 projected financial accounts.
- European developments, including the forthcoming Belgian Presidency Conference, the Joint Programming Initiative and Public Health Programme.
- The forthcoming 20th Alzheimer Europe conference in Luxembourg (September) and the Dementia Ethics Network project.

The next Board meeting will take place in Brussels on 21 June 2010.

Alzheimer Europe Networking

On 2 April (Luxembourg, Luxembourg) Julie met Jean-Paul Reuland from Binsfeld Publishers to discuss the Dementia in Europe magazine.

On 7 April (Luxembourg, Luxembourg) Gwladys met Sylvie Meyer for the Luxembourg Conference.

On 12 April (Brussels, Belgium) Annette met Antoniya Parvanova, MEP, to discuss the European Alzheimer’s Alliance.

On 19 April (Luxembourg, Luxembourg) Gwladys attended the Luxcongres meeting.

On 26 April (Brussels, Belgium) the AE staff attended the AE Board meeting.

On 27 April (Brussels, Belgium) Annette attended the EFPIA Think Tank meeting.

On 27 April (Brussels, Belgium) Annette attended the Employment and Social Affairs Committee meeting when Commissioner Andor presented its 2010 Work Programme.

On 27 and 28 April (Antwerp, Belgium) Dianne attended a joint workshop organised by the EFGCP-EUCROF on the Ethical Challenges in Clinical Research at Both Ends of Life.

On 28 April (Brussels, Belgium) Annette attended the launch of the Mental Health interest group in the European Parliament.

On 28 April (Brussels, Belgium) Annette attended the Industry Committee meeting when Commissioner Geoghan-Quinn presented the 2010 Research Work Programme.

On 28 April (Brussels, Belgium) Annette attended the Internal Market Committee meeting when Commissioner Dalli presented the 2010 Consumer Work Programme.

Buy the latest edition of the Dementia in Europe Magazine online at:

www.alzheimer-europe.org/Publications/E-shop

Highlights of this issue include interviews with the Executive members of the European Alzheimer's Alliance, a review of the 2009 Dementia in Europe Yearbook on healthcare decision making in Europe for people with dementia, updates on the development of national plans in Malta, Cyprus and Portugal, challenges faced by people with dementia in Finland, a carer's account of living with dementia in Spain, a reflection of the work of the Greek Association of Alzheimer's disease and related disorders as well as an indepth interview with Professor Philippe Amouyel, the Chair of the Management Board of the Joint Programming Initiative of Neurodegenerative diseases.

€2.50 plus €2.50 handling and postage costs
European developments

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

31 March 2010: EU Commissioner for Administration and Inter-institutional Affairs, Maroš Šefcovic, unveils details of the 'European citizens initiative'

Following the entry into force of the Lisbon treaty in December 2009, the European Commission presented on 31 March 2010 a proposal for a Regulation of the European Parliament and the Council on the citizens initiative.

The new European citizens initiative is intended to make the EU more democratic by giving citizens a more direct say in its policies. From now on and once the conditions have been met, the European Commission, which drafts legislation, will have a formal obligation to consider proposals from citizens.

To be considered by the Commission, the Treaty states that an initiative must be backed by at least one million citizens from a minimum of one-third of EU countries (9 at present). Thus, elaborating on the concept, the Commission has drawn up a set of rules for Europeans to follow in submitting their petitions. Under the current proposals, the number of signatures from each country must be proportional to its size – 4,500 for the four smallest countries up to 72,000 for the largest. Once at least 300,000 signatures from citizens in a minimum of 3 countries have been collected, the petition will be registered with the Commission and a decision made on whether the initiative falls within the scope of its powers. From that point, the organisers would have one year to provide the outstanding signatures.

To avoid fraud, signatories must provide their home address, date of birth, nationality and a personal identification number – national identity card, passport or social security number. Organisers will also need to disclose who is financing the petition.

Before this initiative comes into force, the European Parliament and the Council must give their approval.

1 April 2010: New Director General takes position at DG Sanco

On 1 April, Paola Testori Coggi took up the position of Director General at DG Sanco. She replaces Robert Madelin who has become Director General for Information Society and Media DG.

Ms Testori Coggi joined DG Sanco in 2007 as deputy director-general in the health and consumers directorate-general. Her educational background is in biological sciences.

7 April 2010: Green light for 18 new MEPs

The Constitutional Affairs Committee voted on 7 April 2010 on Inigo Mendez de Vigo’s report to solve the problem created by the last European elections which took part under the Nice Treaty: the Nice Treaty established the number of MEPs at 736 while the Lisbon Treaty, adopted in December 2009, provides for 751 MEPs.

Twelve countries will send new MEPs: Spain (4), Austria, France and Sweden (2), Bulgaria, Italy, Latvia, Malta, the Netherlands, Poland, Slovenia and the United Kingdom (1 MEP). Germany will lose three seats but only after the next European elections in 2014 as Article 5 of the Act of 20 September 1976 does not allow curtailing an MEP’s mandate.

The Constitutional Affairs Committee has clearly stated that all 18 new MEPs should take up their seats at the same time in order to maintain the balance of nationalities in the House. It thus urges Member States to complete their election procedures in a pragmatic way as soon as possible.

The Constitutional Affairs Committee also agreed with the Council’s recommendation not to summon a Convention to officialise the Treaty change.

The decision will need to be confirmed in the next Strasbourg plenary, and the European Council would be in a position to conclude next June in a brief Intergovernmental Conference.

www.alzheimer-europe.org/Donation

17 April 2010: European Commission contributes close to EUR 2 million to the Joint Programming Initiative on Alzheimer’s disease and neurodegenerative diseases

The European Commission will be supporting the work of the Joint Programming Initiative on Alzheimer’s disease and neurodegenerative diseases (JPI) with an EU contribution of close to EUR 2 million.

The European Commission welcomes the meeting of the Scientific Advisory Board of this very first EU Joint Programming Initiative (15 April, Stockholm).

The Scientific Advisory Board gathers 15 of the top specialists in neurodegenerative disease from Europe and elsewhere in the world. Its role is to advise on the development and implementation of the JPI. Professor Philippe Amouyel, from France, chairs this new initiative Management Board.

The ultimate goal of the JPI is to accelerate progress in understanding the causes of these debilitating conditions, leading to early diagnosis, the development of new treatments and prevention and the provision of more effective medical and social care to improve the quality of life for patients and care-givers.
To achieve this goal, 24 European countries, sharing a common vision, have decided to work together in an unprecedented collaborative initiative in research which is seeking to align their scientific competencies, medical strengths and social approaches to tackle the challenge.

The JPI will start by:

- Developing a strategic research agenda for neurodegenerative diseases encompassing basic, clinical and social research, with the latter also including models of healthcare delivery.
- Implementing that agenda by proposing innovative ways of pooling expertise and resources to address the fragmentation and duplication of current research efforts.

**Policy Watch**

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

15 April 2010: The Alzheimer’s Society considers how the UK political parties election manifestos affect people with dementia

The Alzheimer’s Society has compared the three main UK political parties manifestos in relation to care and support, attendance allowance and dementia research.

The Conservative Party pledges to:

- Introduce a voluntary one-off insurance premium, at a suggested cost of GBP 8,000, to cover the costs of care in a care home,
- Design a system to allow people to top-up this insurance premium to cover the costs of people receiving care in their own home
- Support people to live independently at home and have access to the personal care they need.
- Protect the attendance allowance.
- Give dementia research (including Alzheimer’s) greater priority within NHS and Medical Research Council funding.

The Labour Party pledges to:

- Create a National Care Service which would involve the introduction of free personal care in the home for those with the highest care needs, a cap on the costs of care charges in a residential care home after two years, the establishment of a Commission to reach consensus on financing the system, and the establishment of a comprehensive National Care Service, free at the point of use, for all adults with an eligible care need.
- Rule out changes to the Attendance Allowance in the next Parliament (this was mentioned in their recently published White Paper (Building the National Care Service)
- Commit to ring-fence the science budget in the next Government spending review.
- Not to implement the Free personal Care at Home Act, targeted at people with the highest care needs, but instead use the money intended for this scheme to provide respite care for 1 million carers
- To establish a Commission with cross-party political support to look into the long-term future of social care, based on the principles of affordability, fairness and sustainability.
- To keep the Attendance Allowance according to a spokesperson.
- To prioritise dementia research in the health research and development budget.

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

**Members’ News**

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

12 April 2010: German booklet on rights for people with dementia updated

The German Alzheimer Society (Deutsche Alzheimer Gesellschaft) have published an updated version of their guide to legal and financial issues for people with dementia entitled “Ratgeber in rechtlichen und finanziellen Fragen”. Lawyer, Bärbel Schönhof, reviewed the booklet and said that the guide provides information about legal rights and hopes to encourage people to exercise these rights and not be put off by a laborious application process.

The guide to legal and financial issues for people with dementia and their carers has 160 pages (6th edition) and costs EUR 6.

15 April 2010: Alzheimer’s Society report published on criteria for improving quality of life for people with dementia

Following on from the “Dementia – out of the shadows” report, in which people with dementia spoke out about stigma and the impact that the diagnosis had on their lives, the Alzheimer's Society has undertaken a new project focusing on quality of life in dementia. The new report, “My name is not dementia” presents the findings of the first stage of this project.

Acting Chief Executive, Ruth Sutherland, explains in the preface of the report that “By listening to those who live with dementia, this piece of work begins to bring together what they think is important.” The report identified 10 key quality of life indicators by people with dementia:
Four recommendations were made:

- Relationships or someone to talk to
- Environment
- Physical health
- Sense of humour
- Independence
- Ability to communicate
- Sense of personal identity
- Ability or opportunity to engage in activities
- Ability to practise faith or religion
- Experience of stigma.

Part of the project entailed interviews with people with dementia and it was clear that they want to lead an independent life for as long as possible. This is because they feel secure and maintain their own identity in their own home. The project showed that such independence is a possibility for people with dementia if they are adequately supported in their home environment. Prof. Andreas Kruse said that people with dementia need "protection and support to live alone", with support by a "caring community", in which citizens are sensitive and attentive and are willing to take responsibility.

The project also highlighted the role of municipalities, cities and districts as they can make an important contribution to informing the public about dementia and offering training and networking services for major occupational groups.

The results of the project are to be found in the handbook “Allein leben mit Demenz. Herausforderung für Kommunen” (EUR 10) presented on a DVD, which can be ordered from the German Alzheimer Society. The DVD also contains interviews (from people living alone with dementia about their needs, desires and fears) and training materials (for police officers, firefighters, bank employees, people working in retail and the neighbourhood). The role and scope for action by local authorities is also addressed. Detailed proceedings of the launch event will be made available in May 2010.

16 April 2010: Greek Alzheimer association organises an "Alzheimer’s Chocolate Evening"

Following the well known concept of the Alzheimer’s café, the Greek Association of Alzheimer’s Disease and Related Disorders recently organised an event called "Alzheimer’s Chocolate Evening". The event was held on Thursday, 16 April 2010 in the Military Officer’s Club in the centre of Thessaloniki.

The event was a unique opportunity for people with dementia, their carers, relatives and personnel to meet in a friendly environment in order to socialise and tackle social stigma. Many sponsors have supported this initiative, mainly by providing the necessary chocolate products to treat the guests. The Military Officer’s Club also kindly provided a spacious room within the venue, to host nearly 400 people who attended the event.

Professor Magda Tsolaki, president of the Greek Federation of Alzheimer’s Disease and Related Disorders, who pioneered the idea, had also the chance to present to the audience a brief discussion with one carer, whose experience and advice acted as a guideline for the rest of the families who attended the event. The carer had many experiences to share, since she took care of her mother and her husband as well, both suffering from Alzheimer’s disease. Thus, “Alzheimer’s Chocolate Evening” was not only a social event but also a fruitful exchange of experiences among people with dementia and their carers. The Greek Federation hopes that this initiative will be one of many to follow in their
continuous efforts to improve the quality of life for people with dementia.

23 April 2010: UK – Alzheimer’s Society calls for all nurses to be trained in dementia care

The Alzheimer’s Society called has called for all nurses to be trained in dementia care and has made recommendations on how dementia should be included in the Nursing and Midwifery Council standards.

Andrew Chidgey, Head of Policy and Public Affairs of the Society said, “People with dementia occupy up to a quarter of hospital beds at any one time yet many are receiving inappropriate care and leaving hospital far worse than when they arrived. Nurses regularly tell us they’re not receiving enough training in dementia. This needs to end. The NMC must recommend that all student nurses receive training that equips them to provide the best dementia care possible. The draft standards can also be strengthened to help ensure that dementia training is in all university curriculums.”

26 April 2010: London Marathon runners raise money for the Alzheimer’s Society

The Alzheimer’s Society’s running team raised GBP 360,000 in this year’s London Marathon. Among the Alzheimer Society’s runners were Yasmina Siadatan - who won the 2009 Apprentice programme, Alan White - Oasis drummer, Richard McCourt - television presenter and Rick Guard – Jazz singer.

Director of Fundraising and Marketing, Jo Swinhoe, said: ‘We would like to say an enormous thank you to all our runners who rose to the challenge of the Virgin London Marathon 2010. We are incredibly fortunate to have such dedicated supporters, and are truly grateful for all the training, effort and energy they have put in to completing the Marathon to raise funds for Alzheimer’s Society.”

26 April 2010: Alzheimer’s Society Acting Chief Executive named Chairman of research forum

Alzheimer’s Society’s Acting Chief Executive has been appointed to the top post of an influential UK research forum. Ruth Sutherland has taken on the additional role of chairperson of the UK Age Research Forum (UKARF). She replaces Neil Hunt who stood down from the role and his role as Chief Executive of the Alzheimer’s Society in March this year.

The forum, made up of government, research council and charity representatives makes a positive difference to the lives of older people by promoting high quality research.

Ruth Sutherland said: ‘I am very excited to have the opportunity to chair this influential group. The UK Age Research Forum provides an excellent platform for key funders in the field of ageing research to come together, share their expertise and help shape the future of scientific study to benefit some of society’s most vulnerable members.

‘One in three people over 65 will die with dementia yet dementia research is still drastically underfunded. It is vital that the necessary money and expertise are available for this and research into ageing more generally if advancements are to be made.’

27 April 2010: Research published on carers’ experiences which was commissioned by the Alzheimer Society of Ireland

A report entitled “Care for People with Dementia: Irish Family Carers”, which was commissioned by the Alzheimer Society of Ireland and St Luke’s Home in Cork, describes 14 carers’ experiences following the move of a relative with dementia from the family home into nursing home care.

Lead author of the report, Prof. Murna Downs, said “What is striking about this research is the clear commitment carers have to continuing to care for their relative after admission to long-term care, as well as a desire for their relative to experience the same standards of care they received in the family setting.”

Recommendations are made in the report including:

- Better resourcing of community-based services for people with dementia and their carers, so nursing home admissions are a pro-actively planned choice rather than being crisis-driven.
- Greater recognition by health authorities that carers need guidance and support in order to navigate the care system and when accessing support services.
- Campaigns to challenge the ignorance and stigma associated both with dementia and nursing home care.
- Ensuring nursing homes actively support carers who wish to remain involved in the care of their relative, while respecting the wishes of those who no longer want to play such a role.

28 April 2010: Alzheimer Portugal introduces new Workshops - “Alzheimer’s Disease - A personal challenge: strategies for informal caregivers/ Legal Aspects”

Due to the increasing number of people diagnosed with Alzheimer’s disease, and the great need of support and training by caregivers to provide better care to their relatives with dementia, Alzheimer Portugal has been developing its training program.

In 2010 two new workshops were created: The first one aims to provide caregivers with strategies to cope with the changes that Alzheimer’s disease generates in their daily routines, family activities and personal/professional life. Through a series of practical exercises the participants are able to explore new ways of improving the management of emotions, time and information, they have to deal with, when coping with dementia. This workshop is
given by Henrique Fernandes Silva (a caregiver with several years of experience).

The second workshop aims to give caregivers tactics to deal with legal issues which are essential for providing appropriate and efficient care, based on the rights of people with dementia.

Business management and protective regimes for people with dementia (guardianship) are just a few examples of the themes addressed in a simple and understandable way, using concrete situations.

Training is provided by the President of Alzheimer Portugal Board, Maria do Rosário Zincke dos Reis (who is a lawyer by profession).

**28 April 2010: Alzheimer Scotland launches report on the provision of care to people with dementia**

The report “Let’s get personal – personalisation and dementia” by Lindsay Kinnaird, has been launched which looks at the way social support is provided to people with dementia and their carers. The report focuses on 12 case studies where families were able to organise specialised support by using Direct Payments from the Social Work Department. The support included the employment of personal assistants for overnight support and also support allowing respite breaks for carers. The report highlighted a number of barriers to Direct Payment for people with dementia and makes recommendations on how to use the payment system.

Henry Simmons, 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 approach will be recognised by the forthcoming National Dementia Strategy and will be central to reshaping care in the future.”

**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.

**22 March 2010: Researchers create proposal for future dementia care home design**

In the project, ‘Living with Dementia: Can Design make a Difference?’ researchers visited nineteen care homes, studying the architecture, decor, layout, gardens and lighting and then drew up proposals for future care home design. The researchers noted that more stimulating homes showed improvements in residents physical or mental condition and that this was not necessarily linked to greater luxury or more staff.

The proposals drawn up include special attention being paid to:

- The layout of the premises: A sense of neighbourhood could be achieved if the homes were designed as small single storey ‘villages’ with shops, cafes and gardens.
- Accessibility: Plans should be made to enable residents to take part in activities such as gardening, eg. ensuring accessibility for wheelchair users, using raised flower beds in gardens to allow residents to grow vegetables and using special types of bird feeders, allowing residents to feed the birds.
- Activities: (a) for children and residents. Intergenerational games and exercises should be available to encourage children to visit residents, (b) for residents. The team noted that one care home left out old engine parts which were of interest to residents.
- Natural light: The team urged developers to incorporate natural light and sheltered outdoor seating.
- Ambience: In order to help residents remember a normal life, the researchers highlighted the fact that residents should be made of ordinary activities, such as cooking and laundry going on. One team designed a tea bar which enabled residents to sit and chat with visitors.

The study was led by Professor Hilary Dalke, Director of the Design Research Centre, Kingston University, London and the proposals are being exhibited at the Building Centre, London.

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

**26 March 2010: Study suggests a relationship between amyloid accumulation and the disruption of connections to the hippocampus**

A study which used MRI scans to study Alzheimer’s disease affected brain tissue, found that the “shrinking of the hippocampus was associated with plaque deposits in the temporal inferior cortex”, suggesting that the accumulation of amyloid in the temporal inferior cortex causes neurons to die by disrupting the connections with hippocampus.

The research was led by Dr Perrick Bourgeat, Australian e-Health Research Centre and published in Neurology.
1 April 2010: Study suggests that atrial fibrillation is independently linked to the risk of dementia

A five-year study on over 37,000 people found that “atrial fibrillation” is independently associated with the risk of all forms of dementia. Although dementia is strongly associated with ageing, the highest risk of AD was in the younger group, in support of the observed association. The presence of AF also identified dementia patients at high risk of death.

The study was lead by T Jared Bunch, MD, Intermountain Heart Rhythm Specialist, Intermountain Medical Center, Murray, UT and published in the HeartRhythm Journal.

1 April 2010: Study investigates the effect that some Alzheimer drug candidates have on neural degeneration

Researchers have found that non-amyloidogenic peptides (formed by some Alzheimer’s drug candidates) cause active ion channels to be formed, which in turn cause cells to take in very high levels of calcium ions, damaging synaptic efficiency and eventually kill neurons linked to memory loss.

The research was carried out by Ratnesh Lal, nanobiophysicist, University of California San Diego (UCSD) and colleagues and published in the journal the Proceedings of the National Academy of Sciences.

www.alzheimer-europe.org/Donation

1 April 2010: USD 270,000 awarded to investigate potential therapy for Alzheimer’s disease

A grant of USD 270,000 has been given to the company Signum Biosciences Inc. (USA) so that it can evaluate the role a modulatory compound, known as protein phosphatase 2a (PP2A), can play in disease-modifying therapy for Alzheimer’s disease. The grant has been provided by the Alzheimer’s Drug Discovery Foundation (ADDF). USD 300,000 was awarded to three scientists: Philip Van Damme (Leuven University, Belgium), Einar M Sigurdsson (New York University School of Medicine) and W Haung Yu (The Taub Institute of Columbia University Medial Center).

12 April 2010: Study suggests diet has beneficial effect on the risk of Alzheimer’s disease

A study which monitored over 2000 healthy people over 65 for 4 years has found that the risk of Alzheimer’s disease was lower in those people who adhered to a dietary pattern of olive oil, nuts, fish, tomatoes, poultry and cruciferous vegetables and who ate less red meat, organ meat or high fat dairy products.

The study was conducted by Yian Gu, Columbia University Medial Center, New York, USA and colleagues.

12 April 2010: Animal study suggests that targeting blood-brain barrier may delay the progression of Alzheimer’s disease

A study in which 12 week-old genetically modified mice which expressed the human beta-amyloid protein (associated with Alzheimer’s disease) were treated with a steroid-like chemical that activates a receptor (pregnane X receptor or PXR), found that this in turn increased the expression of a blood-brain barrier protein (P-glycoprotein) which transports beta-amyloid out of the brain.
The study was led by Anika Hartz and supported by the National Institute of Environmental Health Sciences (NIEHS), USA and is due to be published in the May issue of Molecular Pharmacology.

12 April 2010: Study examines the longevity of emotions

A study in which a group of people with amnesia were shown film clips to ascertain whether their experience of firstly sadness and then happiness would persist beyond their memory for the inducing clips suggests that the people had elevated levels of emotion even after their factual memory of the clips had gone. The researchers believe that this could have direct implications for people with Alzheimer’s disease as it shows that a person’s happiness can be influenced even though an actual event may be forgotten.

The research was led by Justin Feinstein, University of Iowa, USA and published in the Proceedings of the National Academy of Science.

12 April 2010: Guidelines issued to help evaluate driving risk in dementia

A guideline has been published which is aimed to help determine when people with dementia should stop driving. Issued by the American Academy of Neurology the paper recommends certain characteristics should be considered including:

- The Clinical Dementia rating scale
- A caregiver’s rating of a person with dementia's driving ability
- A history of crashes or traffic citations
- Reduced driving mileage or self-reported situational avoidance
- Mini-mental state examination scores
- Personality characteristics.

13 April 2010: Phase II study examines effect of antibodies on Alzheimer’s disease

Findings from the Phase II clinical trial (involving 24 people) of Gammagard Liquid and Gammagard S/D Immune Globulin Intravenous (Human) (IGIV) for Alzheimer’s disease suggest that people with Alzheimer’s disease, who received IGIV for an 18 month period had “significantly lower rates of ventricular enlargement and less whole-brain atrophy than control subjects.” Phase III trials are ongoing.

The study was conducted by researchers at the NewYork Presbyterian Hospital/Weill Cornell Medical Center, USA and reported on at the American Academy of Neurology (AAN) meeting in Toronto, Canada.

15 April 2010: Study evaluates the joint effects of physical exercise and computer use on mild cognitive impairment

A study on over 900 people aged 70-90 years old, found that moderate physical exercise and computer use were separately associated with a reduced risk of mild cognitive impairment and that when both activities were carried out that their beneficial join effect was greater than what would have been predicted from their separate effects.

The study was conducted by researchers from the Mayo Clinic, USA and led by Yonas Endale Geda. It will be presented at the American Academy of Neurology Annual Meeting on April 15.

16 April 2010: Study examines the effect brain training has on memory

A study on 64 people who had problems including brain damage, stroke and dementia, found that brain training games on electronic devices proved to be more effective at improving memory than carrying out similar exercises with a pen and paper.

The research was led by Linton Kohr and Dr Simon Moore from London Metropolitan University and presented at the British Psychological Society’s annual conference.

19 April 2010: Study examines link between brain volume and obesity

Researchers from the University of California, Los Angeles, have found a pattern of “diminished brain volume” in people with specific DNA sequence within the fat mass and obesity-associated (FTO) and this finding suggests that these people could be a greater risk of developing dementia.

The research was carried out by April Ho et al, on 206 people and published in the April edition of the Proceedings of the National Academy of Sciences.

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

19 April 2010: Additional analysis of potential Alzheimer’s drug published

The results of the Phase Ila clinical trial of the potential Alzheimer drug PBT2 (developed by Prana Biotechnology) were published in the journal, Lancet Neurology (June 2008 and July 2009). New analysis of the results has been published in the Journal of Alzheimer’s disease which suggests that the drug is effective in reversing dementia symptoms. The analysis was conducted by Professor Ashley Bush of the Mental Health Research Institute and the University of Melbourne, Australia.

23 April 2010: Phase II trials of potential Alzheimer drug to commence in Europe

The potential vaccine against Alzheimer’s disease, AD02, developed by the Austrian biotechnology firm Affiris and British company GlaxoSmithKline, is to be tested in six European countries. 420 people will be recruited to take part in clinical trials in Austria, Croatia, Czech Republic, France, Germany and Slovakia. The drug has been tested for safety and
tolerability and the new Phase II tests will monitor efficacy, with results being expected in 2012.

28 April 2010: US Independent panel determines that there is insufficient evidence that preventive measures reduce the risk of Alzheimer’s disease

An independent panel convened by the US National Institutes of Health has determined that “there is currently no evidence of even moderate scientific quality supporting the association of any modifiable factor—dietary supplement intake, use of prescription or non-prescription drugs, diet, exercise, and social engagement—with reduced risk of Alzheimer’s disease. The evidence surrounding risk reduction for cognitive decline is similarly limited. Low-grade evidence shows weak associations between many lifestyle choices and reduced risk of Alzheimer’s disease and cognitive decline.” Therefore, the panel has called for more public understanding that such “proposed prevention strategies are currently, at best, only loosely associated with improved outcomes.” The panel found that the two non-modifiable risk factors for Alzheimer’s disease are age and a genetic variant of a protein (apolipoprotein E).

The panel acknowledged that whilst there is little evidence that modifiable risk factors may prevent Alzheimer’s disease, they can nevertheless be associated with other benefits.

The panel recommended that the research community and clinicians collaborate to develop, test, and uniformly adopt objective measures of baseline cognitive function and changes over time and they made a number of recommendations regarding the future research agenda.

The conference panel chair, Dr Martha L Daviglus said “Alzheimer’s disease is a feared and heartbreaking disease. We wish we could tell people that taking a pill or doing a puzzle every day would prevent this terrible disease, but current evidence doesn’t support this.”

The 15-member panel included experts in the fields of preventive medicine, geriatrics, internal medicine, neurology, neurological surgery, psychiatry, mental health, human nutrition, pharmacology, genetic medicine, nursing, health economics, health services research, and family caregiving.

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.

29 March 2010: Report highlights that people with newly-diagnosed Alzheimer’s disease do not receive Alzheimer’s drugs as first line-therapy

The report entitled ‘Treatment Algorithms in Alzheimer’s Disease’ by the research firm, Decision Resources, states that of those people who are diagnosed with mild-to-moderate Alzheimer’s disease over a quarter are prescribed an antidepressant and only just over half are prescribed acetylcholinesterase inhibitor (AChEI) (an Alzheimer’s drug).

Long delays between a person’s diagnosis of Alzheimer’s disease to the start of treatment were also highlighted in the report.

26 April 2010: Publication released about Telecare and dementia

“Telecare and dementia” by the University of Stirling and the Dementia Services Development Centre considers how telecare can contribute to the support, protection and quality of life of people with dementia and also the importance of telecare in providing support and reassurance to carers.

Telecare and dementia costs GBP 15.00 (or may be downloaded in Scotland) and received funding from the Scottish Government’s Telecare Development Programme.

27 April 2010: New publication released on methods for managing behaviour changes in people with dementia

The Lewy Body Dementia association has published “Understanding Behavioural Changes in Dementia”, which contains suggestions for effective methods to manage difficult behaviour in people with dementia (such as wandering, aggression, sleep problems).

The book considers issues such as:

- Using routines
- Communicating effectively
- Wandering

Dementia in Society

23 April 2010: Actor David Hyde Pierce receives recognition for his work on Alzheimer’s disease

It has been announced that Actor David Hyde Pierce will receive a Tony Awards® Isabelle Stevenson Award in recognition of his “substantial contribution of volunteered time and effort on behalf of one or more humanitarian, social service or charitable organisation, regardless of whether such organisations relate to the theatre.” Mr Pierce is an honorary member of the Alzheimer’s Association’s national board and he has regularly participated in the Alzheimer’s Action Summit in Washington, DC to advocate for increased investment in Alzheimer’s research.

The actor won a Tony Award for his performance in Curtains, has been on Broadway (Accent on Youth, Spamalot, The Heidi Chronicles and Beyond Therapy) and won an Emmy for his work on the sitcom Frasier.

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Preventing or diffusing aggression
Benefits of exercise
Managing sleep problems
Smoothing the transition on moving day
Finding in-home caregivers
Care for the caregiver
Support groups.

The literature was written by Tanis J. Ferman, PhD, Mayo Clinic, Glenn E. Smith, PhD, Mayo Clinic, and Briana Melom, MA, LSW and can be downloaded from the Lewy Body Dementia association website.

Call for abstracts for 20th AE Conference in Luxembourg is now open

There is the possibility of submitting your abstract via the Alzheimer Europe website on: www.alzheimer-europe.org/conferences

We welcome abstracts for the following subjects:

People with dementia and their carers
- Education and training of people with dementia and their carers
- Relationships and sexuality
- New technologies in the home
- Proxy decision making – Giving a voice to people with dementia

Professional carers
- Innovative care services
- Avoiding neglect, coercive measures and abuse
- Caring professions and their training
- New technologies for the caring professions

Medical professionals and researchers
- Involving people with dementia and their carers in research
- Communicating research results and managing expectations
- Disclosing a diagnosis to people with dementia and their carers
- Dementia research made easy

Policy makers
- Successful campaigning
- National dementia strategies
- Financing care and dementia research
- Policies supporting people with dementia and their carers.
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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<tbody>
<tr>
<td>4 May 2010</td>
<td>Expert meeting (Belgian Presidency conference) (Brussels, Belgium)</td>
<td>Jean, Annette</td>
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<tr>
<td>4 May 2010</td>
<td>Commissioner Dalli presents its 2010 Health Work Programme (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>5 May 2010</td>
<td>Recognition Programme (Berlin, Germany)</td>
<td>Jean</td>
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<tr>
<td>6 May 2010</td>
<td>PharmaCog meeting (Paris, France)</td>
<td>Jean</td>
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<tr>
<td>6 May 2010</td>
<td>Patients Rights Day (EP) (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>13 May 2010</td>
<td>Meeting with Pfizer (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>18 May 2010</td>
<td>European’s Patients’ Forum HTA seminar (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>19 May 2010</td>
<td>European Patient’s Forum General Assembly meeting</td>
<td>Annette</td>
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Future Conferences

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>12-14 May 2010</td>
<td>7th Biennial Conference Barcelona/Pittsburgh, <a href="http://www.fundacioace.com">www.fundacioace.com</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>24-27 June 2010</td>
<td>1st International Congress on controversies in longevity, health and aging (CoLONGY), <a href="http://www.comtecomed.com">www.comtecomed.com</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>8-11 September 2010</td>
<td>International Conference on evidence-based policy in long-term care, <a href="mailto:llconference2010@lse.ac.uk">llconference2010@lse.ac.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>15-17 September 2010</td>
<td>26e Congrès de la Société de Psychogériatrie de Langue Française (SPLF), <a href="http://www.nexcom-events.com">www.nexcom-events.com</a></td>
<td>Limoges, France</td>
</tr>
<tr>
<td>22-25 September 2010</td>
<td>5th Croatian Congress on Alzheimer’s Disease with international participation, <a href="http://www.alzheimer2010.com">www.alzheimer2010.com</a></td>
<td>Zadar, Croatia</td>
</tr>
<tr>
<td>7-9 October 2010</td>
<td>Gemeinschaft leben, <a href="http://www.deutsche-alzheimer.de">www.deutsche-alzheimer.de</a></td>
<td>Braunschweig, Germany</td>
</tr>
<tr>
<td>19-21 October 2010</td>
<td>Coming of Age: Dementia in the 21st Century, <a href="http://www.dementia.stir.ac.uk">www.dementia.stir.ac.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>21-23 October 2010</td>
<td>10th Congress of European society for clinical neuro-pharmacology, <a href="mailto:ivan.rektor@fnusa.cz">ivan.rektor@fnusa.cz</a></td>
<td>Zagreb, Croatia</td>
</tr>
<tr>
<td>3-5 November 2010</td>
<td>Third Conference: Clinical Trials on Alzheimer’s Disease (CTAD), <a href="http://www.ctad.fr">http://www.ctad.fr</a></td>
<td>Toulouse, France</td>
</tr>
<tr>
<td>9-13 March 2011</td>
<td>The 10th International Conference on Alzheimer’s &amp; Parkinson’s Diseases (AD/PD 2011), www2.kenes.com/adpd/Pages/Home.aspx</td>
<td>Barcelona, Spain</td>
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<tr>
<td>14-17 April 2011</td>
<td>The VII International Association of Gerontology and Geriatrics (IAGG) – European Region Congress “ Healthy and Active Ageing for all Europeans II”, <a href="http://www.iaggbologna2011.com">www.iaggbologna2011.com</a></td>
<td>Bologna, Italy</td>
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