



NEWSLETTER

June 2011

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Editorial

Alzheimer Europe was exceptionally busy during the month of June as we attended and hosted various meetings and launched issue 8 of the Dementia in Europe magazine.



Sirpa Pietikäinen, MEP (Finland) and member of the European Alzheimer's Alliance and the AE Board, hosted Alzheimer Europe's 10th lunch debate which was dedicated to the European Joint Action on Dementia. This was a lively debate with nearly 40 participants from a variety of backgrounds. The presentation by Dr Leperre-Desplanques, was extremely clear and informative and I look forward to future participation in the project by members of Alzheimer Europe.

Another European Alzheimer's Alliance member, Nessa Childers, MEP (Ireland), organised a seminar in Ireland on shared dementia policies in Europe and Ireland. I am grateful to her for supporting with this concrete step the development of an Irish dementia strategy.

We hosted our second public affairs meeting with national Alzheimer associations in which we focused our attention on national dementia strategies with the aim of developing a model dementia plan. There is a wide disparity between the different countries regarding the progress of national plans.

Indeed, in this issue of the newsletter you will see that Scotland has carried out a review of the first year of its national strategy, policy makers in Portugal have reaffirmed their

support of a national dementia plan but in Romania there is not yet support at this level. It was clear during our public affairs meeting that by collaborating with each other, all participants felt that progress and our understanding of the challenges ahead can be dramatically enhanced.

In the UK, the importance of collaboration for dementia research was highlighted where the government has launched a 'route map for dementia research' in which 17 experts will participate. I hope that by bringing dementia research to the fore that progress will be made which will in turn help people with dementia and their carers. Alzheimer Europe is also focusing on dementia research and this month we hosted the first working group meeting on the ethical issues of dementia research which will result in recommendations and guidelines being published towards the end of this year.

Issue 8 of the Dementia in Europe magazine was launched this month and I am absolutely delighted that we were able to include a contribution from, amongst others, the European Commissioner for Employment, Social Affairs and Inclusion, László Andor who spoke about how the EU can help address dementia. Issue 8 focuses on policy developments in Italy, Greece, Ireland, Romania as well as information on long-term care in Europe and the PharmaCog project.

I am looking forward to the 21st Alzheimer Europe conference which will be held in Warsaw, Poland in October, especially as we already have received over 300 registrations. If you haven't registered yet you still can do so on the conference section of the Alzheimer Europe website.

Jean Georges
Executive Director

European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 54, representing 17 Member States of the European Union and all of the seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their continued support of the European Alzheimer's Alliance.

Belgium: Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Sterckx Dirk (ALDE), **Bulgaria:** Parvanova Antonyia (ALDE), Cyprus: Triantaphyllides Kyriacos (GUE-NGL), **Czech Republic:** Cabrnock Milan (ECR), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP), **Denmark:** Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jäättteenmäki 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), **Lithuania:** Vilija Blinkeviciute (S&D), **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP), **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP), **Portugal:** Coelho Carlos (EPP), Matias Marisa (GUE/NGL), **Romania:** Antonescu Elena Oana (EPP), **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP), **United Kingdom:** Derek Vaughan (S&D), Hall Fiona (ALDE), Lynne Liz (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

1 June 2011: Frank Engel, MEP (Luxembourg) joins the European Alzheimer's Alliance

Frank Engel, MEP, EPP - European People's Party, Luxembourg, has joined the European Alzheimer's Alliance. He is a member of the Committee of Employment and Social Affairs. He is also a member of the Special Committee on the Financial, Economic and Social Crisis and the Special committee on the policy challenges and budgetary resources for a sustainable European Union after 2013. He is the second MEP from Luxembourg to join the EAA which now has a total of 54 members.



17 June 2011: Nessa Childers organises seminar with the Alzheimer Society of Ireland on dementia

Nessa Childers, MEP (Ireland) and member of the European Alzheimer's Alliance, organised a seminar entitled "Shared Priorities – Dementia and Alzheimer policy in Europe and Ireland" on 17 June in Dublin, Ireland. The seminar offered a platform for policy and planning experts from Europe and Ireland to explore ways in which to help people with dementia and their families as well as ways in which to prevent the onset of dementia.



Ms Childers said: "Our health care system as it stands discriminates against older people, this may not be the intention but reflects a mind-set when it comes to spending policy. I'm calling for the end of the discrimination against illness of later life where there is a cap on medical care for older people that would not be tolerated in cancer care or care for children."

Ms Childers focused on the EU Joint Action on Alzheimer's initiative, which was launched early this year in an effort to step up cooperation and support to improve prevention, diagnosis, treatment and care across the EU.

Ms Childers introduced the following amendments to the new EU Initiative:

- To focus on specific needs of women, who account for twice the amount of people living with dementia, or caring for a family member with dementia.
- To focus on a healthy diet as current research suggests that diet may be a significant causal factor in the development of Alzheimer's.
- That the EU examines use of living wills.

Speakers at the seminar included Maurice O'Connell Alzheimer Society of Ireland; Deirdre Downes, Carer; Dominic Trepel, Health Economist, University of Limerick; Dr. Suzanne Cahill TCD; Michael Smith, Dept. of Health; Enda Connolly, The Health Research Board; Patricia Rickard-Clark, Law Reform Commission; Jean Georges, Alzheimer Europe and Dr. Roisín Rooney, European Commission.

The presentations from the seminar are available on request from Nessa Childers' Ireland East Office

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

Alzheimer Europe

In this section, we report on our current news, including our projects and events.

2-3 June 2011: Alzheimer Europe hosts first working group meeting on the ethical issues of dementia research

Alzheimer Europe hosted the first working group's meeting on the ethical issues of dementia research in Luxembourg on 2-3 June. Discussions centred around:

- Involving people with dementia
- Selecting, monitoring and disseminating research and the ethical procedures for the Brains for Dementia Research brain bank
- Bioethical principals and theories and how they might relate to research

- Ethical issues linked to clinical trials, including the ethical implications of the use of placebos in dementia research
- Research linked to prodromal or pre-symptomatic diagnosis
- Psycho-social and social sciences dementia research
- Ethical issues linked to the wellbeing of people with dementia involved in research.

Recommendations and guidelines on the ethical issues of dementia research will be published by Alzheimer Europe at the end of 2011.



(left to right: Dr Carlo Petrini, Prof. Sandro Sorbi, Dr Thomas Frühwald, Dr Rasa Ruseckiene, Dr Peter Annas, Angela Clayton-Turner, Dianne Gove, Maureen and James McKillop. Not in photograph: Dr Fabrice Gzil, Prof. Van den Block and Julie Fraser).

The working group was chaired by Dianne Gove, Information Officer of Alzheimer Europe and consists of 9 experts from 7 European countries [Austria (Dr Thomas Frühwald, Chief Doctor of the Department of Acute Geriatrics of the Hietzing Hospital, Vienna); France (Dr Fabrice Gzil, Head of Social Studies Department, Fondation Médéric Alzheimer in Paris); Italy (Dr Carlo Petrini, Head of the Bioethics Unit of National Institute, Rome and Prof. Sandro Sorbi, Professor of Neurology, Department of Neurological Science and Psychiatry at the University of Florence); Lithuania (Dr Rasa Ruseckiene, Consultant in adult and old age psychiatry and therapist); Sweden (Dr Peter Annas, Head of research at AstraZeneca and leader of the PharmaCog project); UK (England) Angela Clayton-Turner, volunteer, carer and member of the Alzheimer Society and (Scotland) James McKillop, who lives with dementia and is a founding member of the Scottish Working Group on Dementia, and his wife, Maureen McKillop, carer. Belgium will also be represented by Prof. Dr Lieve Van den Block, Ghent University and the Free University of Brussels but Prof. Van den Block was unable to attend the first meeting].



(left to right: Dr Peter Annas, Julie Fraser, Dr Carlo Petrini, Dianne Gove, Dr Thomas Frühwald, James McKillop, Dr Rasa Ruseckiene, Dr Fabrice Gzil, Angela Clayton-Turner and Maureen McKillop. Prof. Sandro Sorbi and Prof. Van den Block not on photograph).

26 June 2011: Alzheimer Europe Board meeting takes place in Brussels

The Board of Alzheimer Europe held its board meeting in Brussels on 26-27 June. The Board:

1. Reviewed the audited annual accounts for 2010 in preparation of the Annual General meeting (AGM) in September. The 2011 financial accounts, risk assessment and cash flow situation were also reviewed.
2. Discussed the work being carried out in 2011 by Alzheimer Europe (including: the Value of Diagnosis project which is due to be published during the International Conference on Alzheimer Disease in July, the Dementia Ethics Network which is focusing on the ethics of dementia research in 2011, the Legal Rights project on the restrictions of freedom and coercive measures – the results of which will be published in the 2011 Dementia in Europe Yearbook, the 2011 Alzheimer Europe Conference, European Solidarity without Borders”, which will be held in Warsaw in October, the newly-published issue 8 Dementia in Europe magazine and the plans for issue 9 which is due to be published in October).
3. Proposed that the draft paper “Involving people with dementia” be presented to the AGM in October. This includes suggestions for involving people with dementia in the work of Alzheimer Europe during conferences, activities, projects and governance of the organisation. The paper also highlights the changes required to the existing Alzheimer Europe statutes and rules and regulations if the above suggestions are to be implemented.
4. Proposed that the 2012 draft Workplan be presented to the AGM in October which includes a draft programme for the 22nd Alzheimer Europe conference, “Changing perceptions, practice and policy” to be held in Vienna, Austria.
5. Considered the financial situation for 2012. Particular attention was given to potential revenue arising from the application for an Operating Grant, the 2012 Alzheimer Europe conference and the membership fee schedule for 2012.

The next board meeting will be held in Warsaw, Poland, on 6 October, prior to the AGM.

27 June 2011: Alzheimer Europe hosts public affairs meeting for national Alzheimer associations

Alzheimer Europe’s second public affairs meeting for its members focused on a comparison of national dementia strategies within Europe, with the ultimate aim of developing a model dementia strategy.

The meeting was divided up into four discussion areas:

- Social and care issues

- Medical and scientific issues
- Legal and ethical issues and
- Financial and management issues.

The meeting was chaired by Jean Georges (Executive Director, Alzheimer Europe) and various elements of three national plans (Scotland, France and Norway) were highlighted by Henry Simmons (Chief Executive, Alzheimer Scotland), Annette Dumas (Public Affairs Officer, Alzheimer Europe) and Dianne Gove (Information Officer, Alzheimer Europe) respectively. A discussion followed with examples from each participating country of challenges within their countries. Proposals for the essential elements of a model dementia plan were also discussed. A further meeting is scheduled for December.

Twelve countries were represented at the meeting: Cyprus (Antigoni Diakou and Helena Constantina), Czech Republic (Iva Holmerová), Finland (Sirpa Pietikäinen and Pekka Laine), Germany (Heike von Lützu-Hohlbein), Greece (Magda Tsolaki, Paraskevi Sakka and Lorena Androutsou), Ireland (Grainne McGettrick), Malta (Charles Scerri), Poland (Alicja Sadowska), Romania (Maria Moglan), Switzerland (Marianne Wolfensberger) and the United Kingdom (Jeremy Hughes and Henry Simmons).

28 June 2011: New edition of the Dementia in Europe magazine launched



Alzheimer Europe launched edition 8 of the Dementia in Europe magazine during the lunch debate hosted by Finnish MEP Sirpa Pietikäinen on the European Commission's ALCOVE project on 28 June. Issue 8 highlights include:

- An interview with European Commissioner for Employment, Social Affairs and Inclusion, László Andor on how dementia is being addressed at European level.
- An article by Patrizia Toia, MEP (Italy) in which she talks about the situation in Italy for people with dementia and their carers.
- A moving account of the experience of living with dementia in Italy by Alzheimer Uniti and Paola, who has dementia.
- A look at the work carried out by national associations to secure the development of a national dementia plan. Paraskevi Sakka, Chairperson of the Athens Alzheimer's Association and Vice-President of the Greek Alzheimer's Federation talks about the work carried out in Greece and Sarah O'Callaghan, Head of Public Affairs and Communications at the Alzheimer Society of Ireland talks about the organisation's campaign work.
- A paper by Sirkkaliisa Heimonen and Anna Mäki-Petäjä-Leinonen from Finland on how cooperation and collaboration between national and European organisations can be mutually beneficial.

- Information on European activities on long-term care: the subject of Alzheimer Europe's lunch debate hosted by Marina Yannakoudakis, MEP (UK).
- An update on the PharmaCog project by the project coordinator, Olivier Blin and project manager, Alexandra Auffret, as well as information on the Innovative Medicines Initiative by Principal Scientific Manager Elisabetta Vaudano.
- The importance of the work of the European Alzheimer's Alliance by Annette Dumas, EU Public Affairs Officer of Alzheimer Europe, with illustrations of how members have ensured that dementia is a European priority.
- A summary of the 2011 Romanian Alzheimer Conference.
- Updates on recent policy developments, scientific news and national Alzheimer associations current campaigns.

Issue 8 can be ordered on the publication section of Alzheimer Europe's website (EUR 2.50 plus package and posting).

28 June 2011: Sirpa Pietikäinen, MEP (Finland) hosts a lunch debate on the European Joint Action on Dementia

Alzheimer Europe organised its 10th European Parliament lunch debate which was dedicated to a presentation of the Alzheimer Cooperative Valuation in Europe (ALCOVE) project by the project's leader, Dr Armelle Leperre-Desplanques, and hosted by the Finnish MEP, Sirpa Pietikäinen.



Dr Leperre-Desplanques explained that ALCOVE is a Joint Action which is co-financed by the European Commission and it has the aim of capitalising on the work conducted during previous European studies [including Alzheimer Europe's European Collaboration on Dementia (EuroCoDe) project]. Four core questions are to be addressed:

1. How to improve data for better knowledge about dementia prevalence?
2. How to improve access to dementia diagnosis as early as possible?
3. How to improve care for people living with dementia and particularly those with behavioural disorders?
4. How to improve the rights of people with dementia, particularly with respect to advance declarations of will?

It is a 2-year project during which existing information will be collected, analysed, needs and priorities identified and finally recommendations made and information disseminated at the ALCOVE seminar planned in March 2013.

Three main outcomes are anticipated:

1. The establishment of sustainable European network for the exchange of experiences and knowledge at the level of health care institutions in order to improve quality of care and services.
2. To inform and advise decision-makers, health care professionals, care givers and citizens in general through convergent recommendations in terms of health policy, and
3. A reduction in the risks associated with psychotropic drugs, with a common focus on the use of psychotropic drugs, in particular antipsychotics.

Dr Leperre-Desplanques focused on the issue of antipsychotics and highlighted that the knowledge we have now (that antipsychotics can be non-effective, have side effects and can have a negative impact on the quality of life) was not available five years ago. This can lead to different solutions being proposed such as an increase in care and an increase in the quality of life.

Although the main partner is the Haute Autorité de Santé (HAS) in France, a willingness to participate in this voluntary joint action has been shown by 30 partners from 19 countries (Belgium, Cyprus, Czech Republic, Finland, France, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Portugal, Slovakia, Slovakia, Spain, Sweden and the UK) agreeing to work in a collaborative way at European level. Seven countries are leaders of seven work packages and the work package leaders will identify key stakeholders, including national Alzheimer associations, to involve in carrying out their work.

Nearly 40 participants discussed the presentation, including Frieda Brepoels, MEP (Belgium), several MEPs assistants, representatives from DG Research, the Innovative Medicine Initiative, National Health Ministries, Permanent Representations and national Alzheimer associations.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, closed the debate by thanking Dr Leperre-Desplanques for such a clear and interesting

presentation and the audience for their active participation.



Elisabetta Vaudano (IMI) and Maria do Rosario Zincke does Reis (Portugal)



Manuel Romaris, (DG Research) and Heike von Lützau-Hohlbein (Germany)



Magda Tsolaki (Greece) and Charles Scerri (Malta)



Antigoni Diakou (Cyprus) and Alicja Sadowska (Poland)



Henry Simmons (UK, Scotland) and Marianne Wolfensberger (Switzerland)



Sirpa Pietikäinen, MEP (Finland)



Lorena Androutsou, Ministry of Health and Social Solidarity, Greece



Jeremy Hughes (UK – England, Wales and Northern Ireland)

Alzheimer Europe Networking 2011

On 2-3 June (Luxembourg, Luxembourg), Julie and Dianne attended the first working group on the ethics of dementia research.

On 6 June (Brussels, Belgium), Jean met with representatives of Janssen.

On 7 June (Brussels, Belgium): Annette had a meeting with Toni Gelonch and Erick Tyssier, Sanofi-Aventis to discuss the organisation of an event on Alzheimer's disease in the European Parliament on World Alzheimer's Day.

On 14 June (Brussels, Belgium) Annette attended the Interest Group on Carers meeting on the Active and Healthy Ageing Innovation Partnership in the European Parliament.

On 15 June (Brussels, Belgium) Annette participated in the Active and Healthy Ageing workshop on 'assisted living, social inclusion and ageing at work'.

On 17 June (Dublin, Ireland) Jean attended a seminar "Shared priorities – The Dementia Agenda in Europe and Ireland" organised by Nessa Childers, MEP (Ireland) in collaboration with the Alzheimer Society of Ireland.

On 20 June (Rome, Italy), Jean attended the final workshop of the Joint Programming Initiative in neuro-degeneration where the conclusions of previous stakeholder workshops on the strategic research agenda were presented and discussed.

On 20 June (Brussels, Belgium) Annette participated in a meeting organised by Françoise Grossetête, MEP, in her capacity as UMP National Secretary in charge of European policy and health safety.

On 20/21 June (Brussels, Belgium) : Annette participated in the Active and Healthy Ageing workshop on 'prevention, early diagnosis and screening'.

On 21 June (Brussels, Belgium) : Annette met Erick Tyssier, Sanofi-Aventis, to further discuss the organisation of an EP event around World Alzheimer's Day.

On 23 June (Brussels, Belgium) : Annette participated in the Active and Healthy Ageing workshop on 'care and cure'.

On 26-27 June (Brussels, Belgium), the Board and staff of AE attended the AE Board meeting.

On 27-28 June (Brussels, Belgium), AE members organisations, Board and staff attended the AE Public Affairs meeting.

On 28 June (Brussels, Belgium) AE Board and staff attended the AE lunch debate in the European Parliament dedicated to the ALCOVE project.

On 28 June (Brussels, Belgium) Annette presented AE's European activities at Eurodiaconia meeting.

On 28 June (Brussels, Belgium), Jean met with representatives of Lundbeck and Pfizer to discuss areas for collaboration in 2011.

European developments

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

1 June 2011: Call launched for optimally informative biomarkers for neurodegenerative disorders and harmonisation of their use

A Joint Programming Neurodegenerative Disease (JPND) joint transnational call was launched between 20 countries to encourage novel approaches to the development of optimally informative biomarkers and harmonisation of their use. Applications are invited from collaborative consortia of researchers from participating countries. The aim of the call is to establish multi-national, collaborative research projects that will add value to existing research through addressing novel approaches to improve and harmonize the use of biomarkers in the area of neuro-degenerative disorders.

The total fund for this call is over EUR 14 million. Only joint transnational research projects will be funded. Each proposal must involve a minimum of four research centres and involve groups from at least four different countries of the funding organisations participating in this call. Application details can be found on the JPND website and the closing date for submissions is 5 September.

6 June 2011: Council adopts conclusions on European Pact for Mental Health

At its Employment, Social Policy, Health and Consumer Affairs meeting of 6 June, the Council adopted conclusions on the European Pact for Mental Health and Well-Being.

The Council invites the Member States to make mental health and well-being a priority of their health policies and develop strategies or action plans on mental health.

The Council also invites the Member States and the European Commission to continue the cooperation started under the Pact and set up a Joint Action on mental health and well-being under the current EU Health Framework Programme. The Joint Action should provide a platform for exchange of views, cooperation and coordination between the Member States to identify evidence-based policy approaches

and practices in the field of mental disorders through the health and social systems; evidence-based measures against depression, innovative partnerships between the health and other relevant sectors, community-based and socially-inclusive approaches to mental health, data and evidence on the mental health status in the populations.

Besides addressing mental health and well-being in partnership with EU health policy and other policy areas, the European Commission should further develop the European Compass for Action on Mental Health and Well-Being and support the Member States in providing data.

The European Commission should present a report on the outcomes of the Joint Action, including an inventory of evidence-based actions in mental health care, social inclusion, prevention and promotion, as well as a reflection on possible future policy actions as a follow-up to the Pact.

6 June 2011: Council adopts conclusions on how to reconcile work and family life

The Council of the European Union adopted conclusions on how to reconcile work and family life in the context of an ageing population during the Employment, Social Policy, Health and Consumer Affairs meeting in Luxembourg on 17 June 2011.

Flexible work arrangements and various forms of leave for men and women, better provision of care services for dependent people, training and qualifications for care workers, employees benefitting from appropriate family support services from their employers, exchange of best practices among the Member States in the field of family policies were identified as areas for further work.

Through Eurostat, the European Commission could develop a common Europe-wide basis for the compilation of timely and comparable statistics and indicators on the reconciliation of work and family life, including dependent persons' care, flexible working-time arrangements, the use of family-related leaves.

The Commission should develop further research to identify the factors affecting women's and men's possibilities to reconcile work and family life.

6 June 2011: Council adopts conclusions on modern, responsive and sustainable health systems

At its Employment, Social Policy, Health and Consumer Affairs meeting of 6 June, the Council

adopted conclusions on the way forward to modern, responsive and sustainable health systems.

To answer society's growing and changing needs due to the ageing of the population, increasing patient expectations, shortage of health professionals and rapid technology diffusion, the Member States are invited to develop effective, health policy-driven approaches to address macroeconomic, health and societal challenges and shift the perception of health policy from an expenditure to a contributor of economic growth.

Innovative approaches and models of health care responding to the challenges of an ageing population must be developed. Future long-term health sector strategies must also be developed with an emphasis on effective investment in the health sector and in human resources, moving away from hospital-centred systems towards integrated care systems, ensuring equitable access to high quality care and reducing inequalities.

The Member States should address health promotion and disease prevention in an integrated manner in the spirit of the Health in All Policies approach. Health technology assessments and smarter use of e-health solutions should be supported to ensure value for money and benefits for health and health systems. The EU financial programmes, including Structural, should be used to support health system innovation, reduce health inequalities and stimulate economic growth.

To fulfil the objective, the Member States and the European Commission should engage in a reflection process, share and analyse experiences, compare and monitor the effectiveness of the health investments and benefit from the data and evidence gathered by the EU, intergovernmental organisations such as WHO and OECD.

The Commission is invited to present regular reports to the Council to contribute to the reflection process. The first report should be submitted by the end of 2012.

6 June 2011: Council proposes 2012 as the European Year for active ageing and solidarity between generations

The Council of the European Union agreed in principle, subject to the vote of the European Parliament, to designate 2012 as the European Year for active ageing and solidarity between generations.

The promotion of active ageing should create better opportunities and working conditions for women and men in their late 50's and above to play their part in the labour market, combat social exclusion by fostering active participation in society, and encourage healthy ageing.

The purpose is to enable local authorities, social partners and civil society organisations to plan campaigns and activities around this theme.

6 June 2011: Conclusions adopted on "modern, responsive and sustainable health systems" adopted

At the Employment, Social Policy, Health and Consumer Affairs on 6 June, the Ministers adopted

conclusions on 'modern, responsive and sustainable health systems'.

Recognition was given to the fact that health constitutes an important precondition for a prosperous economy and should therefore be considered as an investment rather than solely as an expenditure item. Access to high quality health services must be maintained despite the tightening of resources.

Measures that have been taken or are currently considered in the Member States include the regulation of the pharmaceuticals sector, incentives for buying generic medicines, e-health-prescriptions and prevention. The EU wide reflection process initiated by these conclusions will assist Member States to meet the challenges of the health systems and provide a basis for the exchange of information and best practices.

The European Commission is urged to support the reflection process, stress the major economic role of the health sector and aim to shift health from being regarded as just an expenditure to being recognised as a contributor to economic growth. The Commission is invited to provide effective tools and methodologies to the Member States for assessing the performance of health systems. The Ministers also call upon the Commission to present regular reports to the Council to contribute to the reflection process with a first report by the end of 2012.

15-21 June 2011: Three workshops organised on the Active and Healthy Ageing Innovation Partnership

The European Commission organised three workshops between 15 and 24 June to discuss the leading themes identified by the AHAIP Steering Group after the Commission public consultation.

The first workshop discussed 'assisted living of older people', 'social inclusion for older people' and 'ageing at work'. The second was about 'prevention', 'screening' and 'early diagnosis'. The third was on 'integrated care', 'management of chronic conditions', 'evidence, cost-effectiveness and cost-efficiency'. Stakeholders were invited to identify the objectives of each topic, their barriers and the opportunities.

The Steering Group will discuss the workshop reports and extract the themes to take forward in the Strategic Implementation they will produce.

The Strategic Implementation Plan is scheduled to be published in Autumn, alongside a European Commission Communication on the Plan to be presented by the end of the year.

17 June 2011: Council agreement on 2012 as European Year of healthy ageing and solidarity between generations

At its meeting of 17 June, the Council agreed in principle on 2012 to be the European Year of healthy ageing and intergenerational solidarity.

Active ageing involves creating opportunities and working conditions for citizens in their 50s and above to play their part in the labour market, combatting social exclusion and encouraging healthy ageing.

Local authorities, civil society and social partners will have a role in promoting active ageing through campaigns and activities around this theme.

The objectives are to raise awareness about the value of active ageing and highlight the contribution that older people can make to society and to the economy, facilitate exchange of ideas and good practice on how best to promote active ageing policies, offer a framework for action to support the development of policies and specific activities that will encourage active ageing and solidarity between generations.

The Council is waiting for the European Parliament vote.

17 June 2011: Council discusses the Trio Presidencies work programme

At its meeting of 17 June, the General Affairs Council discussed the Trio Presidencies (Poland, Denmark and Cyprus) draft work programme (July 2011 – December 2012).

The strategic framework of the programme is set within a wide context with long-term objectives running into the subsequent three Presidencies (Ireland, Lithuania and Greece have thus been consulted). The overarching theme will be the recovery from the economic crisis and foundations for future growth

The Trio Presidencies will focus on Europe's demographic challenges, the implementation of the EU 2020 strategy 'New Skills, New Jobs' flagship as a priority, social inclusion and social protection, the promotion of social innovation, the sustainability and reform of national pension systems, the reconciliation of work and family life, healthy ageing (including 2012 as the Year of Active and Healthy Ageing), improvement of EU citizens health and quality healthcare (the three Presidencies will launch work on a EU Health Strategy beyond 2013 and on the third programme of EU action in the field of health), innovation and best practice in the health care sector (as an answer to the challenges of the demographic change in the EU Member States while talking into account the present financial situation in Europe), spreading out of best practice in the health care sector to close the existing health gaps in the EU, and, education (identified in the EU 2020 strategy for jobs and growth as a key contribution to employability, competitiveness and innovation while promoting social cohesion and inclusion).

23 June 2011: The European Commission and Parliament launch Joint Transparency Register

In their endeavours to ensure transparency in the EU's decision-making process, the European Parliament and the European Commission launched on 23 June 2011 a joint public Transparency Register.

The new Register replaces the one set up by the Commission in 2008. It includes any organisation or self-employed individual engaged in influencing EU policy making and implementation (from law firms to NGOs and think tanks etc.).

Those registering have to provide more information than before, such as the number of staff involved in

advocacy, the main legislative proposals they have covered, as well as the amount of EU funding received.

By signing up to the Transparency Register, organisations will commit to a Common Code of Conduct. A complaint mechanism and measures to be applied are also outlined for those who break the Code of Conduct.

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

www.alzheimer-europe.org

Policy watch

27 May 2011: Portuguese political party reaffirms its commitment to a national plan for dementia

Portuguese MP, Teresa Caeiro (Popular Party, CDS-PP) reaffirmed the commitment of the political party CDS-PP within its electoral programme to develop a National Plan for Dementia. Mrs Caeiro announced this during a visit to the Alzheimer Portugal Association, on 27th May 2011 saying, "The Draft Resolution of the CDS-PP, as well as the Party's program, devoted special attention to the problem of Alzheimer's disease, which is an area that remains hidden and for which the Government was unable to find answers. The CDS-PP paid particular attention in its own program to the specific issue of dementia, not only in the domains of general health or social policy.

"In the current social and economic context of the country, the state cannot alienate itself from its special responsibilities to those most vulnerable in society, particularly the elderly and people with severe dependence as in the case of Alzheimer's patients."

In October 2010, the Portuguese Parliament approved two draft resolutions, one of the PSD and another of the Popular Party (CDS-PP), which proposed to the Government the recognition of dementia as a national priority.

A spokesperson from Alzheimer Portugal said, "Issues not addressed such as the lack of equipment, non-recognition of disease status, high costs associated with the disease (including medication not reimbursed) have resulted in a lack of effective responses being found by the Government."

6 June 2011: Report published which reviews the progress of the first year of Scotland's national dementia strategy

"Scotland's National Dementia Strategy: On Year On Report" summarises developments since the Strategy's publication in June 2010. Nicola Sturgeon, Deputy First Minister for Scotland and Cabinet Secretary for Health, Wellbeing and Cities Strategy, states in her forward that "the Dementia Strategy is playing an important role in moving the wider agenda

around older people's services forward; its success over the next two years will be extremely important in demonstrating how integrated services can deliver better quality of care for those with dementia and their families and carers."

The report is divided into 8 areas:

- **Common standards of Care for Dementia:** A document has been published detailing what is expected from service providers of people with dementia in terms of the quality and content of the services.
- **Skills and knowledge Framework:** Over the last year a framework has been developed and published (entitled Promoting Excellence) for all staff who have contact with, and provide support for, people with dementia. It will be implemented in the next two years.
- **Integrated Support for Change:** Three sites (Perth and Kinross, Midlothian and North Lanarkshire) have been selected to participate in the Dementia Demonstrator Sites project which aims to influence the agenda on reshaping care for older people. Work began on the project earlier this year and will run for 15 months.
- **Improved Management and Outcome Information:** A draft dementia balanced scorecard, or benchmarking framework, has been developed which will help to monitor change and improvements made as a result of the Strategy.
- **Continued work on Diagnosis:** Work begun in 2007 to increase the number of people registered with a diagnosis of dementia has continued and updated figures will be published in September 2011.
- **Better response to behaviours that staff and carers find challenging:** A specialist academic baseline assessment on the current use of psychoactive medication for those with a diagnosis of dementia has been commissioned.
- **Accelerated Implementation of the Dementia Integrated Care Pathway:** An implementation plan for Integrated Care Pathways (ICP) to support national health boards develop their own ICPs locally is being developed by National Healthcare Improvement Scotland. Definitions are also being developed about the assessment of suitability for psychological therapy.
- **Continued Action to support dementia research:** A questionnaire by the Scottish Dementia Clinical Research network (SDCRN) and Alzheimer Scotland was carried out to determine what people, including people with dementia, considered to be the priorities for dementia research in Scotland. People who are on the national research register of people with dementia and carers are being contacted to take part in research specifically suited to them and

to seek permission for their details to be linked with health informatics systems.

The One Year On Report also includes information on specialist dementia nurses (funding from the Scottish government and Alzheimer Scotland will facilitate seven new posts), future funding from the BIG lottery in Scotland, the Dementia Forum and the Implementation and Monitoring Group's work.

6 June 2011: Health Minister launches documents on care standards for dementia and on a framework for staff working with people with dementia and their carers in Scotland

Marking the first anniversary of the first-ever National Dementia Strategy in Scotland, the Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy in Scotland, Nicola Sturgeon, launched the publication of two documents: a) Standards of Care for Dementia in Scotland and b) Promoting Excellence - A framework for health and social services staff working with people with dementia, families and carers.

Ms Sturgeon said that the standards in the first report



'represent a consensus on what we mean by good quality care and describe and define what is expected by services in order to meet the level and quality of care we all expect, every time and in all care settings". She added that the standards will empower people to both understand and assert their rights. The standards state, amongst other things, that:

- people with dementia should be treated with respect
- people with dementia and their families and carers should take an active and central part in the care and be fully informed of the care package and decisions taken as dementia progresses
- there should always be an integrated assessment to establish clearly causes of behaviour in order to develop a care plan to manage behaviour challenges. Antipsychotic drugs should never be used just because they are the easiest way of managing difficult behaviour.

The implementation of the recommendations in the report 'Promoting Excellence' will take place over the next two years and involves a range of initiatives including:

- updating professional qualifications
- enhancing existing workforce capability
- developing leadership within the dementia workforce.

The report on the dementia strategy summarises progress in all areas of the strategy over the last year.

Ms Sturgeon said, "It is absolutely essential that older people, and people with dementia, receive the best possible care and are at all times treated with dignity

and respect. Improving the quality of care and support provided to people with dementia is a top priority."

Henry Simmons, Chief Executive of Alzheimer Scotland, said, "Alzheimer Scotland has long campaigned for the human rights of people with dementia to be recognised and we welcome the Minister's commitment to ensuring that people with dementia receive world class support, care and treatment. The new dementia care standards for Scotland, and framework for improving the skills and knowledge of health and social care professionals, means that people with dementia should receive high quality care from the services they need, no matter where they live across Scotland."

"However, we have major concerns about cuts to services by local authorities. These must be avoided at all costs. Cutting or even restricting access to services of this nature for people with dementia and their families is no different from reducing available medical treatments for conditions such as cancer or heart disease. High quality, timely and flexible support is not yet being provided consistently to everyone across Scotland and many support services are either being reduced or cut. This has to stop. No person, no family, partner or friend should have to deal with the very complex, changing and challenging needs of dementia on their own."

Agnes Houston, Chair of the Scottish Dementia Working Group, said of the Standards of Care for Dementia in Scotland, "This is not just another document to sit on a shelf, but something practical that can be used to take to services and show the quality of care you expect- and if you don't get it you can use it to support your complaint and ensure you get the standard of care you are entitled to."

Caroline Brown, carer, said, "These standards should have a great impact; not only on quality of life for people with dementia and families, but also in improving attitudes towards care and support. We have never had access to this sort of guidance before and it is to be welcomed. Personally, I feel that I have been listened to as a carer and that makes a huge difference."

28 June 2011: UK government announces investment in dementia research

A "Route Map for Dementia Research" has been launched in the UK by the Care Services Minister, Paul Burstow, along with 17 experts from Government, universities, charities, industry and research organisations. These parties have combined forces to "look at ways to work together to increase the volume and impact of dementia research and improve the lives those living with this devastating condition" and the Route Map:

- pledges up to £ 20 million from the Department of Health over five years for four new National Institute for Health Research (NIHR) Biomedical Research Units;
- commits the Medical Research Council to increase funding for neuro-degeneration research by 10% to £ 150 million over the next four years to 2015;

- boosts the number of experts in the dementia field through new Academic Clinical Fellowships;
- strengthens links between public and private research sectors to identify new opportunities for partnership, and
- ensures more patients and carers get involved in research through the NIHR's Dementia and Neuro-degenerative Diseases Research Network which will facilitate research in the NHS and care home sector.

The Ministerial Advisory Group on Dementia Research has identified specific areas most urgently in need of good quality research including the evaluation of prevention and public health interventions, the influence of genes and the environment in the development of the disease, alternatives to antipsychotic drugs, stem cell research, and a better understanding of how the brain is affected by dementia.

Members' News

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

31 May 2011: German Alzheimer Association publishes report on good nursing homes for people with dementia



The latest edition of the German Alzheimer Association's journal, *Alzheimer Info*, is dedicated to what constitutes a good nursing home for people with dementia. The report includes an interview with a nurse who sheds some light on what it is really like behind the scenes in a home with a grade 1 rating. The chairperson of the Alzheimer Society of Mannheim reports on visits to four care homes. Even though the maintenance records in all four homes were recorded as being roughly equal, the reality in the homes was that there was a different level of care. Two of the homes had adjusted their practices to care for people with dementia, with consideration evident in the design of the rooms and also the provision of loving assistance. However, in two homes little understanding of dementia was found.

To ensure that residents will receive individual attention which allows for their personal history and preferences to be catered for it is necessary to have a high commitment level from all staff members. The report highlights the fact that home managers need also to be trained and qualified to manage care homes for people with dementia.

There are also articles concerning the selection of a suitable home (including a checklist and useful references websites), the rights of nursing homes residents and an article on problems which may arise from nursing notes.

The Executive Director of the German Alzheimer Association, Sabine Jansen, said, "Our impression is that there are some really good homes for people with dementia but also there are some which are really not good. It is crucial that sufficient, well-

qualified and motivated staff are available and that the home and care is well organised."

The Journal of Alzheimer's Info 2 costs EUR 3 (or EUR 12 for an annual subscription) and can be ordered from the German Alzheimer Association.

1 June 2011: Alzheimer's Society publishes a public policy report



"The Dementia Tax 2011" is a



public policy report by the Alzheimer's Society, UK, which includes data from a large survey of nearly 4,000 people with dementia and their carers in 2011 and found that:

A quarter of people with the condition said they would have bought insurance if it was more affordable

52 per cent of carers said they or their loved one had to contribute to, or pay all of, the cost of their care

Nearly half of all people surveyed (44 per cent of carers and 49 per cent of people with dementia) said on reflection, they did not wish they had taken out insurance

The main reasons people did not take up insurance were: not knowing it existed; not anticipating care needs; not knowing they would have to contribute to care costs.

The Dilnot Commission was set up last July to review the funding system for social care in England and make recommendations to the government about how to achieve an affordable and sustainable system for adults in a range of settings.

Jeremy Hughes, Chief Executive at Alzheimer's Society, said: 'People are often very surprised by the huge amounts they have to pay for care; yet alternative solutions like insurance are currently out of their reach. State support is inadequate. We need a new system that can change this stark reality for millions of people and develop a long term system that works. The opportunity offered by the Dilnot Commission must not be lost.

'We must be able to provide good quality care that provides quality of life for people with dementia. It is vital we have a long term answer to the current broken system. We must stop forcing people to pay a dementia tax for poor quality care.'

1 June 2011: Romanian Alzheimer Society campaigns to secure support from policy makers for a National Dementia Plan

Following the launch in April of the Romanian manifesto which called for the development of a National Dementia Plan, the Romanian Alzheimer Society, Societatea Română Alzheimer, has campaigned to get the support from various policy makers. The Society has contacted the President, Prime Minister, the Minister for Health, the Minister for Labour, Family and Social Protection, the Minister of Education, Research, Youth and Sports as well as the Agency for the Protection of People with Disabilities and the Mental Health Centre.

The society has also been in contact with several Romanian MEPs to encourage them to support the European Alzheimer's Alliance (EAA). Ramona

Manescu, MEP (Romania) will support the EAA by attending Alzheimer Europe's next lunch debate in the European Parliament dedicated to Joint Action.

In addition to raising awareness at a political level, the Society has launched a Free Memory Evaluation Campaign which will run until July 16th.

6 June 2011: Greek Alzheimer's Association participates in craft workshop for people with dementia and their carers



The Greek Association of Alzheimer's Disease and Related Disorders participated in the workshop entitled "A New Hobby for Alzheimer Patients from Anatolia" which was held from 6-10 June.2011 in Eskişehir.

This Grundtvig workshop, held within the framework of the Lifelong Learning programme, involved people with Alzheimer's disease (in the early and middle stages) and their carers. During the workshop, participants were able to engage in a new hobby (jewelry making with beads). During the programme it was possible to explore the culture and country, visit museums and carry out other sightseeing activities.

The Greek Association, which had been invited by the Eskişehir Alzheimer Society and Foundation, participated in the workshop with 2 psychologists who were accompanying one person with dementia and two carers. A spokesperson for the Association said that "their experience proved to be very exciting both for the professionals and for the person with dementia and the carers. The person with dementia and the carers got to know a new hobby that could engage them all and give them an opportunity to spend some quality time together. On the other hand the health professionals were able to interact and exchange good practices with other colleagues from various countries."

9 June 2011: Alzheimer's Society joins in the call for action on the use of antipsychotic drugs for people with dementia



As part of the Dementia Action Alliance, the Alzheimer's Society has joined in the call to action on the use of antipsychotic drugs for people with dementia. The call aims to ensure that the care people with dementia receive is compliant with current best practice guidelines. The Dementia Action Alliance has produced best practice guidance for people with dementia and their carers and health and social care professionals on the use of antipsychotics.

13 June 2011: Alzheimer Society responds to programme on assisted dying

The BBC broadcasted the documentary "Terry Pratchett: Choosing to Die" on 13 June 2011. In the programme Sir Terry Pratchett, who has dementia, meets people who have made different choices about their death. In particular, he met Peter Smedley,

joining him as Mr Smedley decided to die at the Dignitas clinic in Switzerland.

The Alzheimer Society said: "Sir Terry asks important questions in this documentary and we applaud his decision to highlight this debate. While it is a debate that cannot be avoided, it must take place in a considered and measured context. Dialogue must also not be at the expense of focusing on good care. Living well with dementia is possible and it must remain the priority."

"People with dementia and their carers should be supported to make plans for the end of their lives, including the expression of preferences about how they would or wouldn't like to die. If people wish to nominate someone to make decisions about end of life care or to set out the types of treatment they do not wish to receive in an advance decision or living will then that should happen as the law allows. Alzheimer's Society does not support a change in the law on euthanasia or assisted dying."

"Communicating wishes around end of life care is important. Anyone with clear views about their future treatment should talk to those around them as early as possible and make plans using advanced directives and other appropriate means."

18 June 2011: La Ligue Alzheimer's projects presented at a conference organised by the World Health Organisation



Two projects from the Belgian French-speaking association la Ligue Alzheimer were presented at the World Health Organisation's (WHO) "European Healthy Cities Networks Annual Business and Technical Conference", which took place in Liège, Belgium, from 15 to 18 June. The projects presented by the association were the 'Dementia friendly cities' and the 'Alzheimer Cafés'.

The Dementia Friendly Cities are a network of cities which hold and develop activities related to Alzheimer's Disease (training sessions 'Circle of Care'; Alzheimer Cafés; home assistance to carers;...) in consultation with 'La Ligue Alzheimer. These activities must be free of charge.

The objective of the Dementia Friendly Cities initiative is to encourage the inclusion of people with dementia within their community. Each activity must contribute to an improvement of the quality of life of people with dementia and their carers, a goal that was set up on the basis of the World Health Organisation's (WHO's) Age-friendly Cities.

One of the activities developed within the Dementia Friendly Cities' framework is the Alzheimer Café. This Café gives the opportunity to talk about the disease and share experiences in informal and friendly surroundings, outside places such as hospital or nursing homes.

Moreover, the Alzheimer Café can be the place where carers identify what a person with dementia is still able to do and also identify those tasks which may be too challenging. This, in turn, can spur people with dementia and his/her carer on going out more often and to regain self-esteem and confidence in their ability to socialize.

"These initiatives", says a spokesperson of La Ligue Alzheimer – representative of patients and their carers – "proves that the association is part of the solution and is able to find equal partnerships for people with dementia in their familiar surrounding background. It also illustrates the willingness to find solutions: Where there is a will there is a way."

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.

31 May 2011: Study examines the role of the MS4A gene cluster and Alzheimer's disease

A study on over 1000 people from the Spanish population has shown the importance of international efforts combining genome wide association study (GWAS) datasets to isolate genetic loci for complex disease, such as Alzheimer's disease. New research suggests that a novel location within the MS4A gene cluster, which is associated with Alzheimer's disease, has been identified as a result of combining research results with four public genome-wide association study (GWAS) data sets.

Researchers from Spain and the USA were sponsored by non-profit Fundación Alzheimer and Fundació ACE and the study was published in the journal Genome Medicine.

1 June 2011: Mouse study examines potential use of cancer drug for people with dementia

A study using a cancer-treatment drug known as Suberoylanilide hydroxamic acid (SAHA) suggests that it may be useful to treat familial fronto-temporal dementia (FTD). Symptoms of FTD include progressive deterioration in decision-making ability, behavioural control and/or language skills. The mouse study appeared to show that treatment with SAHA could overcome the chemical deficiency (an imbalance in the levels of the protein progranulin (GRN) associated with FTD. Further studies are required to see if SAHA can cross the blood-brain barrier.

Joachim Herz, University of Texas Southwestern Medical Center, Dallas, USA and colleagues and published on line in the Journal of Biological Chemistry.

2 June 2011: Mouse study identifies potential drug candidate for Alzheimer's disease

A mouse study has identified a new compound, JM6, which appears to "diminish the effects of both Alzheimer's disease and Huntington's disease". The researchers found that JM6 blocked the enzyme kynurenine 3-monooxygenase (KMO), which is believed to play a role in neurodegenerative diseases. JM6 appeared to prevent memory deficits and the loss of synaptic connections between brain cells by "inhibiting KMO in the blood. The blood cells then send a protective signal to the brain, to stabilise brain-cell function and prevent neurodegeneration."

As JM6 does not penetrate into the brain, the impact of JM6 could be confirmed with a blood test. The researchers are hoping to continue to carry out Phase 1 safety trials of JM6 in humans by 2013.

JM6 was named after the researcher's father, Dr Joseph Mchaowski, who helped his son, Paul, devise the KMO inhibitor.

The study was conducted by Paul Muchowski, an associate investigator at the Gladstone Institutes, USA in collaboration with the University of Maryland and the University of California, San Diego, USA.

9 June 2011: Study examines prevalence rates of dementia in the African-Caribbean and White population

A UK study on over 400 people aged 60 and over suggests that "there is an increased prevalence of dementia in older people of African-Caribbean country of birth in the UK and at younger ages than in the indigenous White population. These findings have implications for service provision and preventive interventions. Further research is needed to explore the role of vascular risk factors and social adversity in the excess of dementia in this population."



A study was led by Dr Simon Adelman and researchers from University College London (UCL), UK and published in the British Journal of Psychiatry.

9 June 2011: Mouse study identifies antibodies which may help to prevent the onset of Alzheimer's disease

A mouse study suggests that two antibodies, (ICSM-18 and ICSM-35) may be able to block the damaging effects on brain tissue caused by amyloid beta, which is often associated with Alzheimer's disease. The work was carried at the Medical Research Council Prion Unit at University College London, in collaboration with colleagues at the Laboratory for Neuro-degeneration at University College Dublin and Trinity College Dublin. It was published in the journal Nature Communications.

In 2012 clinical trials will commence to determine whether drugs based on the two antibodies are able to mitigate the damage caused to the brain as a treatment for people with Creutzfeldt-Jakob disease (CJD).

13 June 2011: Study compares the relationship of diet and biomarkers of Alzheimer's disease

A study on 49 adults suggests that "diet may be a powerful environmental factor that modulates Alzheimer disease risk through its effects on central nervous system concentrations of A β 42, lipoproteins, oxidative stress, and insulin". Researchers found that signs that can indicate early development of Alzheimer's disease dropped within weeks of people who had no signs of brain decline but who started to eat healthily.



The study was conducted by researchers from the University of Washington, Seattle and reported in the journal Archives of Neurology.

20 June 2011: Study suggests protective mechanism at work in Alzheimer's disease

A study has found that a molecular chaperone, known as HspB1, is "working like a waste management company to collect and detoxify high levels of toxic amyloid beta peptide found in Alzheimer's disease." Researchers have called for further tests to examine the effect on Alzheimer's disease if the levels of HspB1 are elevated, if smaller versions of HspB1 are administered directly into the bloodstream and to explore a way in which to increase brain cell's natural production of HspB1.

The research author was Juhi Ojha, Georgia health Science University, USA and the study was published in the journal Molecular and Cellular Biology.

20 June 2011: Study suggests doctors struggle to identify people in the early stages of dementia

A study suggests that general practitioners (GPs) are "struggling to correctly identify people in the early stages of dementia resulting in both missed cases (false negatives) and misidentifications (false positives). The researchers examined 30 previous studies involving 15,277 people in primary care for cognitive disorders, including 7,109 assessed for dementia. GPs managed to identify eight out of ten people with moderate to severe dementia. However, most with early dementia were not recognised.

The research was conducted by the University of Leicester, UK, the National Collaborating Centre for Mental Health, UK and the Department of General Practice, Düsseldorf, Germany.

21 June 2011: Mouse study suggests that an ingredient in coffee may increase protection against Alzheimer's disease



A mouse study suggests that a component in caffeinated coffee induces an increase in blood levels of a growth factor called granulocyte colony stimulating factor (GCSF) and may offer possible protection against Alzheimer's disease. In people with Alzheimer disease GCSF is decreased, but an interaction with caffeine seems to boost blood levels of GCSF.

The study was published in the Journal of Alzheimer's disease and led by Dr Chuanhai Cao, University of South Florida, USA.

22 June 2011: Potential new biomarker identified for Alzheimer's disease

A three-year study suggests that people who developed Alzheimer's disease had significantly higher levels of a protein called soluble amyloid precursor protein beta (sAPP) in their spinal fluid than those who did not develop Alzheimer's disease. Researchers found the best predictor of whether someone would develop Alzheimer's disease was a combination of the sAPP, the tau protein and the age of the individual.

Study author was Robert Perneczky, MD, of the Technical University Munich in Germany and the research was published in the American Academy of Neurology's journal.

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

Dementia in society

In this section we report on how dementia is portrayed by the general media (for example, on television and in films).

13 June 2011: Former chairperson of the Scottish Dementia Working Group receives M.B.E



In recognition of his work in raising awareness of dementia as well as his demonstrating ways in which people can live well with the disease, Edward McLaughlin, former chairperson of the Scottish Dementia Working Group (SDWG), has been awarded an M.B.E (Member of the Order of the British Empire) in the Queen's Birthday Honours List.

The Chief Executive of Alzheimer Scotland, Henry Simmons, said "Alzheimer Scotland are greatly pleased that Edward's achievements and those of the Scottish Dementia Working Group have again been publicly recognised. Edward has never shied away from discussing his illness and helping others to improve their understanding of it.

"Edward and the other members of the SDWG have brought an important and much-needed new perspective of dementia to health & social care professionals, politicians and the media – their impact cannot be underestimated."

The SDWG is an independent group run by people with dementia, the purpose of which is to campaign to improve services for people with dementia and to improve attitudes towards people with dementia.

22 June 2011: Country music star diagnosed with Alzheimer's disease



Grammy Award winner and US country music star, Glen Campbell, has been diagnosed with Alzheimer's disease. He plans to retire this year with a series of farewell concerts. Famous hits include "Rhinestone Cowboy" and "Wichita Lineman".

23 June 2011: Actor Peter Falk dies with Alzheimer's disease

Actor Peter Falk, who played the character "Columbo", has died with Alzheimer's disease.

Mr Falk's 50-year career included work on Broadway (e.g. Don Juan, Diary of a Scoundrel), on TV and in films (e.g. Wind Across the Everglades, Murder Inc., Pocketful of Miracles, Husbands and A Woman under the Influence). He was nominated for Best Supporting Actor in 1961 for his role as Abe Reles in the film Murder Inc. He is perhaps best known as Lieutenant Columbo in the TV crime series "Columbo" for which he won four Emmy Awards and a Golden Globe.



An accomplished artist, Mr Falk exhibited his artwork in 2006 at the Butler Institute of American Art. He also published his memoir, "Just one more thing" in 2006.

23 June 2011: Call for the US and countries worldwide to develop a global approach to tackle Alzheimer's disease

At a hearing on "Global strategies to combat the devastating health and economic impacts of Alzheimer's disease", Eric Hall, President of the Alzheimer's Foundation of America and the Alzheimer's Foundation International, presented Congressional testimony calling on the United States and countries worldwide "to step up now to tackle Alzheimer's disease and to collaboratively develop and global approach to this pandemic."

Mr Hall called for an international meeting with current or planned national strategies relating to Alzheimer's disease to consider the different approaches to national plans and provide a platform for an exchange of care programmes.

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.

24 June 2011: Book published about personal experience of living with Alzheimer's disease

Norm Mcnamara has written about his experience of living with Alzheimer's disease in the book entitled "Me and My Alzheimer's". Mr McNamara said, "At the age of 50yrs old i was diagnosed with Alzheimers, I am now 53yrs old and have every intention of beating it!! Please join me on my journey, my highs and my terrible lows as I fight the biggest battle of my life."



"Me and My Alzheimer's" has 142 pages and costs USD 16 and is available at Amazon.com (ISBN: 978-1460958520).

AE Calendar

The following meetings will be attended by representatives of
Alzheimer Europe

Date	Meeting	AE Representative
17-21 July 2011	International Conference on AD (Paris, France)	Heike and Jean
18 July 2011	Meeting with Alzheimer's Disease International (Paris, France)	Heike and Jean
19 July 2011	Meeting with Bristol Myers Squibb (Paris, France)	Heike and Jean
20 July 2011	Launch of "Value of knowing results" (Paris, France)	Heike and Jean
28 July 2011	The Ageing Crisis: A Health Systems Response (Venice, Italy)	Dianne

Future Conferences

Date	Meeting	Place
13-15 June 2011	14th Kuopio Bio-NMR Workshop: MRI of stroke, epilepsy and neurodegenerative diseases and the PredictAD Workshop, http://www.uef.fi/predictad-ws	Kuopio, Finland
22 June 2011	Arts and Dementia: Promoting quality of life of people with dementia and their carers through the creative arts, www.eminence-grise.co.uk	Oxford, UK
1-4 September 2011	Joint Conference on Ageing and Neuro-degeneration presented by the German Center for Neurodegenerative Diseases (DZNE) and the Max Planck Institute for Biology of Ageing (MPI), www.conference-ageing-neurodegeneration.de	Bergisch Gladbach, Germany
14-16 May 2011	27ème Congrès de la Société de Psychogériatrie de langue Française (SPLF), http://www.celsius-net.com/splf/	Toulouse, France
10-13 September 2011	15 th Congress of the European Federation of Neurological Societies (EFNS), www.efns.org/efns2011	Budapest, Hungary
12-13 September 2011	Université d'été Alzheimer éthique & société 2011, www.espace-ethique.org	Aix-en-Provence, France
20 September 2011	Symposium: "Mes comportements vous dérangent?", www.alzheimerbelgique.be	Brussels, Belgium
20-21 September 2011	3rd International Conference "Senior's training and non-pharmacological interventions form Alzheimer's disease", www.alzheimer.sk	Bratislava, Slovakia
6-8 October 2011	Alzheimer Europe's 21 st Annual Conference "European Solidarity without borders", http://www.alzheimer-europe.org/EN/Conferences/Warsaw-2011	Warsaw, Poland
20-23 October 2011	7 th International Congress on vascular dementia: Facing the challenges of dementia, www.kenes.com/vascular	Riga, Latvia
3-5 November 2011	4th edition of our Clinical Trials for Alzheimer's Disease CtaD 2011, www.ctad.fr	San Diego, USA
2-4 November 2011	38 th Congress of European Association of Geriatric Psychiatry (EAGP), www.apgerontopsiquiatria.com	Porto, Portugal
8-11 November 2011	Thailand dementia 2011 and 14 th Asia-Pacific Regional Conference of ADI, www.azthaimeting.com	Bankok, Thailand
27-29 January 2012	5th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland
7-10 March 2012	27th ADI Conference, http://www.adi2012.org/	London, UK

8-11 March 2012	The 6th World Congress on Controversies in Neurology (CONy), www.comtecmed.com	Vienna, Austria
9-12 May 2012	12th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Stockholm, Sweden