



NEWSLETTER

October 2012

Highlights in this issue

21 September: France extends Alzheimer Plan	10
3-4 October: 1st meeting of European Group of People with Dementia	2
4 October: Alzheimer Europe elects new Board at AGM	3
4-6 October: AE holds 22nd Annual Conference in Austria	3
18 October: EMA approves florbetapir for PET imaging	12
30 October: 2 new clinical trials for Alzheimer's disease	13



Table of contents

Editorial	1
Alzheimer Europe	2
In Memoriam	5
EU Projects	5
Alzheimer Europe Networking	5
EU Developments	6
Members' News.....	8
Policy Watch.....	10
Science Watch.....	11
Dementia in Society	13
New Publications & Resources	14
AE Calendar	16
Future Conferences	16

Editorial

Thank you to all the participants who helped to make our Annual Conference a success!



There were 520 delegates in Vienna, including some of the top names in dementia research, experts from the EU and the Austrian government and leaders from most of our member associations. More than 140 speakers presented the evolving insights and developments in the way we perceive and treat dementia - and also how we can influence policymakers to provide needed resources.

We were particularly happy to welcome more than 15 people with dementia and their caregivers. Their presence had a special significance this year, as 11 of them also attended the first meeting of the European Working Group of People with Dementia (EWGPWD). The group elected a Board and Officers and also set out its objectives, which in turn will help to guide the activities of Alzheimer Europe.

Alzheimer Europe also elected a new Board during its AGM and welcomed the Croatian and Slovenian associations as new full member organisations.

We have a large collection of presentations, videos and pictures from Vienna. These will appear on our website over the next several weeks and the next issue of Dementia in Europe magazine will also have extensive coverage.

We were also glad to see a high response rate to the satisfaction survey. Our delegates generally gave the conference a positive vote, with notable praise for the plenary sessions and the relevance

and quality of topics presented in the Parallel sessions. Nearly all respondents said that they would recommend attending a future conference: we're taking that as a sign that you'll join us in Malta next year.

Just a few days after the conference, we were sad to hear of the untimely passing of Ornella Porro Possenti. She was a founding member of Federazione Alzheimer Italia and ardent supporter of Alzheimer Europe. We extend all our heartfelt condolences to her sister, Gabriella Salvini Porro.

This newsletter continues the coverage of our members' World Alzheimer's Day activities. These include Memory Walks and concerts, seminars for children and a visit to the Vatican. The 2012 prize for marking World Alzheimer's Day must surely go to France, where President Hollande announced the extension of the "Plan Alzheimer". The UK came in a close second as the government announced the launch of a national dementia campaign.

In other news from our members, Portugal has finally legalised living wills and Cyprus produced a musical based on Alzheimer's disease. Belgium bolstered its dementia-friendly communities while Jersey launched a new counselling service.

On the scientific front, the EMA approved the use of florbetapir. This radioactive agent, used together with PET scans, highlights amyloid in the brain and will help to diagnose Alzheimer's disease.

There are also new Phase 3 clinical trials, which will test the LMTX drug in people with both mild and moderate Alzheimer's disease. The same drug is also being tested for fronto-temporal dementia.

Jean Georges
Executive Director

Alzheimer Europe

3-4 October: European Working Group of People with Dementia meets for first time in Vienna

The European Working Group of People with Dementia (EWGPWD) held its first official meeting during 3-4 October in Vienna.

The group of 11 people with dementia and their carers was welcomed by Jean Georges, Executive Director of Alzheimer Europe. He outlined that the purpose of the group was to advise the organisation and to ensure the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia.

After a tour de table which allowed all participants to present themselves, the group proceeded to hold elections for the EWGPWD Board and elected the following people:

Chairperson: Helga Rohra (Germany)

Vice Chairperson: Jean-Pierre Frognet (Belgium)

Vice Chairperson: Jan Frederik Meijer (Netherlands)

Vice Chairperson: Agnes Houston (United Kingdom - Alzheimer Scotland)



The EWGPWD Board: (L-R) Jean-Pierre, Helga, Agnes, Jan Frederik.

The other members of the group are: Nina Balackova (Czech Republic), Raoul Grönqvist (Finland), Ingegärd Pousard (Sweden), Dermod Slevin (Ireland), Rozel Snell (Jersey), Bojan Španja (Slovenia) and Daphne Wallace Daphne (United Kingdom - Alzheimer's Society).

This concluded the activities of the Group on 3 October.

On 4 October, the new Chair opened the meeting and proposed that the aim of the meeting would be to collect ideas that were important for the group. These ideas would be further discussed at the next EWGPWD meeting and then presented to the Alzheimer Europe Board. Ms Rohra stated that it was important to demonstrate that the Group is capable of thinking in a structured manner, saying what it needs and explaining how it can improve the lives of their fellow people with dementia. The following topics emerged as important issues:

- Early diagnosis
- Delays in obtaining a diagnosis
- Loss and gain of talents and skills
- The need for a chain of care and treatment
- Coping
- Understanding each person with dementia
- Raising awareness

- Stereotypes and “the new dementia”
- The need for understanding from others

These issues will be further explored and the findings will be presented to the Alzheimer Europe Board in December 2012. As Chairperson of the EWGPWD, Ms Rohra is also a member of the AE Board with full voting rights.

The group also discussed how members can become involved in Alzheimer Europe activities - one of the main objectives of this working group. As a first step, the group will actively participate in AE's next lunch debate. This will be entitled “Living with dementia” and will take place in the European Parliament in December 2012. Several members of the group will speak during the debate and they will also meet the MEPs from their home countries.



The European Working Group of People with Dementia.

4 October: Alzheimer Europe holds Board meeting in Vienna

The Alzheimer Europe Board met on 4 October in Vienna, Austria. The Board members discussed various financial and operational matters, including a new statute that will enable the organisation to set up an independent foundation. This was the last meeting of the current Board, which took office in 2010. Sabine, Liane and Sigurd will be stepping down from the Board. Ms von Lützu-Hohlbein concluded the meeting by thanking all the members for their efforts and dedication to Alzheimer Europe.

4 October: Alzheimer Europe holds Annual General Meeting in Vienna

Alzheimer Europe's Annual General Meeting (AGM) took place on 4 October in Vienna. The meeting was quorate, with more than half of member organisations present or represented. The AGM was attended by 62 people, including representatives from 27 of 30 full member associations. There were also observers, notably from the European Working Group of People with Dementia (EWGPWD) and Alzheimer's Disease International (ADI).

During the meeting, delegates were introduced to Ms Helga Rohra, Chairperson of the EWGPWD, who will henceforth be a full voting member of the Board.

There was also an election of a new Board: Charles Scerri from Malta is the new Honorary Secretary. He replaces Sigurd Sparr, who stepped down from the Board along with Sabine Henry and Liane Kadusch-Roth. There were no other changes and all Board candidates were unanimously approved.

In addition, delegates voted to raise both Alzheimer Croatia and Slovenia's Spominčica association to full member status. Alzheimer Europe will now have 30 full member associations and four provisional members:

Alzheimer Bulgaria, Alzheimer Uniti ONLUS (Italy), Compassion Alzheimer Bulgaria and the Estonian Alzheimer's Association.

Other highlights are listed below:

- Adoption of the agenda and minutes of the 2011 AGM in Warsaw.
- Discussion and adoption of the 2011 annual and financial reports.
- Discussion and adoption of statutory changes to comply with Luxembourg legislation.
- Retention of external auditor Mazars for the current financial year.
- Discussion and adoption of the new membership fee system.
- Discussion and approval of the 2013 Work Plan and Budget.

The next AGM will take place in October 2013 in Malta. All reports and financial statements are available on the Alzheimer Europe website.

www.alzheimer-europe.org



4 October: Alzheimer Europe elects new 2012-2014 Board

Alzheimer Europe elected a new Board at its Annual General Meeting held in Vienna on 4 October. The new Board includes a permanent seat for a person with dementia and a new Honorary Secretary.

The new Board Officers are:

- Chairperson: Heike von Lützu-Hohlbein (Germany)
- Vice-Chairperson: Iva Holmerová (Czech Rep.)
- Honorary Secretary: Charles Scerri (Malta)
- Honorary Treasurer: Maria Do Rosário Zincke dos Reis (Portugal).

The new Board Members are:

- Patrick Maugard (France)
- Maurice O'Connell (Ireland)
- Sirpa Pietikäinen (Finland)
- Helga Rohra (Germany), Chairperson of EWGPWD
- Alicja Sadowska (Poland)
- Henry Simmons (Scotland).

Alzheimer Europe is a strong advocate of involving people with dementia in every aspect of their life, care and community. The European Working Group of People with Dementia (EWGPWD) was established in 2011 for this purpose and Alzheimer Europe changed its statutes to

enable the Chairperson of this Group to serve on the Alzheimer Europe Board. Helga Rohra, who lives with dementia, was elected as the first Chair of the EWGPWD on 3 October and joined the Board the next day. The members of the new Board will serve until 2014.



2012-14 Alzheimer Europe Board: (L-R) Henry, Rosário, Heike, Alicja, Charles, Iva, Maurice, Helga, Patrick. Absent: Sirpa.

4-6 October: Alzheimer Europe holds successful 22nd Annual conference in Austria

The 22nd Alzheimer Europe Conference took place on 4-6 October in Vienna. The conference, entitled "Changing perceptions, practice and policy", was organised by Alzheimer Europe together with Alzheimer Austria and attracted some 500 delegates from 42 countries.

Participants represented a wide range of backgrounds within the dementia field, including people with dementia and their carers, leaders of national Alzheimer associations and volunteer caregivers. The conference was also attended by healthcare professionals, academics and researchers, representatives from the pharmaceutical industry as well as national and EU policy makers.

The organisers were particularly glad to welcome more than 15 people with dementia from 12 countries. Alzheimer Europe provided a special bursary to provide most of these special guests with transport and accommodation.

The conference was opened by Heike von Lützu-Hohlbein and Antonia Croy, respectively Chairpersons of Alzheimer Europe and Alzheimer Austria. They greeted the delegates and introduced Rudolf Hundstorfer, Austria's Federal Minister of Labour, Social Affairs and Consumer Protection. Mr Hundstorfer announced that the Austrian government would work toward establishing a national dementia plan within five years. He also praised the work of Alzheimer Austria and assured Ms Croy that the association will have a significant role in developing the plan.

This year's conference featured some 120 speakers in plenary and parallel sessions, special symposia and workshops. The four plenary sessions focused on the changes needed to cope with the growing number of people with dementia in Europe. Delegates learned that no country is spared: every country needs to develop a national dementia plan - and also collaborate in European research programmes - in order to address the challenges of dementia. These research programmes include clinical trials for cures but also efforts to exchange best practices and investigate the psycho-social effects of living with dementia. The first plenary session, "Changing policy - national strategies and European collaboration on dementia", was a round-table discussion chaired by Andreas Winkler. Prof Alistair Burns (England) and Ms Teresa di Fiandra (Italy) described the development of their respective national plans. Ms Caitriona Creely

(Ireland) presented the ambitious aims of the Joint Programming on Neurodegeneration whilst Mr Michael Hübel of the European Commission outlined the place of dementia in the European programmes for active ageing and public health.

The second session, named “Changing practice - medical and clinical aspects”, was chaired by Dr. Charles Scerri (Malta). Prof Bruno Dubois (France) talked about changing the criteria for diagnosing Alzheimer’s disease, while Prof Eric Larson (USA) offered prospects for the prevention of dementia in our increasingly ageing society. Dr. Achim Schneeberger (Austria) presented an overview of the latest dementia research and Dr. Giovanni Frisoni (Italy) followed up with new insights from research projects using imaging to diagnose dementia.

The third plenary session was led by Ms Stefanie Auer (Austria) and explored the topic “Changing practice - social and care aspects”. Ms Kerstin Zimmermann (Austria) updated delegates on the Ambient Assisted Living Joint Programme and its focus on the mobility and independence of people with dementia. She was followed by Dr. Armelle Leperre-Desplanques (France), who presented ALCOVE - the European Joint Action on dementia to exchange good practices. INTERDEM, another collaborative project, was presented by Prof Bob Woods (United Kingdom), an expert in psychosocial research. Finally, Dr. Marilène Filbet (France) presented the European Association for Palliative Care (EAPC), which is involved in palliative care for older people with dementia.

Dr. Myrra Vernooij-Dassen (Netherlands) chaired the final plenary session, named “Changing perceptions”. Ms Helga Rohra (Germany) gave a talk about the importance of involving people with dementia. The ethical implications of technology and dementia were outlined by Prof Cees Hertogh (Netherlands), who was followed by Dianne Gove’s overview of the latest conclusions and recommendations of the European Dementia Ethics

Network on dementia research. Helga Müller-Ebner (Austria) closed the session with a presentation on guardianship and advocacy in the Austrian healthcare system.

This session was notable for having a keynote speaker with dementia. Ms Helga Rohra, a former translator, lives with dementia with Lewy bodies. She spoke to delegates about the difficulties she has faced, including the urgent need to raise awareness and eliminate the stigma associated with dementia.

The conference also included 24 parallel sessions. These dealt with specific topics such as diagnosis, activities of people with dementia in their community, carer support and palliative care. Many of these presentations illustrated how national Alzheimer associations are developing effective solutions to help improve the quality of life of people with dementia and their carers. Delegates also learned how assistive technologies can provide relief for families and saw examples of how to design a dementia-friendly community. Several of these sessions featured speakers with dementia, who spoke about stigmatisation and the need for involvement on local and national levels.

The conference ended with closing remarks by Heike von Lüttau-Hohlbein and Antonia Croy, along with an invitation to Malta for the 23rd Alzheimer Europe Conference in 2013.

Alzheimer Europe and Alzheimer Austria are very grateful to all the presenters and delegates that helped make the conference a success. It is hoped that participants will continue to share their research projects, initiatives and activities to help in the ambitious task of changing perceptions, policy and practice in dementia.

The 22nd Alzheimer Europe Conference received funding from the European Commission’s Public Health Programme.

Impressions from the 22nd Alzheimer Europe Conference



Rudolf Hundstorfer, Austrian Federal Minister of Labour, Social Affairs and Consumer Protection



Plenary Session 1: Michael Hübel (European Commission), Teresa di Fiandra (Italy), Catriona Creely (Ireland), Alistair Burns (UK), Andreas Winkler (Austria)



Full house at the Alzheimer Europe Conference



Prof Bruno Dubois (France), Plenary Session 2 speaker



Poster exhibition



Gala Dinner at the Piaristenkeller in Vienna



Kerstin Zimmermann (Austria) presents during Plenary Session 3



Prof Myrra Vernooij-Dassen (Netherlands) and Helga Müller-Ebner (Austria) during Plenary Session 4



Organisers & Chairpersons: Antonia Croy (Alzheimer Austria) with Heike von Lützu-Hohlbein (Alzheimer Europe)

In Memoriam

14 October: Ornella Porro Possenti

We are very sad to announce that Ornella Porro Possenti unexpectedly passed away on 14 October.

Ornella was one of the founding members of Alzheimer Milano and Federazione Alzheimer Italia and also a great supporter of Alzheimer Europe and our activities. Many of our readers will remember her kindness, dedication and great sense of humour, as recently as our Annual Conference in Vienna which she attended as one of the representatives of Federazione Alzheimer Italia. She will be greatly missed!



We extend our heartfelt condolences to her sister, Gabriella Salvini Porro, as our thoughts are with her in these difficult times.

EU Projects

1 October: NILVAD project holds pre-trial meeting

On 1 October, the Steering Committee of the NILVAD project held a progress meeting in Amsterdam. The meeting was attended by 23 partners who discussed the progress and challenges of the various workgroups. The Steering Committee is confident that the partners will be able to begin clinical trials of Nilvadipine in early 2013.

NILVAD is funded by the European Commission within the 7th Framework Programme.

<http://www.nilvad.eu>



Alzheimer Europe Networking

On 1 October (Brussels, Belgium) Annette met with the Ligue Alzheimer Workshop "Dementia Friendly Cities: state of play and perspectives".

On 1 October (Schiphol, The Netherlands) Alex attended the NILVAD Steering Committee meeting.

On 2 October (Brussels, Belgium) Annette attended the European Innovation Partnership on Active and Healthy Ageing – meeting of the Action Group on Age Friendly Cities.

On 3-4 October (Vienna, Austria) AE organised the first meeting of European Working Group of People with Dementia (Vienna, Austria).

On 4-6 October (Vienna, Austria) AE Board & staff attended the Alzheimer Europe Board Meeting and the 22nd Alzheimer Europe Conference "Changing perceptions, practice and policy".

On 5 October (Vienna, Austria) Heike and Jean met with Jacob Roy and Marc Wortmann from Alzheimer's Disease International.

On 7 October (Vienna, Austria) Dianne attended the 1st meeting of Alzheimer Europe's working group on the ethical issues linked to restrictions of freedom.

On 12-13 October (Nicosia, Cyprus) Alex visited the premises of Alzheimer Cyprus.

On 19 October (Chilly-Mazarin, France) Annette attended the Sanofi meeting on Alzheimer's disease.

On 25 October (Brussels, Belgium) Annette went to the European Society of Radiology kick off meeting.

On 30 October (Brussels, Belgium) Annette attended the EFNA General Assembly Meeting and meeting with corporate sponsors.

On 31 October (London, UK) AE Board members and Jean had a meeting with Novartis.

Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 66, representing 22 Member States of the European Union and all 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:



Austria: Becker K. Heinz (EPP), Werthmann Angelika (NI). **Belgium:** Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGI). **Czech Republic:** Cabrnoc Milan (ECR), Kohlíček Jaromír (GUE/NGI), Roithova Zuzana (EPP). **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), 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), Juvin Philippe (EPP), Morin-Chartier Elisabeth (EPP), Pargneaux Gilles (S&D). **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:** Mauro Mario (EPP), Panzeri Pier Antonio (S&D), Toia Patrizia (S&D). **Lithuania:** Vilija Blinkевичiute (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP). **Poland:** Łukacijewska Elżbieta (EPP). **Portugal:** Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL). **Romania:** Antonescu Elena Oana (EPP), Busoi Cristian (ALDE), Sârbu Daciana Octavia (S&D). **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badia i Cutchet Maria (S&D). **United Kingdom:** Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

EU Developments

5 October: JPND set to launch calls for proposals



The EU Joint Programme – Neurodegenerative Disease Research (JPND) will announce two calls for proposals in December 2012. Both are likely to have March 2013 submission deadlines.

The first call will be “A call for European research projects for the identification of genetic, epigenetic and environmental risk and protective factors”. Its objective is to establish innovative, multinational, multidisciplinary and collaborative research projects that will add value to existing research through identifying novel genetic, epigenetic and environmental risk and protective factors associated with neurodegenerative disorders.

The other call will be “A call for European research projects for the evaluation of health care policies, strategies and interventions”. This is expected to assess and compare policies, strategies and interventions related to neurodegenerative disease care, with regard to quality, access and cost-effectiveness. Examples of areas to be evaluated include care pathways, psychosocial interventions, end-of-life strategies, and educational programmes. Studies should benefit persons with neurodegenerative diseases and their carers/families.

These calls stem from JPND’s Strategic Research Strategy, which was launched in February 2012 with five priorities for future research:

- The origins of neurodegenerative disease
- Disease mechanisms and models
- Disease definitions and diagnosis
- Developing therapies, preventive strategies and interventions
- Healthcare and social care

JPND is an initiative led by EU member states to tackle one of the “grand challenges” which faces European society, namely that of neurodegenerative diseases. Grand challenges are issues such as climate change, food and energy security. Realistically they are beyond the capacity of any individual country to resolve, and would benefit from a coordinated approach to research.

The calls for proposals will appear on the project’s website.

www.jpnd.eu

10 October: Commission publishes call for proposals for ERC Synergy Grant

On 10 October, the European Commission published a call for proposals for European Research Council (ERC) Synergy Grants.

ERC Synergy Grants are part the EU’s Seventh Framework Programme (FP7). They aim to enable small groups of principal investigators and their teams to bring together complementary skills, knowledge and resources, in order to jointly address new research problems that are beyond what individual investigators could achieve alone.

The indicative budget is EUR 150 million from the 2013 budget. The final budget awarded to this call may vary by up to 10% of the total value of the call.

The EU will reimburse up to 100% of the total eligible and approved direct costs and of flat-rate financing of indirect costs on the basis of 20% of the total eligible direct costs.

The Commission has produced the “IDEAS Work Programme (WP)” to guide applicants through the background to the WP, the broad policy objectives and the underlying principles of ERC funding. The WP also explains the common features and requirements for ERC grants as well as a budget breakdown by activity.

The submission deadline is 10 January 2013. It is expected that all projects start within 6 months from the award of the grant.

http://ec.europa.eu/research/participants/portal/page/ideas;efp7_SESSION_ID=466nQWTFtyshn62v1DQ5vWmCWq8I2SpVQYtKD4VYjnp5JsDTsM8f12017552818?callIdentifier=ERC-2013-SyG

16 October: Health Commissioner John Dalli resigns



On 16 October, John Dalli, European Commissioner for Health and Consumer Policy, resigned as a member of the Commission following an investigation by OLAF, the EU antifraud office. Mr Dalli categorically rejected the investigation findings.

The OLAF report showed clearly that the European Commission’s decision making process and the position of the services concerned has not been affected at all by the matters under investigation.

Mr Barroso, President of the European Commission, decided that Vice President Maros Sefcovic will take over the portfolio of Mr Dalli on an interim basis until a new Commissioner of Maltese nationality is appointed.

http://europa.eu/rapid/press-release_MEMO-12-788_en.htm

23 October: European Commission adopts 2013 Work Programme

On 23 October 2012, the European Commission adopted its 2013 Work Programme.

The number one task of the Commission will be to tackle the economic crisis and return to sustainable growth. The Programme calls for a Europe able to compete in the global economy and reshaped to seize the opportunities of the future.

The Programme sets out the long term vision of what the EU should look like in key policy areas, summarises what is missing today and explains how the Commission will tackle these challenges. By prioritising the right kind of initiatives, the EU can contribute to growth and job creation and move closer to its longer term vision.

Some 50 new initiatives will be tabled during 2013-2014, aiming to:

- Promote a genuine Economic and Monetary Union with additional legislation to enhance stability, transparency and consumer protection in the financial sector.
- Boost competitiveness in the Single Market and industrial policy through initiatives that will cut costs for businesses, tackle obstacles to competitiveness and encourage key growth sectors through public-private partnerships in research.
- "Connect to compete: building tomorrow's networks today" through modernising networks: liberalising in energy, boosting investment in infrastructure like broadband and modernising Europe's transport and logistics.
- Promote growth for jobs with inclusion and excellence by building up support to the unemployed in areas like public employment services, and making sure the EU does its utmost to support social inclusion.
- Use Europe's resources to compete better by giving a long-term perspective to sustainable growth with a framework for energy and climate change to 2030 and dedicated action on air quality and waste.
- Build a safe and secure Europe by working to boost justice through a European Public Prosecutor's Office to protect the EU's financial interests, security by fighting traffic in firearms and consolidating citizenship in the European Year of Citizens.
- Ensure that Europe is a global actor by driving forward Europe's interest and values through a new generation of trade agreements, targeted action in Europe's neighbourhood, and furthering the Millennium Development Goals as the world's leading development cooperation partner.

The adoption of the Commission Work Programme is the result of dialogue with the European Parliament, the Committee of the Regions and the European Economic and Social Committee on the priorities for the Union.

The Commission will work closely with the European Parliament and the Council, as well as stakeholders to take forward these objectives and provide tangible results for Europe's citizens.

http://ec.europa.eu/atwork/pdf/cwp2013_en.pdf
http://europa.eu/rapid/press-release_SPEECH-12-756_en.htm



www.alzheimer-europe.org/Donation

26 October: Commission launches consultation on direction for future technologies research

On 26 October, the European Commission launched a public consultation on directions for future and emerging technologies research. The aim is to identify promising and potentially game-changing directions for future technological research.

The Commission is looking for research directions that are more general than an idea for a single research project. They may, for instance, identify a crucial but underdeveloped scientific/technological domain that requires development and structuring; stimulate multi-disciplinary explorations around inspiring questions, even non-technological ones; propose unifying concepts that can lead to new synergies from previously unrelated research; set an ambitious and concrete challenge that is far beyond the state-of-the-art, the achievement of which would open up radically new possibilities for technology.

The consultation deadline is 30 November 2012.

http://cordis.europa.eu/fp7/ict/fet-proactive/fetconsult2012_en.html

30 October: WeDO project team publishes EU Quality Framework for Long-Term Care Services

On 30 October, the EU Quality Framework for Long-Term Care Services was posted on AGE Platform EU website. This Framework is the final output of the WeDO project. A summary of the Framework is also available.

WeDO (Wellbeing and Dignity of Older people) is a European project involving 18 partners from 12 countries. Their objective is to develop a partnership of organisations to promote the wellbeing and dignity of vulnerable and disabled older people and prevent elder abuse through the promotion of quality long-term care. The 2010-2012 project is coordinated by AGE Platform Europe and co-financed by the European Commission.

The Framework documents will be presented at the final project conference on 14 November at the European Parliament. This conference will be hosted and chaired by Heinz Becker, MEP (Austria) and member of the European Alzheimer's Alliance. The Framework presents:

- Background information including an analysis, the vision and common values of the WeDO partnership.
- Quality principles and areas of action for the quality of services for older people in need of care and assistance.

- Recommendations for implementation, with examples of quality development, control and labelling tools.
- A methodology for implementation, based on the WHO improvement cycle of the Age-friendly Cities Program.
- A list of around 30 good practices from 12 different countries.

<http://wedo.ttp.eu/european-quality-framework-long-term-care-services>
<http://wedo.ttp.eu/wedo-events>
<http://wedo.ttp.eu/>

Members' News

18 September: Alzheimer Hellas holds press conference for World Alzheimer's day



On 18 September, Alzheimer Hellas gave a press conference for World Alzheimer's Day. Marc Wortmann, Executive Director of Alzheimer's Disease International (ADI) opened the press conference by describing the efforts that the Greek associations are making in the country. A special report about dementia in Greece, written in collaboration with ADI, was also presented during the conference.

After the press conference, Prof Tsolaki, President of the Panhellenic Alzheimer's Federation, met with Greek President Karolos Papoulias.



During the meeting, the President learned about the initiatives regarding dementia care in Greece and about the new report, which includes the first mapping of dementia in the country. He also heard about the economic problems faced by the local Alzheimer associations due to the crisis.

The President is genuinely interested in the fight against dementia and all the interventions and initiatives that are taking place in Greece. He agreed that all involved stakeholders should work hard in order to follow the good practices from other European countries. He also declared that he fully supports people fighting with dementia and their carers.

20 September: Alzheimer France holds Memory Walk and exhibition on World Alzheimer's Day



On 20 September, hundreds of people showed their solidarity by joining the Memory Walk organised by Alzheimer France to mark World Alzheimer's Day.

This was followed by an event featuring a photo exhibition entitled "Alzheimer's disease without filters". Eleven families of people with dementia presented photos of their daily lives. Through the eyes of the families, the exhibition showed that despite the disease, people with dementia and their carers can live a life filled with emotion and joy.



20-21 September: Alzheimer Unita Italy holds conference and visits Vatican for World Alzheimer's Day



Alzheimer Unita held its 14th annual Alzheimer conference at the Campidoglio in Rome. The conference, which was open to the public, featured keynote speaker Prof Marco Trabucchi, President of the Italian Psychogeriatric Association and various government officials from Rome and the Lazio Region. There were a variety of speakers including neurologists, geriatricians and therapists who presented subjects such as prevention, services, new technologies and caregiver support.

During the conference, the annual Savvy Caregiver Prize was awarded to an 83 year old woman from Sardinia, who has been caring for three sisters with dementia.

On 1 October, the association also organised a visit to the Vatican Gardens for persons with advanced-stage dementia from the Alzheimer Day Center of the Rome Foundation. This activity was very special and enjoyable and provided cognitive and sensorial stimulation. Furthermore, the visit had a spiritual component, since it included stops at various chapels within the gardens. The group enjoyed the walk around the Vatican Gardens, which are very well-tended and rich with lush and fragrant plants, fountains and other multisensory stimuli. The participants were also able to rest in pleasantly shaded areas.



The visit was a great success, as revealed by the words of the participants and also afterwards through the comments of their caregivers.

The visit was a great success, as revealed by the words of the participants and also afterwards through the comments of their caregivers.

22 September: Luxembourg leads a Memory Walk on World Alzheimer's Day



The Luxembourg Alzheimer Association held its 11th Memory Walk to commemorate World Alzheimer's Day. This year, the itinerary wound in and around the capital city of Luxembourg on a bright, sunlit day that brought out many followers. The walk ended in the city centre, where volunteers provided information about dementia, served food and drink and even provided musical entertainment.

www.alzheimer.lu/de/actualites/l-association/memory-walk-2012.html



28 September: Slovenian association educates children on dementia



On 28 September, the Slovenian Alzheimer Association organised an event in Šentjur to mark World Alzheimer’s Month. This included a press conference, a concert and a variety of activities to raise awareness of dementia.

In particular, the association presented a new brochure for children and teens entitled “Grandma is becoming a little strange - she always forgets things”. Volunteers were on hand to explain the importance of educating young people about dementia.

The association has also been conducting a series of workshops about Alzheimer’s disease for children. This project has been co-financed by The European Agricultural Fund for Rural Development and the Slovenian Ministry of Agriculture, Forestry and Food.



1 October: Jersey introduces Counselling and Family Support service



The Jersey Alzheimer’s Association has introduced a free Counselling and Family Support service. The service is run by Sian Wareing-Jones, MA, BSc (Hons), Adv.Dip.Couns, MBACP. Sian recently completed her MA on Carers’

Experiences of Living with Dementia.

Counselling gives people the opportunity to talk to a trained professional who is there to listen and support people through difficult times, to help bring about effective changes and enhanced well-being. It is often about making changes or moving forward, with the counsellor helping people find new ways to feel stronger for the future.

Family Support is a service provided by Jersey Alzheimer’s Association to help support families or individuals going through a difficult time. This can be with or without the person with dementia being present, and can be for just a

brief chat or for more practical support over a much longer time.

Sian is a qualified and experienced counsellor with a special interest in working with people with dementia and their families. She also works part-time as a teacher and is currently undertaking a research Ph.D. in dementia care.

1 October: Belgium adds two cities to dementia-friendly communities



On 1 October, Belgium’s Ligue Alzheimer held a workshop dedicated to dementia-friendly cities and the inclusion of people with dementia in these cities.

The network of dementia-friendly-communities launched in Belgium in 2011. It consists of cities that are willing to strengthen, diversify and multiply the initiatives promoting the inclusion of people with dementia and their carers in their communities.

Workshop participants heard about the on-going efforts to make Lausanne, Switzerland part of the network. They also learned how Arnsberg (Germany) became the first dementia-friendly city.

At the end of the workshop, the towns of Soignies and Nivelles joined the network, bringing to 17 the total number of dementia-friendly cities in Belgium.

2 October: 2013 calendar encourages year-round activity in Germany



The German Alzheimer Society has released a 2013 calendar entitled “Dream Garden”. Each month features a picture of a flower and also verses from various songs, encouraging people to complete the song verse or sing the entire song.

Sabine Jansen, Managing Director of the German Alzheimer Society, said: “Gardens with flowers, grass and trees are often a great source of childhood memories and also represent the full cycle of life. We hope the calendar will encourage people to plan activities throughout the whole year.”

The calendar is available for purchase on the association’s website.

www.deutsche-alzheimer.de/index.php?id=48&news=155

18 October: German Alzheimer Society holds 7th Annual Conference

The 7th Annual Conference of the German Alzheimer Society took place in Hanau on 18-20 October. The conference, entitled "Living together & learning from each other", was held under the patronage of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth. The Ministry is headed by Dr. Kristina Schröder, a keynote speaker at the conference along with Mr Stefan Gruettner, Hessian Minister for Social Affairs.

Delegates heard about the importance of increasing dementia awareness and also new methods for early diagnosis. While these are currently only used in research, they have the potential to become mainstream - as long as there are no effective treatment options. There was also a session dedicated to the burdens of caregivers and

family members – and the local services that exist to relieve those burdens. These include a dedicated discussion group and various specialised day care facilities in the area.

During the conference, the Board of the society voted to approve funding for two research projects that will help people with dementia and their families. One project will provide legal education and support for caregivers of people with dementia, while the other will ensure that comorbidity is properly recognised and treated among people who live with both dementia and diabetes.

The conference closed with an award ceremony to honour five volunteer caregivers who have provided care to people with dementia for ten years or more. Wilfried Georgi, Heidi Juhl Damberg, Gabriele Quick, Almut Schauss and Elizabeth Zapfe were all thanked and presented with award certificates by Heike von Lützu-Hohlbein, Chair of the German Alzheimer Society.

www.kukm.de/alzheimer2012



18 October: Alzheimer Scotland opens new Dementia Resource Centre



On 18 October, Alzheimer Scotland opened a new Dementia Resource Centre in Dumfries. The new Centre will increase the local support opportunities available to people with dementia. It will run day and evening care services, therapeutic activities, carer support and education, peer support groups, self-management courses and training for staff and health care workers. It will also provide an advice and information service.

The Centre will also be used to develop new activities such as exercise groups, football reminiscence activities, singing groups, a café and baking/cooking groups. Such activities are vital in reducing the social isolation of people affected by dementia; providing a relaxed social environment and an opportunity for people with dementia and their carers to meet others in the same situation. It will also display volunteering opportunities and be a resource for other organisations and Alzheimer Scotland services in the region.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: "We believe that no-one should have to face dementia on their own and that anyone affected by the illness should be able to find help quickly and easily. Our new Dementia Resource Centre in Dumfries will be a strong community hub offering information, advice, practical support and a wonderful, welcoming space for people living with dementia – in the town and beyond."



30 October: Romanian Alzheimer Society shows a busy conference calendar



The Romanian Alzheimer Society has had a busy October: its members attended six conferences during the month. On 1 October - the International Day of Older People - they participated in a symposium on care of the elderly in a Bucharest hospital. They were also at the Alzheimer Europe Conference in Vienna, presenting a poster on 6 October of the Society's successful memory testing campaign. On the same day, Prof Catalina Tudose, Chairperson of the Society, made a presentation about episodic memory at Romania's 2012 National Conference of Psychiatry. On 9 October, the Society was represented at a conference launching the World Report on Disability 2011 and - two days later - at a symposium exploring the "Role of the associations in the development of the society". Finally, on 31 October, the Romanian Alzheimer Society took part in "Health Forum: Health Financing System 2013".

Policy Watch

21 September: President Hollande announces continuation of the French Alzheimer Plan



On 21 September, President François Hollande marked World Alzheimer's Day by announcing that the French Alzheimer Plan will be continued. The announcement came during a meeting with the members of the French Alzheimer Plan pilot team, Health and Social Affairs Minister Marisol Touraine and Minister of Higher Education and Research Geneviève Fioraso.

The president noted that the previous plans have brought concrete benefits to people with dementia and their families. He particularly singled out MAIA, a one-stop shop where a dedicated case-manager designs an integrated plan of health and social care suitable for the individual, training of dementia professionals and mobilisation of research efforts.

He also acknowledged that the current debates on the isolation of the elderly people and on dependence and end of life issues will continue. This is particularly true for Alzheimer's disease, he said, adding that a reform on dependence will soon be presented and financed. This reform will bring a global approach to the ageing of the population.

President Hollande said that the new Plan will prioritise the dignity of people with dementia and the training of their carers. He concluded by saying that the Alzheimer Plan would be pursued after an evaluation and that the plan will be broadened to include all neurodegenerative diseases.

<http://www.elysee.fr/president/les-actualites/communiqués-de-presse/2012/communique-comite-de-suivi-de-lutte-contre-la-13951.html?search=Alzheimer&xtmc=alzheimer&xcr=1>

<http://www.elysee.fr/president/les-actualites/discours/2012/intervention-du-president-de-la-republique-lors-de-13956.html?search=Alzheimer&xtmc=alzheimer&xcr=2>

21 September: UK government announces dementia campaign on World Alzheimer's Day



The UK Department of Health, supported by the Alzheimer's Society, launched a three-month national dementia campaign on World Alzheimer's day. The campaign is called "A Day to Remember" and will raise awareness of the condition and the initial signs and symptoms of Alzheimer's disease.

It will also encourage people to have that first "difficult conversation" with a friend or family member when they spot the signs and symptoms of dementia and encourage them to visit their GP.

Jeremy Hughes, Chief Executive at Alzheimer's Society, said: "Talking to a loved one about dementia will probably be one of the most difficult conversations you ever have, but it will be worth it. Early diagnosis is crucial in helping people with dementia to access the support and help they need to live well with the condition."

A campaign brochure is available on the NHS website.

www.nhs.uk/dementia/Documents/dementia_memory_loss_leaflet.pdf

1 October: Living wills become legally binding in Portugal



The Portuguese government has enacted a law allowing adult able-bodied citizens to prepare a document clarifying the treatment they want, or want to refuse, in case of future incapacity.

Currently, this document must still be prepared before a notary. However, the new law includes a Living Will National Registration. This will soon allow people to create and store a living will online at no charge. Health care professionals will be able to consult this database if someone becomes incapable of giving consent to health care interventions.

Alzheimer Portugal welcomes this initiative as an important achievement for the respect of individual autonomy and self-determination. The association also hopes to see similar directives for issues other than clinical treatments.

Science Watch

26 September: Human stem cells regenerate AD brains in mice

Korean stem cell researchers have demonstrated the ability to regenerate Alzheimer's disease brains in mouse models.

The team infused fat-derived adult human stem cells intravenously in Alzheimer model mice multiple times, two weeks apart, in mice from three to 10 months old. The stem cells decreased levels of both beta amyloid and Amyloid Precursor Protein (APP). The study also confirmed that stem cells infused intravenously can reach the brain across the blood brain barrier.

The researchers were jointly led by Prof Yoo-Hun Suh from Seoul National University and Dr. Jeong-Chan Ra from RNL Bio Stem Cell Technology Institute (SCTI).

www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0045757

28 September: Rapamycin eases frontotemporal lobar degeneration

Researchers at Taiwan's Institute of Clinical Medicine and Institute of Basic Medical Science (NCKU) have determined that the drug rapamycin may be a possible treatment to alleviate frontotemporal lobar degeneration (FTLD), one of the causes of dementia.

Rapamycin is an immunosuppressant drug used to prevent rejection in organ transplantation. In this study, researchers used the drug's ability to act as an autophagy activator, i.e. to cause other cells to digest themselves.

The team led by Prof Kuen-Jer Tsai created a mouse model with excessive levels of the TDP-43 protein, which is typical in FTLD. After administering rapamycin to the mice, they noted a significant reduction in TDP-43 levels. The animals saw a reduction of loss of motor function and also maintained their learning and memory abilities.

The research team also showed that spermidine, carbamazepine and tamoxifen – all autophagy activators like rapamycin – can be used with similar effect.

Rapamycin is also known as sirolimus and is marketed by Pfizer as Rapamune.

www.pnas.org/content/109/37/15024.abstract?sid=f353ef71-165f-461a-9fbd-c156a882e639

1 October: Vitamin C and beta carotene may reduce risk of dementia

Researchers at the German University of Ulm have found that antioxidants could potentially protect the body against neurodegeneration. They determined that the levels of vitamin C and beta carotene, both antioxidants, are lower in people with mild Alzheimer's disease.

The researchers, Dr. Christine von Arnim, Professor of Neurology, and Dr. Gabriele Nagel, Professor of Epidemiology, were investigating whether oxidative stress contributes to the development of Alzheimer's disease. Oxidative stress constrains the exploitation of oxygen in humans.

In a population-based study sample, the team evaluated 74 people with Alzheimer's disease and 158 healthy controls between the ages of 65 and 90. Results showed that the serum concentration of vitamin C and beta-carotene are much lower in patients with mild dementia than in control persons.

Dr. Nagel said: "Longitudinal studies with more participants are necessary to confirm the result that vitamin C and beta-carotene might prevent the onset and development of Alzheimer's disease".

<http://iospress.metapress.com/content/h3215182vr7h5830/?issue=4&genre=article&spage=717&issn=1387-2877&volume=31>

1 October: The medial temporal lobe may affect perception as well as memory

A new study from Georgia Tech (USA) and the University of Toronto suggests that memory impairments in people with early stage Alzheimer's disease may be partly due to problems in determining the differences between similar objects. The findings also suggest that the brain's medial

temporal lobe plays a role in object perception – not just in memory as is generally thought.

Researchers tested people with MCI on their ability to determine whether two rotated, side-by-side pictures were different or identical. In the “high-interference” trial, many photos of the same were shown. The photos varied only slightly when they weren't a perfect match, either by shape, colour or fill pattern. The test subjects had difficulty to identify identical pairings.

In the “low-interference” trials, these photos were interspersed with trials in which non-matches were more extreme and varied widely. For example, a picture of a butterfly was shown next to a photo of a microwave. Interspersing the very similar objects with photos of dissimilar objects greatly reduced the amount of confusion. These findings suggest that reducing “visual clutter” can help people with MCI get through everyday tasks.

Project leader Rachel Newsome, a University of Toronto Ph.D. student and Georgia Tech graduate, said: “Minimizing the degree of perceptual interference improved patients' object perception by reducing the number of visually similar features.”

Dr. Audrey Duarte, Assistant Professor of Psychology at Georgia Tech, said: “People often associate MCI and dementia solely with memory impairment. Memory and perception appear to be intertwined in the same area of the human brain.”

The research team believes that damage to the perirhinal cortex, a small area of the brain's medial temporal lobe, affects object perception. Dr. Morgan Barense, Assistant Professor of Psychology at the University of Toronto, said: “Not only does memory seem to be very closely linked to perception, but it's also likely that one affects the other. Alzheimer's patients may have trouble recognizing a loved one's face, not only because they can't remember it, but also because they aren't able to correctly perceive its distinct combination of features to begin with.”

<http://onlinelibrary.wiley.com/doi/10.1002/hipo.22071/abstract>

4 October: Scientists convert pericytes into active neurons

Researchers from the Ludwig-Maximilians University in Munich have demonstrated the ability to convert adult human brain cells known as pericytes into functioning neurons.

Pericytes are known as “support” cells, in that they help to defend and heal “working” neurons and other parts of the brain and spine. The research team, led by Dr. Benedikt Berninger, Senior Scientist at the University, changed pericytes into neurons by reprogramming their genomes.

To achieve this, the team introduced two proteins known as transcription factors into the pericytes. The first one, MASH 1, activated the right combination of genes for a neuron. The second protein, called Sox2, loosened the chemical bonds holding the pericyte together. Together, the two transcriptions turned pericytes into neurons.

[www.cell.com/cell-stem-cell/abstract/S1934-5909\(12\)00422-5](http://www.cell.com/cell-stem-cell/abstract/S1934-5909(12)00422-5)

12 October: Caffeine blocks the chain reaction leading to brain inflammation

A research team from the University of Illinois (UI) has shown how caffeine reduces the inflammation associated with Alzheimer's disease. The team headed by Prof Gregory Freund, Head of Pathology at UI's College of Medicine, determined that hypoxia initiates a chain reaction resulting in cognitive decline and that caffeine minimises the impacts of this chain reaction.

The study involved two groups of mice, one of which was given caffeine. Scientists induced hypoxia in both groups by interrupting their breathing and blood flow and then measured their ability to form new memories. The mice that consumed caffeine recovered their ability to form a new memory 33% faster than the mice that did not.

Hypoxia causes the release of adenosine molecules into neurons. Adenosine is the primary energy source in cells, but overproduction makes it “spill” outside the neuron. This spillage triggers the activation of the caspase-1 enzyme, which acts to “mop up” the excess. In doing so, the enzyme activates production of beta cytokine IL-1, a protein that is known to be an active player in brain inflammation. Caffeine prevents adenosine from activating caspase-1, thereby stopping the chain reaction before it starts.

www.jneurosci.org/content/32/40/13945.abstract



15 October: SUMO 1 protein increases beta amyloid production

A group of scientists at the Korea National Institute of Health (KNIH) have identified a protein called SUMO 1 that contributes to the cause of Alzheimer's disease.

The KNIH team found that SUMO 1 (small ubiquitin-related modifier 1) increased in the brain tissue of Alzheimer mouse models. It also combined with beta-secretase (BACE) which causes beta-amyloid to increase the amount of the toxic amyloid. The team also found that the creation of beta-amyloid could be restrained by restraining the gene expression of SUMO 1.

The researchers were led by Dr. Koh Young-ho, Deputy Scientific Director of KNIH. He said: “Until now SUMO 1 was known as a protein that combined with the target protein to control its functions but through this research, a new function (inducing the creation of toxic amyloid) has been found.”

[www.neurobiologyofaging.org/article/S0197-4580\(12\)00427-7/abstract](http://www.neurobiologyofaging.org/article/S0197-4580(12)00427-7/abstract)

18 October: EMA approves florbetapir for PET imaging

The European Medicines Agency (EMA) has recommended marketing authorisation for Amyvid (florbetapir 18F) as a diagnostic agent in people who are being evaluated for Alzheimer's disease and other causes of cognitive decline.

Amyvid, marketed by Lilly, is a radiopharmaceutical agent used in positron emission tomography (PET) imaging in the brains of living human adults. It can highlight amyloid protein plaques in the brain, and assist in the diagnosis of Alzheimer's disease.

The full text of the EMA opinion is available on the agency's website.

www.ema.europa.eu/docs/en_GB/document_library/Summary_of_opinion_-_Initial_authorisation/human/002422/WC500134101.pdf

EMA rejects medicine combining memantine and donepezil

On the same day, the EMA gave a negative opinion on two drugs which combine memantine hydrochloride and donepezil hydrochloride into a single medicine.

Balaxur (Merz) and Acrescent (Lundbeck) are both intended for the treatment of moderate to moderately severe Alzheimer's disease in patients who are already taking memantine and donepezil.

www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicine_s/002424/smops/Negative/human_smop_000442.jsp&mid=WC0b01ac058001d127

www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicine_s/002708/smops/Negative/human_smop_000432.jsp&mid=WC0b01ac058001d127

22 October: CSF study may allow earlier detection of Alzheimer's disease

A research team at Sahlgrenska Academy, University of Gothenburg (Sweden), is developing a new method to differentiate between Alzheimer's and Parkinson's diseases by analysing cerebrospinal fluid (CSF) samples. This may eventually permit earlier detection of Alzheimer's disease.

Due to the similarity of the symptoms, it is often difficult to differentiate people with Alzheimer's from those with other types of dementia or people with Parkinson's disease from those with other motor disorders. This study, led by Dr. Kaj Blennow, Professor in Clinical Neurochemistry at the University of Gothenburg, tested five proteins that serve as biomarkers for the two diseases. The trial was conducted among 450 patients at Skåne University Hospital and Sahlgrenska University Hospital.

Dr. Annika Öhrfelt, a researcher at Sahlgrenska Academy, said: "Previous studies have shown that Alzheimer's disease is associated with biochemical changes in specific proteins of the brain. This study has found that the inclusion of a new protein can differentiate patients with Alzheimer's disease from those with Lewy body dementia, Parkinson disease dementia and other types of dementia.

"Additional studies are needed before the biomarkers can be used in clinical practice during the early stages of disease, but these results represent an important step along the way."

<http://archneur.jamanetwork.com/article.aspx?articleid=1355364>

30 October: Nutricia will conduct a clinical study on medical nutrition

Nutricia Advanced Medical Nutrition, the specialised healthcare unit of Danone, has announced plans to invest

in a new study of the effects of its product Souvenaid, a medical nutrition formulation.

Nutricia completed two successful Souvenaid trials in 2010 and 2012 on people with Alzheimer's disease. The new study will be a continuation of that work: the company seeks to demonstrate that specialised nutrition can play an important role in supporting brain function. The study may start as early as 2013, targeting people at the earliest measurable stage of Alzheimer's disease.

www.nutricia.com

30 October: TauRx launches two Phase 3 trials for Alzheimer's disease

On 30 October, TauRx Therapeutics, a private pharmaceutical company, announced the launch of two Phase 3 clinical trials of its LMTX compound for mild to moderate Alzheimer's disease. These studies will aim to confirm the results of a successful Phase 2 trial.

The first study will involve 833 people with mild to moderate Alzheimer's disease over 12 months. The second study will include 500 people with mild Alzheimer's disease over 18 months. In Europe, trials will take place in the following countries: Belgium, Finland, France, Germany, Italy, The Netherlands, Russia, Spain and the UK.

According to the company, LMTX targets a process in the brain whereby a normal form of tau protein begins to self-aggregate due to binding neuronal waste-products. Once the process has started, the aggregates are able to propagate themselves indefinitely, using up normal tau protein and converting it into the toxic aggregates. After destroying the nerve cells where they are initially formed, the aggregates go on to infect nearby healthy neurons, progressively spreading and accelerating the destruction throughout the brain. LMTX stops this aggregation process and releases the trapped tau protein in a form which can be easily cleared by nerve cells.

The studies will be led by Prof Claude Wischik, Professor of Old Age Psychiatry at the University of Aberdeen (Scotland) and CEO of TauRx Therapeutics. In September 2012, TauRx also launched a Phase 3 clinical trial of LMTX for Fronto-temporal dementia.

TauRx Therapeutics is based in Singapore and is a spin-off company from the University of Aberdeen.

www.sciencedirect.com/science/article/pii/S1552526008005980
www.clinicaltrials.gov/ct2/show/NCT01689246

Dementia in Society

12 October: New musical with dementia theme debuts in Cyprus



"Dementia", a new musical theatre stage work, was presented in Nicosia on 12 October by Silver Spotlight, a Cypriot production company, along with the Cyprus Alzheimer's Association. The Greek-language musical features an all-professional cast with songs in both Greek and English. The action is mostly set in Cyprus but includes several interludes in London, which holds a considerable expatriate Cypriot community.

Ulysses is a successful musician who develops Alzheimer's disease and must deal with the physical and psychological consequences of the diagnosis. His own emotions and the evolving symptoms cause considerable turmoil in his relations with both his family and friends. His estranged brother Peter, a corrupt Cypriot politician, is involved in a scheme to steal public funds destined for dementia care.

A meeting of the brothers causes repercussions for their whole circle of family and friends. Their reactions to Ulysses' advancing dementia and the family's dark secret are in turn poignant and humorous, interspersed with songs about life, hope and betrayal. Their conflicts seem irreconcilable until - at Ulysses' funeral - they discover that they are strong enough to come to terms with their differences. "Farewell, live fully in the present moment, our lives are like a tempest which passes away. Farewell, you are taken away by the oblivion."

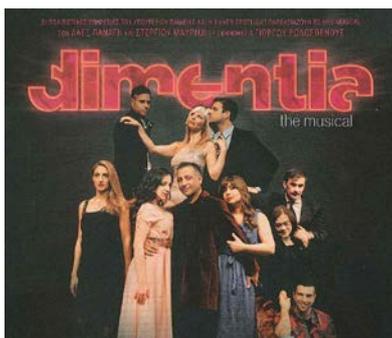
Ulysses is played by Alex Panagis, a professional singer and musician who also conceived the original idea and wrote all the music. He is also the co-producer, along with Katerina Christofidou. His portrayal of a man gradually succumbing to dementia is based on his mother Klery, who was diagnosed with Alzheimer's disease thirteen years ago.

Klery Panagi, now 80, lives at home with her husband Panos and they have three children. Alexis, Nicolas and Victoria don't live at home anymore, but they have always been there to help care for her. Klery was not able to attend the premiere of Dementia; she suffered an epileptic seizure on the same day. Her family described it as a consequence of Alzheimer's disease.

As the show progresses, Alex enacts many of the symptoms and behaviours that Klery has displayed over the years. These include memory loss, misplacing objects, restless wandering and aggression - but also the gentle, repetitive hand gestures that evoke Klery's earlier life as a professional pianist.

Dr. Androula Agroti, Cypriot Minister of Health, cited Dementia for its accurate portrayal of the advancing symptoms of dementia. She remarked that the production could be a valuable training tool for raising awareness of Alzheimer's disease and other forms of dementia.

Dementia, directed by Giorgos Rodosthenous, played for five nights in Nicosia and was also performed in Paris. The production was made possible by UNESCO, the Ministry of Health and the A.G. Leventis Foundation. Silver Spotlight and the Cyprus Alzheimer's Association are now seeking new funding to help bring the musical to a wider audience.



19 October: UK foundation launches Dementia Without Walls project

The Joseph Rowntree foundation, which funds research and development programmes throughout the UK, has issued an early-activity update on its Dementia Without Walls project.

This project aims to challenge the attitudes, understanding and behaviours around dementia which reinforce stigma, isolation and exclusion. This includes raising dementia awareness and understanding among local communities, organisations and businesses. An additional objective is to support the collective engagement of people with dementia, as their involvement is essential to the project.

Dementia Without Walls is made up of three main strands:

- Empowering people with dementia: enabling people with dementia to better connect with and support each other, so their experiences can shape policy, practice and attitudes.
- Dementia-friendly communities: developing the idea that people with dementia want to carry on living their lives. This will require businesses, organisations and statutory agencies to think of the person first, as a citizen, member, participant, client or customer in their own right - but also with particular needs because of their dementia.
- Thinking differently about dementia: supporting the development of conceptual thinking around dementia for research as well as policy and practice.

Dementia Without Walls began in July 2012 and will run until 2015.

www.jrf.org.uk/work/workarea/dementia-without-walls

New Publications & Resources

1 October: Video shows Alzheimer's disease research in Iceland

In July, we reported on a mutation of the APP gene that may delay or prevent early-onset Alzheimer's disease. This was the result of a project led by Dr. Kári Stefánsson in Iceland. Now we have received a video link which features Dr. Stefánsson speaking about his research. There is also a short interview of Ms Fanneý Eiríksdóttir, Chair of the Alzheimer Society of Iceland.

<http://uk.reuters.com/video/2012/07/17/alzheimers-discovery-spurs-new-hope-for?videoId=236538902>

1 October: UN and HelpAge report calls for urgent action to address the needs of the elderly

On 1 October - the International Day of Older Persons - a new report entitled "Ageing in the Twenty-first Century: A Celebration and a Challenge" was released by the United Nations Population Fund (UNFPA) and HelpAge International.

The new report underlines that ageing societies present huge challenges and require completely new approaches to health care, retirement, living arrangements and intergenerational relations.

The report analyses the current situation of older persons and reviews progress in policies and actions that have been taken by governments and other stakeholders. It provides examples of innovative programmes that successfully address ageing issues and the concerns of older persons.

The report also identifies gaps and provides recommendations for the way forward to ensure a society for all ages in which both young and old are given the opportunity to contribute to development and share in its benefits.

A unique feature of the report is a focus on the voices of older persons themselves, captured through consultations with older men and women around the world. Finally, ten priority actions to maximise the opportunity of ageing populations are presented in the report.

<http://unfpa.org/ageingreport/>
<http://www.unfpa.org/webdav/site/global/shared/documents/publications/2012/UNFPA-Exec-Summary.pdf>

2 October: University of California produces videos for people with dementia



The University of California in Los Angeles (UCLA) has produced a series of three short films about Alzheimer's disease, including aspects of research, personal experiences and support for families and carers.

Episode 1 - "Alzheimer's Long and Costly Goodbye": The first episode offers an overview of the looming Alzheimer's epidemic and the fear and grief experienced by people with the disease and their families.

Episode 2 - "Alzheimer's Diagnosis and Clinical Trials": The projections for Alzheimer's disease and other forms of dementia are alarming, but not all the news is bad. The second instalment assesses the progress UCLA researchers have made in understanding the disease and highlights some promising clinical trials and diagnosis techniques that could slow its progression, possibly the first step towards prevention and cure.

Episode 3 - "Alzheimer's Patient and Caregiver Support": Alzheimer's affects everyone differently, but all people with the disease and their families experience some form of grief and fear, not to mention the stress. The final instalment offers up new models for healthcare and caregiver support that emphasise early diagnosis and support networks for everyone touched by the disease.

www.youtube.com/uctvprime

10 October 2012: Bupa produces toolkit for talking to people with dementia



Bupa, a private UK healthcare company, has produced a "Talking Toolkit" that provides tips on talking to people with dementia. It is intended to raise awareness of dementia and therefore remove the fear of interacting with people living with the illness. The toolkit may also help caregivers to reduce the emotional distance between themselves and their loved ones.

The Talking Toolkit can be freely downloaded from the company website.

www.bupa.co.uk/individuals/care-homes/understanding-dementia

25 October: UK Alzheimer's Society publishes new dementia report



The UK Alzheimer's Society has released a new report entitled "My life until the end: Dying well with dementia" by Martina Kane, Senior Policy Officer at the Society.

The report provides a broad overview of the key issues relating to end of life planning and end of life care as experienced by people with dementia. It summarises existing evidence and presents new evidence from current carers, bereaved carers and people with dementia. It also makes recommendations about planning for end of life and improved, coordinated care through to the end of life.

"My life until the end: Dying well with dementia" is intended for a range of audiences including central and devolved government, policy makers, health commissioners and health and care providers. Its recommendations are intended to raise awareness, inform policy and change practice. It can be freely downloaded from the Society's website.

www.alzheimers.org.uk/endoflife

Contact Alzheimer Europe at:

Alzheimer Europe, 145 route de Thionville, L-2611, Luxembourg
info@alzheimer-europe.org, www.alzheimer-europe.org

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AE Calendar

Date	Meeting	AE Representative
1 November	Study visit of Lilly's Erl Wood Research Centre (London, UK)	Jean
6 November	European Commission EIP AHA conference of partners (Brussels, Belgium)	Annette
8 November	Meeting with Heather Clarke (EPDA) (Brussels, Belgium)	Annette
13 November	Pfizer Stakeholder day on clinical trials and IMI debate in the European Parliament (Brussels, Belgium)	Annette
20 November	AGE thematic seminar "Creating an age-friendly EU" (Brussels, Belgium)	Annette
22 November	Autumn Conference 2012 of the Dementia Services Information Development Centre entitled "Ethics and Dementia Care" (Dublin, Ireland)	Dianne
27 November	6 th meeting of the Health-EU Editorial Board (Luxembourg, Luxembourg)	Alex
31 November	GSK Advisory Board (London, UK)	Jean
3 December	2nd EWGPWD meeting (Brussels, Belgium)	AE staff
4 December	Alzheimer Europe Board Meeting (Brussels, Belgium)	AE staff
4 December	Lunch debate at the European Parliament (Brussels, Belgium)	AE staff
10 December	PharmaCog Steering Committee meeting (Lille, France)	Alex

Future Conferences

Date	Meeting	Place
7-8 November 2012	Options and challenges for ethical assessment in the clinical trial regulation proposal, www.efgcp.eu	Brussels, Belgium
8-10 November 2012	2 nd International Congress on Neurology & Epidemiology (ICNE), www.neuro-conference.com/2012/	Nice, France
8-11 November 2012	International Conference on Clinical Practice in Alzheimer Disease (CPAD), www.paragon-conventions.com	Budapest, Hungary
15 November 2012	Social care in times of crises: Does Europe care?, www.redcross.eu	Brussels, Belgium
19 November 2012	EFGCP Interactive investigator training for inspections, www.efgcp.eu	London, UK
19-21 November 2012	European Conference: One Step Up in later life: learning for active ageing and intergenerational solidarity	Brussels, Belgium
20 November 2012	AGE Platform Europe conference: Creating an Age-Friendly EU by 2020, www.age-platform.eu	Brussels, Belgium
22 November 2012	EMA workshop on access to clinical trial data and transparency, www.ema.europa.eu	London, UK
26-27 November 2012	Developing a Person-centred model of care for patients with dementia, www.phealthcare.org.uk	London, UK
27-29 November 2012	International courage in Europe conference and satellite symposium, www.courageproject.eu	Milan, Italy
29 November 2012	Reinventing healthy ageing, www.aim-mutual.org	Brussels, Belgium
3 December 2012	Closing conference of the European Year of Active Ageing and Solidarity between Generations 2012	Brussels, Belgium
5-7 December 2012	Nursing Ethics: intensive course on foundational approaches, contemporary and educational issues in the field of nursing ethics, www.masterbioethics.org	Leuven, Belgium
7-10 December 2012	8 th International Winter Conference on Alzheimer's Disease, www.ad-zuers.com	Zuers, Austria
25-27 January 2013	5 th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland
29-30 January 2013	EFGCP Annual Conference: Virtual future: what are the ethical dimensions of using emerging technologies in clinical trials and research?, www.efgcp.eu	Brussels, Belgium
6-10 March 2013	11th International Conference on Alzheimer's and Parkinson's Diseases, www.kenes.com/adpd	Florence, Italy
21-23 March 2013	57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Leipzig, Germany
11-14 April 2013	The 7th World Congress on Controversies in Neurology (CONY), www.comtecmed.com/cony/2013/	Istanbul, Turkey
18-20 April 2013	28th International Conference of Alzheimer's Disease International: Dementia: Action for global change, www.adi2013.org	Taipei, Taiwan
18-21 April 2013	9th International Congress on Mental Dysfunction & Other Non-Motor Features in Parkinson's Disease and Related Disorders – MDPD 2013, www.kenes.com/mdpd2013	Seoul, Korea
23-24 May 2013	3 rd International Conference on Neurodegenerative Disorders: Immunotherapy and Biomarkers, http://eventus.trippus.se/immunotherapy_uppsala2013	Uppsala, Sweden
23-27 June 2013	The 20th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
3-5 October 2013	23 rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", www.alzheimer-europe.org/EN/Conferences	St Julian, Malta
17-20 October 2013	8 th International Congress on Vascular Dementia – ICVD 2013, www.kenes.com/icvd	Athens, Greece
20-23 March 2014	58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Berlin, Germany
21-24 March 2014	30 th International Congress of Clinical Neurophysiology (ICCN), www.iccn2014.de	Berlin, Germany

23rd Alzheimer Europe Conference
Living well in a dementia-
friendly society
St. Julian's, Malta, 10-12 October 2013
Mark the dates!

www.alzheimer-europe.org/conferences



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