Highlights in this issue

28 February: New Irish Working Group of People with Dementia

March: Three MEPs join the European Alzheimer’s Alliance

1 March: New EMIF project holds first conference

3 March: EMA aims to reduce medication errors

5 March: Slovenia approves national dementia plan

5 March: MEP Wortmann-Kool speaks at CEO Conference

28 March: ALCOVE project holds final conference

Table of contents

Editorial ............................................... 1
Alzheimer Europe ................................ 2
AE Projects .......................................... 2
European Alzheimer’s Alliance ........... 3
AE Networking ........................................ 3
EU Developments ................................ 5
Policy Watch ......................................... 8
Members’ News ..................................... 8
Science Watch ..................................... 12
Dementia in Society ............................ 15
New Publications & Resources.......... 16
Job opportunities ............................... 17
AE Calendar 2013 ............................ 18
Future Conferences ............................ 18

Editorial

March was a busy month for us - and also for our readers, judging by the contributions we received. Our happiest news was the arrival of Emma Lizzie McInerney, daughter of Gwladys and Sean, who was born on 29 March.

In March, AE joined a new European project called EMIF that aims to create a common information framework of Alzheimer’s disease patient data. Meanwhile, the DECIDE project has ended and we’re looking at several opportunities to join new projects.

We also hosted the first meeting of the Incontinence Care project and attended the final meeting of the ALCOVE Joint Action: this pan-European project has yielded new knowledge about dementia and will help to improve the health, quality of life, autonomy and dignity of people living with dementia and their carers. We also attended various meetings and symposia, including several in the European Parliament. Our next Lunch Debate will take place there in June and we’ll soon be announcing the speakers and the topic.

In European affairs, the Commission is gearing up for the European Month of the Brain, with many events and activities around brain research during May. The European Medicines Agency is taking steps to reduce medication errors and has also appointed new members to its Board.

We are very pleased to welcome three new members to the European Alzheimer’s Alliance, bringing total membership to 70 MEPs from 23 countries. We also report on the recent activities of our current EAA members: MEP Corien Wortmann-Kool spoke about the fiscal challenges of dementia and MEPs Daciana Sarbu and Cristian Busoi took part in Romania’s National Alzheimer Conference, organised by the Romanian Alzheimer Society.

Amongst our members, the best news came from Slovenia, where the government has approved the working document that will guide the country’s national dementia strategy. In Portugal, the parliament approved a new Social Economy law and Alzheimer Hellas held a successful annual conference amid adverse conditions. A new alliance in the UK and Ireland is helping people with dementia to stay in their homes and the new Irish Working Group of People with Dementia held its first meeting. Belgium’s LINAL issued a position paper on euthanasia and the Flemish association held an event for children of people with dementia.

In scientific news, a new clinical trial will focus on agitation and aggression in Alzheimer’s disease. Meanwhile, the Connectome project intends to create a new brain map and has already released some extremely detailed images.

March was a good month for new publications: an EU report explores the number of healthy years that we may expect to live and a UK survey reveals the huge scale of the adult social care sector. There is also an interesting study on the benefits of gardens in dementia care homes. Finally, the EU and the UN have produced an online index that measures how older people can live up to their full potential in terms of employment, participation in social life and independent living.

Jean Georges
Executive Director
Alzheimer Europe

21 March: AE hosts meeting of Good Incontinence Care working group

On 21 March, Alzheimer Europe hosted the kick-off meeting of the project on "good incontinence care for people with dementia". The meeting was chaired by Dianne Gove, Information Officer for Alzheimer Europe and project leader. The participants included Jean Georges, Executive Director of Alzheimer Europe and Nicole Huige of SCA Global Hygiene. Also present were Vicky Morris, Daniela Hayder and Kai Leichsenring, independent experts and researchers in dementia, incontinence care and social and welfare policy.

The focus of the meeting was on the methodology and the literature review. It was agreed that there was a dearth of evidence-based scientific literature on incontinence care of people with dementia, particularly in the home care setting and that the scope of the project should be on good incontinence care for people with dementia living at home, provided by informal and professional carers. Due to the lack of existing research in this particular area, it was also agreed that an integrative literature review and expert consultation should form the basis for the development of guidelines, rather than of a care standard, targeted at formal and informal carers, as well as service providers and policy makers. A number of issues will be explored such as data on the prevalence of incontinence and dementia in the home setting, access to incontinence care, the training of carers, ethical issues, assessment and diagnosis.

The next step will consist of an expert discussion about the literature review and possible recommendations involving the full working group and reference group. The European Working Group of People with Dementia will be represented in this project by Chairperson Helga Rohra. The project, which officially started in January 2013 will end in October 2014 with the presentation of the results at Alzheimer Europe’s annual conference in Glasgow. The project is fully funded by SCA Global Hygiene.

29 March: Alzheimer Europe welcomes new baby staff member

Alzheimer Europe is very happy to announce the safe arrival of Emma Lizzie McInerney. Emma was born on 7:33 AM at a weight of 3.19 kg for 48 cm. Gwladys is in fine form and both her and Sean are very proud of their new daughter.

AE Projects

22 February: DECIIDE project team holds final workshop

On 22 February, the DECIIDE team members presented the project’s results during a workshop entitled "e-Infrastructures for medical research and clinical praxis: achievements and the way forward" at the Italian Ministry of Health in Rome.

The workshop was hosted by Dr. Gaetano Guglielmi, representing the Italian Minister of Health and Ms Claudia Battista, Deputy Director of the GARR Consortium. GARR is an organisation providing high-bandwidth connectivity to the Italian academic and research community and also led the DECIIDE project.

Ms Battista greeted the 45 delegates and gave a brief presentation of GARR, including its involvement in the DECIIDE project. She was followed by Dr. Guglielmi, who explained that the Ministry has worked closely with GARR since 2005, specifically to develop the role of ICT (information and communications technology) in medical research. He added that the Ministry was very pleased with the progress shown by the DECIIDE partners and promised support for the post-project phase.

The next presenter was Prof Stefano Cappa, who is from the San Raffaele University and Science Institute and also sits on the JPND scientific committee. He gave an overview of the challenges posed by dementia and outlined the various EU health and research programmes that are addressing these challenges. Prof Cappa pointed out that DECIIDE is an excellent example of how ICT can help to improve the lives of people with dementia: it is relatively inexpensive, easy to use and can already be used all over Europe.

He was followed by Prof Roberto Barbera from the University of Catania in Sicily. Prof Barbera described the evolution and operation of distributed (or grid) computing, which provides the backbone of the DECIIDE project. Currently, there is a large effort to ensure that the various grids across the world are able to communicate with one another. Prof Barbera foresees a future where grids will be as common as today’s mobile telephone networks. He also pointed out that DECIIDE was specially designed with standards that allow the service to already operate worldwide today.

Dr. Giovanni Frisoni, Scientific Manager of DECIIDE, then gave a detailed demonstration of how the service actually works. He took the audience through all the steps of the "Physician" service, which is one of the three services available. Dr Frisoni described how a neurologist can upload an MRI or PET scan and then have it compared to the thousands of existing records in the DECIIDE database. This comparison takes the form of a statistical report that gives the physician indications of whether his scan presents signs of dementia.

The morning session ended with a summary by Dr. Fulvio Galeazzi, DECIIDE Project Manager. He thanked all the project partners for their efforts and pointed out that the DECIIDE services will continue to be used even as the project now reaches its end.
The EMIF project has received support from EFPIA companies and the European Union (IMI JU).

European Alzheimer’s Alliance

March: Three MEPs join the European Alzheimer’s Alliance (EAA)

The European Alzheimer’s Alliance is pleased to welcome three new members: Martina Anderson, MEP (UK), Joseph...
Delegation for relations with Japan. He joined the Alliance on 28 March 2013.

Committee on Transport and Tourism. He joined the Alliance on 21 March.

Ms Wortmann-Kool predicted that investing in Alzheimer’s disease today will have huge payoffs in the decades ahead. The structure of such an investment will be complex, as it must be based on a global, cross-sector and cross-discipline solution. It will also involve a wide range of government sectors, including health, finance, social welfare, family and employment. However, it will alleviate the burden of dementia, as the syndrome prevents millions of people from participating in the workforce and contributing to economic growth.

The Global CEO Initiative on Alzheimer’s Disease is an advocacy effort led by George Vradenburg of “USAgainstAlzheimer’s”. The CEO Initiative is a coalition of pharmaceutical companies – including AC Immune, Pfizer and Sanofi – and other companies who realise the impact of Alzheimer’s on our society – such as Bank of America, General Electric and Nestle.

During this meeting, delegates confirmed the following recommendations:

- Alzheimer’s disease must be recognised as a priority, notably in the area of Research and Innovation.
- Alzheimer’s disease needs more investment that is better targeted and better coordinated. At the least, this should be done at EU level but preferably at a global level.
- There is an urgent need for comprehensive plans to address the impact of Alzheimer’s disease, both at national and European level.
- Health and social care services must be adapted to take better account of the specific needs of Alzheimer’s patients.

The launch event was chaired by Avril Doyle, former Irish MEP. In addition to Corien, other EAA members attended the meeting: Heinz Becker (Austria), Cristian Busoi (Romania) and Martina Anderson (UK - Northern Ireland), who has just joined the Alliance. The CEOs of Lilly and AC Immune also participated in the successful launch event, as did representatives of the media and various European institutions. Jean Georges represented Alzheimer Europe at the meeting and provided an overview of the organisation’s campaign to make dementia a European priority.

5 March: EAA member Corien Wortmann-Kool presents the fiscal challenges of dementia

On 5 March, Corien Wortmann-Kool, MEP (Netherlands) and member of the European Alzheimer’s Alliance (EAA), was a keynote speaker during the launch event of the “CEO Initiative” in the European Parliament. Her speech focused on Alzheimer’s disease as a future fiscal and economic challenge that should already be addressed today.

She pointed out that many national governments are currently working to solve their financial crises and to avoid them in the future. This is mainly done by looking for macro-economic imbalances and other issues that may provoke future crises. Ms Wortmann-Kool explained that the rapid aging of the population is such an issue - particularly as there is a close correlation between advancing age and the risk of Alzheimer’s disease.

If it is left unchecked, the current situation will become a fiscal nightmare in the 21st century, overshadowing the other health and social challenges we face. In 2010, the worldwide costs of dementia, including Alzheimer’s disease, were estimated to exceed one per cent of global gross domestic product (GDP), at more than USD600 billion (EUR 477 billion).

In the EU 27 region, this cost was estimated at EUR 160 billion or EUR 22,000/patient/year for 2008. Informal care costs were estimated at nearly EUR 90 billion (56% of the total cost), resulting mainly from productivity loss, adverse impacts on physical and mental health of carers and out-of-pocket expenses.

Ms Wortmann-Kool predicted that investing in Alzheimer’s disease today will have huge payoffs in the decades ahead. The structure of such an investment will be complex, as it must be based on a global, cross-sector and cross-discipline solution. It will also involve a wide range of government sectors, including health, finance, social welfare, family and employment. However, it will alleviate the burden of dementia, as the syndrome prevents millions of people from participating in the workforce and contributing to economic growth.

The Global CEO Initiative on Alzheimer’s Disease is an advocacy effort led by George Vradenburg of “USAgainstAlzheimer’s”. The CEO Initiative is a coalition of pharmaceutical companies – including AC Immune, Pfizer and Sanofi – and other companies who realise the impact of Alzheimer’s on our society – such as Bank of America, General Electric and Nestle.

During this meeting, delegates confirmed the following recommendations:

- Alzheimer’s disease must be recognised as a priority, notably in the area of Research and Innovation.
- Alzheimer’s disease needs more investment that is better targeted and better coordinated. At the least, this should be done at EU level but preferably at a global level.
- There is an urgent need for comprehensive plans to address the impact of Alzheimer’s disease, both at national and European level.
- Health and social care services must be adapted to take better account of the specific needs of Alzheimer’s patients.

The launch event was chaired by Avril Doyle, former Irish MEP. In addition to Corien, other EAA members attended the meeting: Heinz Becker (Austria), Cristian Busoi (Romania) and Martina Anderson (UK - Northern Ireland), who has just joined the Alliance. The CEOs of Lilly and AC Immune also participated in the successful launch event, as did representatives of the media and various European institutions. Jean Georges represented Alzheimer Europe at the meeting and provided an overview of the organisation’s campaign to make dementia a European priority.

11 March: Former Alliance member elected as Maltese Prime Minister

Dr. Joseph Muscat took office as Malta’s new Prime Minister on 11 March.

Previously, he served as a Member of the European Parliament in 2004-2008. During that time, he was also the Vice-Chairperson of the European Alzheimer’s Alliance.

Ms Annette Dumas, EU Public Affairs Advisor for Alzheimer Europe, said: "Dr. Muscat was always very supportive of the dementia cause while he was an MEP. His tenure as Vice Chair of the European Alzheimer’s Alliance was of great benefit to the Alliance."
Alzheimer Europe Networking 2013

On 1 March (Brussels, Belgium) Annette attended the European Innovation Partnership on Active and Healthy Ageing action group meeting on "age-friendly communities".

On 4 March (Brussels, Belgium) Annette attended a meeting with representatives of Parliament Magazine to discuss an event in the EP with A. Werthmann on Neurodegenerative diseases.


On 7 March 2013 (Brussels, Belgium) Jean attended a symposium on Alzheimer’s disease at a joint meeting of the Innovative Medicines Initiative and the Critical Path Initiative.

On 8 March (Sankt Augustin, Germany) Dianne attended the Aetionomy F2F project meeting.

On 9 March 2013 (Brussels, Belgium) Dianne attended the advisory board RightTimePlaceCare meeting.

On 12 March (Brussels, Belgium) Dianne attended the advisory board RightTimePlaceCare meeting.

On 15 March 2013 (Luxembourg, Luxembourg), Jean met with Michael Hübel and Jürgen Scheftlein from the European Commission.

On 21 March 2013 (Brussels, Belgium) Annette attended the RightTimePlaceCare event.

On 21 March 2013 (Brussels, Belgium) Annette had a meeting with MEP J. Cuschieri to discuss Alzheimer Europe’s work in the EU.

On 25 March 2013 (Brussels, Belgium) Annette met with Parliament Magazine, EMSP and EPDA representatives to discuss an event on neurodegenerative diseases in the EP.

On 28 March (Paris, France) Heike, Helga, Annette, Dianne, Alex and Jean attended the presentation of ALCOVE’s project results.

On 28 March (Paris, France) Heike, Helga, Annette, Dianne, Alex and Jean attended the presentation of ALCOVE’s project results.

EU Developments

1 March: The European Month of the Brain is in May 2013

The European Commission invites you to “Open your mind!” during May 2013, the European Month of the Brain.

This will be a full month packed with events and activities to make decision-makers, stakeholders, the media and the public aware of the successes achieved and the challenges still laying ahead for brain research.

Understanding the human brain and its diseases is one of the greatest scientific and philosophical challenges. During the last decades, brain research has made great progress on all fronts but much more is still to be discovered. Advances in neuroscience are crucial to keep our ageing societies and our economy healthy. Brain-related disorders will affect at least one in every three of us during our life and treating these disorders costs already now some EUR 800 billion in Europe every year. Deciphering how our brain works is good for our health, our society and our industrial competitiveness. It also has an important role to play for the achievement of the European 2020 strategy and of the Innovation Union.

The Commission has organised two conferences, one on 14 May in Brussels and the other on 27-28 May in Dublin. There will also be activities in other member states and the Commission is encouraging people to send in ideas about events to rtd-monthbrain@ec.europa.eu.

12 March: European Commission adopts proposal for 2014 elections

On 12 March, the European Commission adopted a proposal that calls for political parties to nominate a candidate for European Commission President in the next European elections and to display their European political party affiliation. The proposal aims to better inform voters about the issues at stake in next year's European Parliament elections, encourage a Europe-wide debate and ultimately improve voter turnout. The Commission is also calling on Member States to agree on a common
voting date for the elections, traditionally spread out over a period of four days.

The 2014 European elections will be the first to be held under the Lisbon Treaty, which enhances the role of citizens as political actors in the EU. The Treaty also strengthens the powers of the European Parliament, consolidating its role as co-legislator and giving it additional responsibility: it elects the President of the Commission on the basis of a proposal by the European Council taking into account the results of the European elections.

The Commission will put forward its proposals for Treaty changes in time to allow a real debate on the future of Europe before the elections.


www.alzheimer-europe.org/Donation

13 March: European Parliament proposes reforms to allocation of seats after 2014

On 13 March, Members of the European Parliament backed the overall reform of the EU voting system at a plenary sitting. This reform was needed because of Croatia’s entry into the EU in summer 2013. The new Croatian MEPs will cause the Parliament to exceed the limit of 751 MEP seats specified in the Lisbon Treaty.

During the plenary session, MEPs agreed that reallocation of seats per Member State should be viewed in two steps:

- reallocation should be done in line with the principle of degressive proportionality and with due respect to the lower (6 MEPs/Member State) and upper (96 MEPs/Member State) limits set by the Lisbon Treaty,

- a political compensation between the gains and losses, according to the principle that no-one gains and no-one loses more than one seat.

They also noted that the future system of the distribution of seats among Member States in the European Parliament must be transparent, based on objective criteria and decided in conjunction with the reform of the voting system in the Council.

This proposal now goes to the heads of state and government in the European Council, who must decide by a unanimous vote.


15 March: Active Ageing Index is now available online

On 15 March, the European Commission (DG Employment, Social Affairs and Inclusion) and the United Nations Economic Commission for Europe (UNECE) published the Active Ageing Index (AAI) on a dedicated website.

The AAI is a statistical tool that offers national and European policy makers a way to measure the untapped potential of seniors in the EU and beyond. It measures the extent to which older people can realise their full potential in terms of employment, participation in social and cultural life and independent living. It also measures the extent to which the environment they live in enables seniors to lead an active life.

The website is open to all and will be continuously updated with the latest information available. It includes a special introductory policy brief, information on the AAI conceptual framework, methodology and results. It also provides potential users with access to an excel file that contains detailed data sets for EU Member States.

The AAI is a product of a joint project undertaken in 2012 by the European Commission Directorate General for Employment, Social Affairs and Inclusion together with the Population Unit of the UNECE and the European Centre for Social Welfare Policy and Research in Vienna.

http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newId=1837&furl=he/News+and+Events+and+Publications+Page+Order+Number+Codes+007723.html

http://www1.unece.org/stat/platform/display/AAI/Active+Ageing+Index+Home

25 March: EMA Management Board welcomes new civil-society members

On 25 March, the European Medicines Agency’s Management Board welcomed four new civil-society members as full members.

Nikolaos Dedes (European AIDS Treatment Group) and Dr. W. Wientjens (International Diabetes Federation Europe) will represent patient organisations.

Dr. Wolf-Dieter Ludwig (Standing Committee of European Doctors) and Dr. Christophe Hugnet (Federation of Veterinarians of Europe) will represent healthcare professionals. They all have a three-year mandate.

www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2013/03/news_detail_001749.jsp&mid=WC0b01ac058004d5c1

26 March: Commission answers question on costs incurred by people with disabilities

On 26 March, the European Commission answered a question from Adam Kosa, MEP (Hungary) and Chair of the EP Intergroup on Disability. His question dealt with the additional costs incurred by people with disabilities; it was raised in relation to the EP Resolution of October 2011 on mobility and inclusion of people with disabilities and the European Disability Strategy 2010–2020. This states that people with disabilities face additional costs in their daily lives, which has a considerable impact on their quality of life.

Mr Kosa asked the Commission to present the average extra costs incurred by people with disabilities in each disability category (sight or hearing impairment, reduced mobility, mental disability, autism, etc.) in order to clarify the magnitude of the expenses incurred in each Member State to decision makers in the context of the fight against poverty.

The reply came from Viviane Reding, Commissioner for Justice, Fundamental Rights and Citizenship. She stated that the Commission recognised that many persons with disabilities are facing additional costs in their daily lives as a consequence of their disability. The Commission does not have detailed data about such extra costs. She added...
that one can safely assume that there will be a great variety in the levels of costs depending on the nature of the disability, its degree and also the personal living circumstances including the place of residence. This will make it a complex exercise to calculate meaningful average data on this subject as a basis for policy making in the context of the fight against poverty. The direct competence for such policy lies with the Member States. The Commission does not know whether any Member State or any organisation active in the field of disabilities possesses this kind of aggregated data.

28 March: ALCOVE project holds final conference

ALCOVE, the two-year Joint Action on Alzheimer Cooperative Valuation in Europe, held its final conference on 28 March in Paris.

The project brought together 30 partners from the health and scientific authorities of 19 countries. Their aim was to improve knowledge on dementia and its consequences, as well as promote the exchange of information to preserve health, quality of life, autonomy and dignity of people living with dementia and their carers in Europe. ALCOVE was funded by the European Commission’s Public Health Programme and dealt with four main issues:

1. Epidemiological data on dementia: improving knowledge on dementia, including prevalence, available data and best practices for data collection.
2. Early dementia diagnosis: exploring operational criteria in health care systems for timely dementia diagnosis in ambulatory and nursing home settings.
3. Support systems for behavioural and psychological symptoms of dementia (BPSD): improving knowledge of the availability and efficacy of BPSD management at home, in hospitals and in care homes.
4. Rights, autonomy and dignity of people living with dementia: improving the basic rights of people living with dementia, with a focus on advance declarations of will and competence assessments.

The project also explored ways to prevent the excessive prescription of psychotropic drugs to people with dementia.

During the conference, some 200 delegates heard the results of the seven work packages and received the final report and a list of recommendations. In addition, a panel of six dementia experts provided insights and answered questions throughout the day.

The conference was opened by Jean-Paul Delevoye, President of France’s Economic, Social and Environmental Council and Dr. Jean-Luc Harousseau, President of the French National Authority for Health. They welcomed the delegates and explained that efforts such as ALCOVE are invaluable, because dementia is a problem with social, economic and medical aspects - as well as a major challenge for public health policy.

They were followed by Michael Hübel, Head of Programmes & Knowledge management, Directorate General Health & Consumers, European Commission. Mr Hübel stressed the importance of adapting the way we think about dementia. He added that the Commission intends to leverage the results of the ALCOVE project to benefit all EU citizens, including those living with dementia. The next speakers were Prof Alistair Burns, National Clinical Director for Dementia in the UK and Dr. Jean-Yves Graal, France’s National Chief Medical Officer and representative of the French Ministry of the Elderly and Autonomy. They closed the opening session with an overview of how ALCOVE would help to address the dementia challenges in their respective countries.

The morning session was co-chaired by Dr. Armelle Leperrre-Desplanques, ALCOVE project leader and Manager of the Department of Pilot Programmes at the French Ministry of Health, along with Dr. Michal Novák, Professor of Neuroscience, Immunology and Microbiology at the Institute of Neuroimmunology of the Slovak Academy of Science. This session featured four presentations that described the project methodology and the results of the first two work packages:

1. The challenges of dementia
2. ALCOVE general presentation
3. Understanding prevalence & epidemiological data about dementia

In the afternoon, delegates heard the results of the remaining work packages and participated in a lively Q&A session with the panel experts. The afternoon session was chaired by Dr. Carlos Segovia, Deputy Director of the International Research Programmes and International Relations Department of Spain’s Instituto de Salud Carlos III. The presentations were:

1. Strategy for behavioural and psychological symptoms of dementia
2. Ethical & legal issues for advanced directives & competence assessment in dementia
3. Contribution to safety: the ALCOVE toolbox for antipsychotics limitation in dementia.

The afternoon session concluded with a presentation by Jürgen Scheftlein from the European Commission’s Directorate General for Health & Consumers. Mr Scheftlein expressed his appreciation to all of the project team members, saying that the Commission would be very pleased with the results of the project. He added that this work must continue and invited delegates to identify topics that could be included in a follow-on project to ALCOVE.

The final ALCOVE Report, the List of Recommendations and various videos can be found on the project website.

www.alcove-project.eu/images/pdf/ALCOVE_SYNTHESIS_REPORT_VF.pdf
Policy Watch

5 March: Slovenia adopts guidelines for a national dementia plan

On 5 March, Minister of Health Tomaž Gantar officially approved the document that will be the basis of Slovenia’s national dementia plan.

This document will guide the activities of a new, dedicated Dementia Working Group within the Ministry. The working group consists of ten people, including Dr. Aleš Kogoj (President of Alzheimer Slovenia - Spomincica), Ms Štefanija Lukič Zlobec (Vice President), Dr. Gorazd Bernard Stokin and Dr. Tatjana Cvetclo.

13 March: FDA will relax rules to approve dementia drugs

The American Food and Drug Administration (FDA) is studying plans to loosen the rules for approving new treatments for Alzheimer’s disease.

Under the new rules, drugs in clinical trial would qualify for approval if people at very early stages of the disease subtly improved their performance on memory or reasoning tests, i.e. before they developed any obvious impairments. Moreover, companies would not have to show that the drugs improved daily, real-world functioning. Currently, drug approval requires proof of improvement in physical activities as well as cognitive performance.

The proposal was published by the FDA in The New England Journal of Medicine (NEJM), following the publication of a set of guidelines. Together, they intend to explain the new perspective to a wider audience and to solicit comments from health professionals, industry and the public.

Dr. Nicholas Kozauer, co-author of the NEJM paper and FDA clinical team leader in neurology products, said: “Our goal was to provide as much regulatory clarity as possible. We would encourage companies to start thinking along these lines.” In a separate statement, FDA spokeswoman Sandy Walsh said that the FDA is ready to move forward with the plan.

20 March: Portugal approves draft of the Social Economy law

On 20 March, the Portuguese parliament unanimously approved a draft basic law on the Social Economy.

The law originates from a 2009 European Parliament resolution. This urged the Commission to promote the Social Economy in its new policies and to defend the concept of a different business approach, one whose main driver is social profitability rather than financial profitability.

The draft text states that the Social Economy represents 5.64% of Portugal’s GDP and 4% of employment. This is based on a social network of nationwide coverage. There has clearly been growth in economic and business activities, mainly fuelled by associations of persons who, in accordance with participatory and social principles, direct their activities to their members’ collective interest and to the general interest. However, the Social Economy has not yet succeeded in getting the status it deserves.

Alzheimer Portugal welcomes this initiative as an important step towards the recognition of the social sector as a key sector for the social cohesion and as a response to the crisis.

Members’ News

27 February: Romanian Alzheimer Society holds annual National Alzheimer Conference

The Romanian Alzheimer Society held its annual National Alzheimer Conference between 27 February and 2 March in Bucharest.

The conference was themed “Dementia - between Demographic and Economic Crisis” and included the following workshops:

- “Rights of dementia patients”: coordinated by Helga Rohra (Chair of the European Working Group of People with Dementia) and Maria Moglan (Romanian Alzheimer Society).
- “Memory Centre: Comparison between Sweden and Romania” - coordinated by Dr. Simona Săcuiu and Maria Moglan.
- “Social Deconstruction of Abuse Toward Old People in The Post-Modern and Global Society” - coordinated by Dr. Radu Vrasti.
- Book Launch - “Stepping out of the Shadow” by Helga Rohra.
- National Alzheimer Alliance meeting: “Optimising the Patient’s Circuit in the Romanian Health System” - coordinated by Dr. Catalina Tudose (President of the Romanian Alzheimer Society).

Delegates were also able to attend presentations such as the following:

- “Dementia: A Public Health Priority” - presented by Marc Wortmann (Executive Director of ADI).
- “Challenges Facing People with Dementia” - presented by Helga Rohra.
- “First Diagnosis in Alzheimer Dementia in Romania - National Alzheimer Alliance Report” - presented by Dr. Cătălina Tudose.

The full conference programme can be found on website of the Romanian Alzheimer Society.

www.alzcongres.ro/EN/
28 February: Alzheimer Society of Ireland creates a Working Group of People with Dementia

The Alzheimer Society of Ireland has established the first Irish Working Group of People with Dementia. The purpose of the Working Group is to explore ways to promote and encourage the direct involvement of people with dementia in its work and to ensure that the voice of people with dementia influences the public policy that impacts on their lives.

The establishment of the Working Group comes at a crucial time as Ireland prepares to develop a National Dementia Strategy. It will be critical that the voice of people with dementia is heard through the National Dementia Strategy and in the planning of service provision for the future.

Maurice O’Connell, CEO of The Alzheimer Society of Ireland, says that it is only by gathering information from people that are directly affected by the condition, that the full potential of a national approach to dementia service planning can be realised.

He added: “Over the past number of years we have been working tirelessly to enable the voice of the person living with dementia and their carer. This includes a major public awareness and anti-stigma campaign which promoted the early signs and symptoms of Alzheimer’s and dementia in order to encourage people to seek an early diagnosis.

“We are pleased to announce that this work has culminated in the establishment of the first National Working Group for People with Dementia in Ireland. Through our work we have met some extraordinary people living with dementia who want to get more involved in having their voice heard. We want to harness this willingness and motivation and grow it through the National Working Group. The rights and the voice of people with dementia have been neglected in the past and we need to address this.”

Mr Dermot Slevin participated in the first meeting of the Working Group for People with Dementia and he emphasises why it is important for him to be involved.

“The group has given me an insight into other peoples experience and also a sense of purpose and confidence. You are talking to others who understand and who are going through the same experiences,” he says. Mr Slevin is also a member of the European Working Group of People with Dementia.

The first meeting of the Irish group was held in late February and the next one is planned for May 2013.

28 February: Greece holds 8th Conference of Alzheimer’s Disease and Related Disorders

The 8th Pan-Hellenic Interdisciplinary Conference of Alzheimer’s Disease and Related Disorders took place in Thessaloniki, Greece on 28 February-3 March 2013. The conference was organised by The Pan-Hellenic Institute of Neurodegenerative Disorders and the Greek Association of Alzheimer’s Disease and Related Disorders.

More than 300 delegates attended the three day event, including academic and medical professionals from around the world and representatives of the Greek dementia associations. A series of roundtables and poster sessions provided for some 170 presentations on the latest developments in medical treatments, non-pharmacological interventions and prevention, as well as sharing best practice and advice on care. This included presentations of researchers and scientists from Belgium, France, Ireland, Poland, Portugal, Sweden, Turkey and the UK.

The number of Greeks with dementia has been rising quickly over the last few years - and so have the effects of the economic crisis. Looking ahead, the organisers expressed the need to maintain and further develop the current services to improve the quality of life for people with dementia and their caregivers. This is particularly urgent, as harsh recovery measures are placing even basic care services at risk.

After the conference, all of the Board members, employees and volunteers of the Pan-Hellenic Institute of Neurodegenerative Disorders and the Greek Association of Alzheimer’s Disease and Related Disorders expressed their commitment to achieve a better quality of life for people with dementia.

2 March: Flemish Alzheimer association holds event for children of young parents with dementia

On 2 March, the Vlaamse Alzheimer Liga organised an all-day workshop called “Dad forgets, Mom does not remember who I am” for children of people with early-onset dementia who are younger than 65. According to the Liga, there are 6,000-20,000 Belgian children and young people living in homes where one parent has developed an early form of dementia.

In comparison with dementia at an older age, early onset dementia affects families in the prime of their lives. A young person with dementia may have school-going children, a working spouse and parents that are still living. He/she could still be working when diagnosed and physically very fit.
A dementia diagnosis can often disrupt family life and routines, especially for the younger members. One participant said: “Now that my mother suffers from early onset dementia, I am expected to adapt myself to her new behaviour. And this demands patience, creativity, courage and flexibility. Sometimes I don’t know what to do anymore, all these changes drive me crazy and I ask myself: how do other kids deal with this?”

The workshop attracted 21 participants aged 12-35 and included a presentation about new or different ways of dealing with the parent’s behaviour. The young delegates heard about successful existing techniques and also proposed new ideas of their own. They also participated in an interactive session where everyone shared their experiences and assisted in preparing their dessert course.

The participants were very pleased to attend this event and everyone seemed to enjoy it. The organisers have taken note of the many ideas that were proposed and are now discussing further initiatives.

3 March: Alzheimer Scotland supports quilt project in the Parliament

On 3 March, Ann Hill, Alzheimer Scotland’s Quilter-in-Residence, held an exhibition of quilts at the Scottish Parliament. This was part of the “Yes we can - together” project campaign led by Ann Hill. This project has involved Ann working with people with dementia, their carers, partners and families to create quilts that convey emotive and poignant experiences from their lives.

The exhibition was very popular and Ann was made very welcome by everyone who works in the Parliament building, including First Minister Alex Salmond (pictured with Ann). The display is just a small selection of the thousands of quilts she has received during the project.

Henry Simmons, Chief Executive of Alzheimer Scotland said: “Ann’s work has been a real inspiration to us at Alzheimer Scotland. Quilting has proved to be a truly meaningful and emotional way of connecting with people affected by dementia and we are extremely happy to be involved in the ‘Yes we can – together’ project.”

www.annhillquilter.co.uk/alzheimer-quilt-project.html

9 March: Lloyds Bank gives money tips to people with dementia

On 9 March, Lloyds Banking Group released a set of money management tips for people with dementia and their carers to kick-start its two year charity partnership with Alzheimer Scotland and the UK Alzheimer’s Society.

The charities and the bank will tackle some of the problems faced by people with dementia and their carers when dealing with personal finances and explore ways to make the banking sector more dementia friendly.

Today’s launch of the top tips should encourage people living with dementia, their family members and carers to think about what they need to do to future-proof the management of their finances. The top tips include information from arranging a power of attorney and applying for the correct benefits, to organising bank accounts and preventing salesmen from calling.

Over the course of the partnership Lloyds Banking Group hopes to raise at least £2 million (EUR 2.3 million) to fund “Live Well” - Alzheimer Scotland’s and Alzheimer’s Society’s first UK-wide support programme for people with dementia and their carers.

Glenda Mackenzie, Deputy Director for Fundraising at Alzheimer Scotland said: “One of Alzheimer Scotland’s key aims is to ensure that people with dementia and their families are given all the information and the support they need to make important early decisions about their finances. Coming to terms with dementia is a difficult process – planning for the future shouldn’t be.

“We are delighted to be working with Lloyds Banking Group for the next two years. The money raised will enable us to improve the lives of thousands of people with dementia and carers across the country.”

www.alzheimer-europe.org/Donation

14 March: German Alzheimer Society launches new website

On 14 March, the German Alzheimer Society launched a new version of its website to provide easier operation and greater clarity. The revised design features simpler menus and a new arrangement of content that will allow quicker access to information.

The new homepage also carries a new short film about the work of the Society. This includes providing contacts for people with dementia and their families, hosting groups for sharing and support and various other relief and support services.

www.deutsche-alzheimer.de
www.youtube.com/watch?v=ex_zgquVAC

19 March: New alliance helps people with dementia to stay at home

A new alliance in the UK & Ireland has launched a two year campaign to help people with dementia stay at home rather than move into a care home. The alliance members are Alzheimer Scotland, the Alzheimer Society of Ireland and the UK Alzheimer’s Society, along with retail chains Argos and Homebase.

The alliance members call on people living with dementia to seek support early, in order to remain living in the comforts of their own home and their community. They will conduct various awareness and fundraising
campaigns, starting with a new set of tips for living well with dementia at home. This was published on 19 March and covers everything from contacting social services to ways to make everyday life easier.

Jeremy Hughes, Chief Executive at Alzheimer’s Society said: “Home means something special to all of us. Many people living with dementia have been forced to leave their safe-havens which is unacceptable. By seeking support early, people living with dementia may avoid reaching a crisis point unnecessarily which results in them moving in to long term care. The money raised through this partnership with Argos and Homebase will help us enable them to live at home for longer, maintaining the lifestyle and independence which makes them who they are.”

www.alzheimers.org.uk/hometips

20 March: Royal couple visits Luxembourg nursing home

Hereditary Grand Duke Guillaume of Luxembourg and his wife, Grand Duchess Stephanie, recently visited the “Beim Goldknapp” nursing home that is operated by ALA, the Luxembourg Alzheimer Association.

The royal couple toured the home and attended a presentation about ALA’s activities around the country. They also donated a new car to the care home, on behalf of the benevolent “Fondation du Grand-Duc et de la Grande-Duchesse”.

www.wort.lu/de/view/guillaume-und-stephanie-besichtigen-altenheim-5149954ae462246d54af90dca3

20 March: Belgium’s LINAL debates euthanasia in the Senate

Sabine Henry, President of Belgium’s LINAL (Ligue Nationale Alzheimerliga), recently attended a debate in the Belgian Senate about amendments to the country’s euthanasia laws. She presented a LINAL position paper on various aspects of the law that apply to people with dementia.

The paper highlights several discrepancies in the law that exclude people with dementia from the euthanasia decision process. It also shows cases where these people have unequal or non-existent access to euthanasia, even if they specifically request it. The paper examines the seeming contradiction that wills and other “future documents” written by people before developing dementia may not be honoured or accepted. Finally, the position paper explores problems with the roles and limitations of legal and family representatives of people with dementia as regards euthanasia.

LINAL holds that people with dementia have the same rights as any other citizen. However, this is not always borne out by the current law and the paper gives specific recommendations on how to address these discrepancies. These include amendments to the law but also quicker and clearer responses from lawmakers: the paper concludes that LINAL would prefer to see more concrete efforts to improve the living conditions of people living with dementia - rather than endless debates about whether their rights are being respected.

www.alzheimer-belgium.be

28 March: James McKillop receives an honorary Doctorate

Mr James McKillop, founder of the Scottish Dementia Working Group (SDWG), has been awarded an honorary Doctorate from Strathclyde University in Glasgow.

SDWG is a national campaigning group run by people with dementia. It acts as the independent voice of people with dementia within Alzheimer Scotland. The Working Group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia.

James’ honorary degree has been awarded for his work in establishing the group and helping to make it an effective advocate of people with dementia in Scotland.

In 2001, James, diagnosed with vascular dementia, and Heather Wilkinson, Social Researcher, met to discuss why there was no support group for people with dementia, similar to the group for carers. The next year, Heather and James organised a successful conference that attracted both professionals and people with dementia. They endorsed the idea for a group for people with dementia. The SDWG was established soon thereafter, with James as the first Chairperson. In 2003, the Group accepted an invitation to work under the umbrella of Alzheimer Scotland, but retained its freedom and independence to determine its own agenda.

James chaired the Group with great success from 2002 until 2008. He remains an active member of the Group and an inspiration to all that meet him. His graduation ceremony will take place in November 2013. The Group is incredibly proud of him and James is well deserving of this achievement.

www.sdwg.org.uk

www.alzheimer-europe.org/Donation
Science Watch

21 February: EMA approves 3 memantine generics

On 21 February, the European Medicines Agency (EMA) approved three versions of memantine generics based on Ebixa. Nembdate, which is marketed by Actavis Group, received approval for 5, 10, 15 and 20 mg tablets. Memantine Mylan is marketed by Generics (UK) and saw approval for 10 and 20 mg tablets. Memantine LEK also received approval for 10 and 20 mg tablets and is marketed by Pharmathen.

An additional generic version was approved on 21 March: Memantine ratiopharm, marketed by Ratiopharm, received approval for 5, 10, 15 and 20 mg tablets.

1 March: Elan begins recruitment for a trial on agitation and aggression in Alzheimer’s disease

Irish biotech company Elan Corporation has begun recruitment for a new clinical trial that will study agitation and aggression in around 400 people with moderate to severe Alzheimer’s disease (AD) over 12 weeks.

The phase 2 trial, entitled ‘Harmony AD’, will evaluate the efficacy, safety and tolerability of Elan’s oral compound ELND005, which has scyllo-Inositol as its active ingredient.

In previous studies, ELND005 has been shown to inhibit the aggregation of beta amyloid in the brains of mouse models - and also acted to reduce the levels of myo-Inositol. This is a chemical found in excess quantities in biological effect on beta amyloid in human cerebrospinal fluid (CSF) during a 2010 phase 2 study.

In this six month study, 90 participants were divided into three groups. The first group received individualised instruction at regular intervals. A second group also received the same instruction, but at varying intervals dependant on their learning speeds. The third group consisted of controls who did not receive any individual instruction.

The results showed significant increases in Mini-Nutritional Assessment scores and body mass index for the first and second groups. These groups also showed significant reductions in their Cornell Scale for Depression in Dementia scores. The lead researchers said: “The improvement in nutritional status may have led to reduced fatigue and increased vitality. Once the participants perceived the improvements in their health, pessimism, the sense of multiple illnesses, hopelessness, or even worthlessness seldom emerged.”

3 March: EMA aims to reduce medication errors

The European Medicines Agency (EMA) recently held a workshop to improve the reporting and prevention of medication errors, the single most common preventable cause of adverse events in medication practice.

These errors are a major public-health burden with an estimated annual cost between EUR 4.5 and 21.8 billion. Medication errors refer to mistakes in the processes of prescribing, supplying, dispensing, preparing, administering or monitoring medicinal products in clinical practice.

5 March: The Human Connectome Project is creating a new brain map

In Europe, the medication-error rate in primary care is estimated at 7.5% at prescription and 0.08% at the dispensing stage, whereas in the hospital setting the rates vary between 0.3–9.1% and 1.6–2.1% respectively.

Current EU pharmacovigilance legislation provides a clear legal framework for sharing data on medication errors causing harm. Since July 2012, it has required reporting of all suspected adverse drug reactions resulting from medication errors to EudraVigilance, the EU database of adverse drug reactions.

European Medicines Agency (EMA) recently held a workshop to improve the reporting and prevention of medication errors causing harm. Since July 2012, it has required reporting of all suspected adverse drug reactions resulting from medication errors to EudraVigilance, the EU database of adverse drug reactions.

5 March: Study shows that good nutrition reduces depression rates

A recent study from Taiwan shows lower levels of depression in institutionalised dementia patients who received individual instruction on good eating habits.

The study was led by Professor Li-Chan Lin from National Yang-Ming University and Assistant Professor Hua-Shan Wu from Chung Shan Medical University. They explained that people with dementia often miss out on proper nutrition. Identifying foods, transferring foods, chewing and swallowing all become progressively more difficult for people with cognitive problems. Furthermore, previous studies have linked poor nutritional status to depression, both in healthy adults and those with dementia.

5 March: The Human Connectome Project is creating a new brain map

Scientists from The Human Connectome Project have published a series of brain scan images that are the most detailed ever produced. This project aims to map all of the neural pathways that underlie brain function and behaviour.

Deciphering this large and complex wiring diagram is expected to advance knowledge of brain connectivity, its relationship to behaviour and the contributions of genetic and environmental factors to individual differences in brain circuitry and behaviour. In simpler terms, it will reveal much about what makes us uniquely human and what makes each person different from others.
Researchers are mapping the brains of 1,200 healthy adults using four non-invasive neuroimaging techniques: resting-state functional MRI (rsfMRI) and diffusion imaging (dMRI) both provide information about brain connectivity. Task-evoked fMRI examines brain function and structural MRI captures the shape of the cerebral cortex. In addition, behavioural data will provide the basis for relating brain circuits to individual differences in cognition, perception, and personality. Finally, 100 participants will be studied using magnetoencephalography (MEG) and electroencephalography (EEG).

Connectome is an international consortium led by Washington University and the University of Minnesota and is funded by the American National Institutes of Health (NIH). European partners include Oxford University, Warwick University and Radboud University in the Netherlands.

All datasets and images are freely available to the scientific community on the project website.

http://humanconnectome.org/

6 March: New scan technique finds AD risk factor in healthy brains

A UCLA study team led by Dr. Paul Thompson, Professor of Neurology, has identified the SPON1 gene variant as a new genetic risk factor for Alzheimer’s disease.

The team screened DNA samples from more than 1,000 healthy people, looking for genetic code variations that might raise their future risk for developing dementia. These people were also tested with the new “Connectome” scan, which measures water diffusion in the brain and maps the strength of cerebral connections. More specifically, the scan provides images of the brain’s circuit pathways and how information is routed along these pathways.

When researchers combined these images with the screening results, they determined that people with the SPON1 variant had weaker connections between the brain areas controlling reasoning and emotion. Alzheimer’s disease further erodes these connections, making SPON1 a clear risk factor.

Dr. Thompson said: “Much of your risk for disease is written in your DNA, so the genome is a good place to look for new drug targets. If we scan your brain and DNA today, we can discover dangerous genes that will undermine your ability to think and plan and will make you ill in the future. If we find these genes now, there is a better chance of new drugs that can switch them off before you or your family get ill.”

www.pnas.org/content/early/2013/02/28/1216206110

www.alzheimer-europe.org/Donation

11 March: Aβ immunisation reduces blood vessels and plaque

A research team from the University of British Columbia (UBC) has developed an immunisation protocol that reduces the number of brain capillaries and also plaque buildup in mouse brains.

This follows recent UBC research that showed a near doubling of blood vessels in the brains of mice and humans with Alzheimer’s disease. This seems to be a compensatory response to impaired cerebral blood flow. It suggests that neangiogenesis - the formation of new blood vessels - is a key mechanism underlying plaque formation.

The scientists were headed by Prof Wilfred Jefferies, a researcher at UBC. He said: “The discovery provides further evidence of the role that an overabundance of brain blood vessels plays in AD, as well as the potential efficacy of amyloid beta as basis for an AD vaccine.

"Now that we know blood vessel growth is a factor in AD, if follows that drugs targeting blood vessels may be good candidates as an AD treatment.”

http://humanconnectome.org/

11 March: Clinical trial shows small memory improvement

A recent phase 2 trial of the compound ORM-12741 showed a slight improvement in overall memory.

www.nature.com/srep/2013/130228/srep01354/full/srep01354.html

www.jneurosci.org/content/33/10/4494.abstract

11 March: Clinical trial shows small memory improvement

A recent phase 2 trial of the compound ORM-12741 showed a slight improvement in overall memory.
The trial included 100 people with moderate Alzheimer’s disease who took memantine plus ORM-12741 or placebo over a three month period. The people who took the placebo saw an average 33% decline in memory test scores, while those who took the new compound improved their scores by 4%.

ORM-12741 is an adreno-receptor antagonist, meaning that it acts to reduce activity in the parts of the brain that respond to the release of adrenaline. In earlier studies, Alzheimer rodent models treated with the compound appeared to improve their memory and ability to function.

The trial was conducted by Finland’s Orion Pharmaceuticals and led by Dr. Juha Rouru, MD. She said: "The results of the study were clearly positive. The beneficial effects were seen particularly on episodic memory, which is one of the most important functions affected by Alzheimer’s disease. In addition, caregiver distress was significantly relieved."

These study results were released ahead of their presentation at the American Academy of Neurology (AAN) 65th Annual Meeting.


14 March: Chronic stress increases dementia risk in mice

A new doctoral thesis shows that chronically elevated levels of the stress steroid allopregnanolone accelerate the development of Alzheimer’s disease. It also demonstrates that high levels of beta-amyloid correspond to brain synapse dysfunction.

The thesis was written by Ms Sara Bengtsson, a Ph.D. candidate at Sweden’s Umeå University. In her study, mice which were given elevated levels of allopregnanolone were compared with those given a placebo. The results showed that 41% of the mice given the placebo exhibited an impaired memory, compared to 79% of the mice which were given high levels of the stress hormone.

http://urn.kb.se/resolve?urn=urn:nbn:se:umu:diva-66572

15 March: New EMA symbol will tag drugs needing further approval

On 15 March, the European Medicines Agency (EMA) updated its product information template with a new symbol to label medicines subject to additional monitoring and encourage adverse-reaction reporting.

This template is used by companies to create product information for medicines marketed in the EU. The revised template includes a black inverted triangle, which all medicines subject to additional monitoring will have to include in their summary of product characteristics and package leaflet from September as well.

The EMA will publish a list of medicines that will need to carry this symbol within the next few months. It will include all medicines that contain a new active substance and all biological medicines authorised after 1 January 2011, medicines for which certain additional information is required after authorisation and medicines subject to conditions or restrictions on their safe and effective use.


20 March: Oleocanthal improves amyloid clearance in mouse models

Oleocanthal, a component of extra-virgin olive oil, has been recently linked to reduced risk of Alzheimer’s disease in two different mouse models.

Previously, this benefit was attributed to the monounsaturated fats in the oil. In this study, researchers from the University of Louisiana at Monroe (ULM) showed that oleocanthal acted to decrease the accumulation of beta amyloid in the brains of mouse models.

Specifically, the presence of oleocanthal boosted the production of P-glycoprotein (P-gp) and LDL lipoprotein receptor related protein-1 (LRP1). Both of these proteins act as garbage trucks, carrying excess amyloid beta out of the brain.

He study was led by Dr. Amal Khalil Kaddoumi, Assistant Professor of Pharmaceutics at ULM and lead author of the paper. She said: "Extra-virgin olive oil-derived oleocanthal associated with the consumption of Mediterranean diet has the potential to reduce the risk of AD or related neurodegenerative dementias."

http://pubs.acs.org/dolc/doi/10.1021/nn400024q

21 March: Piramal seeks authorisation to market [18F] florbetaben

Piramal Imaging, a spinoff company of the Piramal pharmaceutical group, has submitted applications to the EMA and FDA for authorisation to market [18F] florbetaben, a PET amyloid imaging agent. Florbetaben is used in the visual detection of beta amyloid in the brains of adults with cognitive impairment who are being evaluated for Alzheimer’s disease and other causes of cognitive decline.

These applications are based on a successful clinical programme, including a phase 3 trial. This trial was the first to make a direct comparison between in-vivo PET imaging of the brain using florbetaben and post-mortem analyses of brain tissue. The study confirmed that florbetaben binds to beta amyloid in the brain at the regional level and is useful for Alzheimer’s disease diagnosis.

www.aan.com/globals/axon/assets/R547.pdf


25 March: Sleep disorder may signal dementia with Lewy bodies

A new study shows that REM sleep behaviour disorder (RBD) greatly increases the likelihood of developing...
dementia with Lewy bodies in men who already have risk factors of the syndrome.

RBD sleep behaviour disorder is when the brain is in REM (rapid eye movement) sleep but the body moves to act out dreams in the form of kicking, jumping and other motions.

The study included 75 people who had "probable" diagnoses of dementia with Lewy bodies. Researchers conducted MRI brain scans on the study participants and analysed their sleep history to see if they had experienced RBD. They found a strong association between having the sleep disorder and having a definite dementia diagnosis. The association was particularly strong among men and significantly lower among women.

The research project was led by Dr. Melissa Murray, Neuroscientist at Florida’s Mayo Clinic. She said: “Screening for the sleep disorder in a patient with dementia could help clinicians diagnose either dementia with Lewy bodies or Alzheimer’s disease. It can sometimes be very difficult to tell the difference between these two dementias, especially in the early stages, but we have found that only 2 to 3 percent of patients with Alzheimer’s disease have a history of this sleep disorder.”

This study was presented at the 2013 annual meeting of the American Academy of Neurology.

26 March: Lundbeck and Otsuka will develop a new AD drug

Pharmaceutical firms Lundbeck and Otsuka will jointly develop and commercialise Lu AE58054, a Lundbeck compound for the treatment of Alzheimer’s disease.

A Lundbeck press release reveals that the clinical programme will begin in 2013, involving several trials and more than 2,500 participants. The first phase 3 study will test Lu AE58054 as an adjunct treatment to donepezil in people with mild-to-moderate Alzheimer’s disease. Additional studies are expected to start towards the end of 2013.

In May 2012, it was announced that Lu AE58054 had met its primary endpoint in a fixed dose, randomized, placebo-controlled, 24-week clinical study in 278 patients. The study was conducted in patients suffering from moderate Alzheimer’s disease, with Lu AE58054 administered as an add-on to donepezil, a commonly used acetylcholinesterase inhibitor. The clinical data from this study will be presented at the annual Alzheimer’s Association International Conference (AAIC) in Boston on 13-18 July 2013.

Lu AE58054 is known as a selective 5-HT6-receptor antagonist. It is primarily found in areas of the brain involved in cognition. The drug does not provoke a biological response itself, but binds to a receptor and acts as a catalyst to block the operation of the receptor.

29 March: Carmustine reduces amyloid beta in mouse models

Researchers from Florida’s Torrey Pines Institute for Molecular Studies have shown that carmustine, a cancer drug, can decrease the amount of amyloid beta and reduce the number of amyloid plaques in Alzheimer’s mouse models.

The study arose when scientists noticed that people with cancer tended not to get Alzheimer’s disease and vice versa. The research team screened a library of all FDA approved cancer drugs for their ability to reduce amyloid beta levels in cells expressing amyloid precursor protein. The results showed that carmustine decreased the conversion of precursor protein to amyloid β levels by 60%. When tested in a mouse model, long term treatment with carmustine was able to reduce amyloid beta levels by 75%.

The team was led by Dr. Madepalli Lakshmana, who said: "The level of carmustine needed to achieve reduction in amyloid β is much lower than the dose already used in the treatment of some types of brain cancer. Also carmustine does not appear to act by activating microglia or by blocking secretases which reduces possible side effects seen with other anti-amyloid investigational new drugs. While more work still needs to be done carmustine appears to be a powerful candidate drug for treatment and prevention of Alzheimer’s disease."

29 March: Carmustine reduces amyloid beta in mouse models

Researchers from Florida’s Torrey Pines Institute for Molecular Studies have shown that carmustine, a cancer drug, can decrease the amount of amyloid beta and reduce the number of amyloid plaques in Alzheimer’s mouse models.

The study arose when scientists noticed that people with cancer tended not to get Alzheimer’s disease and vice versa. The research team screened a library of all FDA approved cancer drugs for their ability to reduce amyloid beta levels in cells expressing amyloid precursor protein. The results showed that carmustine decreased the conversion of precursor protein to amyloid β levels by 60%. When tested in a mouse model, long term treatment with carmustine was able to reduce amyloid beta levels by 75%.

The team was led by Dr. Madepalli Lakshmana, who said: "The level of carmustine needed to achieve reduction in amyloid β is much lower than the dose already used in the treatment of some types of brain cancer. Also carmustine does not appear to act by activating microglia or by blocking secretases which reduces possible side effects seen with other anti-amyloid investigational new drugs. While more work still needs to be done carmustine appears to be a powerful candidate drug for treatment and prevention of Alzheimer’s disease."

26 March: Lundbeck and Otsuka will develop a new AD drug

Pharmaceutical firms Lundbeck and Otsuka will jointly develop and commercialise Lu AE58054, a Lundbeck compound for the treatment of Alzheimer’s disease.

A Lundbeck press release reveals that the clinical programme will begin in 2013, involving several trials and more than 2,500 participants. The first phase 3 study will test Lu AE58054 as an adjunct treatment to donepezil in people with mild-to-moderate Alzheimer’s disease. Additional studies are expected to start towards the end of 2013.

In May 2012, it was announced that Lu AE58054 had met its primary endpoint in a fixed dose, randomized, placebo-controlled, 24-week clinical study in 278 patients. The study was conducted in patients suffering from moderate Alzheimer’s disease, with Lu AE58054 administered as an add-on to donepezil, a commonly used acetylcholinesterase inhibitor. The clinical data from this study will be presented at the annual Alzheimer’s Association International Conference (AAIC) in Boston on 13-18 July 2013.

Lu AE58054 is known as a selective 5-HT6-receptor antagonist. It is primarily found in areas of the brain involved in cognition. The drug does not provoke a biological response itself, but binds to a receptor and acts as a catalyst to block the operation of the receptor.

29 March: Carmustine reduces amyloid beta in mouse models

Researchers from Florida’s Torrey Pines Institute for Molecular Studies have shown that carmustine, a cancer drug, can decrease the amount of amyloid beta and reduce the number of amyloid plaques in Alzheimer’s mouse models.

The study arose when scientists noticed that people with cancer tended not to get Alzheimer’s disease and vice versa. The research team screened a library of all FDA approved cancer drugs for their ability to reduce amyloid beta levels in cells expressing amyloid precursor protein. The results showed that carmustine decreased the conversion of precursor protein to amyloid β levels by 60%. When tested in a mouse model, long term treatment with carmustine was able to reduce amyloid beta levels by 75%.

The team was led by Dr. Madepalli Lakshmana, who said: "The level of carmustine needed to achieve reduction in amyloid β is much lower than the dose already used in the treatment of some types of brain cancer. Also carmustine does not appear to act by activating microglia or by blocking secretases which reduces possible side effects seen with other anti-amyloid investigational new drugs. While more work still needs to be done carmustine appears to be a powerful candidate drug for treatment and prevention of Alzheimer’s disease."

26 March: Lundbeck and Otsuka will develop a new AD drug

Pharmaceutical firms Lundbeck and Otsuka will jointly develop and commercialise Lu AE58054, a Lundbeck compound for the treatment of Alzheimer’s disease.

A Lundbeck press release reveals that the clinical programme will begin in 2013, involving several trials and more than 2,500 participants. The first phase 3 study will test Lu AE58054 as an adjunct treatment to donepezil in people with mild-to-moderate Alzheimer’s disease. Additional studies are expected to start towards the end of 2013.

In May 2012, it was announced that Lu AE58054 had met its primary endpoint in a fixed dose, randomized, placebo-controlled, 24-week clinical study in 278 patients. The study was conducted in patients suffering from moderate Alzheimer’s disease, with Lu AE58054 administered as an add-on to donepezil, a commonly used acetylcholinesterase inhibitor. The clinical data from this study will be presented at the annual Alzheimer’s Association International Conference (AAIC) in Boston on 13-18 July 2013.

Lu AE58054 is known as a selective 5-HT6-receptor antagonist. It is primarily found in areas of the brain involved in cognition. The drug does not provoke a biological response itself, but binds to a receptor and acts as a catalyst to block the operation of the receptor.
### 13 March: Sex "champions" will train UK care home staff

A UK care provider called Family Mosaic has appointed sex "champions" to educate staff to see sex as a natural part of life for older people and those with disabilities. This training programme stems from a 2012 research project which found that many older people are being denied their basic right to have sex. This includes care home residents being unable to lock their doors and only being given single beds. The research project also found that most care homes do not have formal policy guidelines or staff training aimed at allowing residents to continue being sexually active. The training programme will also aim to dispel the perception that older people are asexual. This can lead to older people's sexuality in care homes being overlooked and even discouraged.

The training addresses the issues of the right to a sex life regardless of age, disability and sexuality, safeguarding issues and risk, professional boundaries and guidance on how to support people around sexual health issues.

Ms Howard works with people in all stages of dementia and maintains that healing through words cannot be underestimated. She said: "So many people are saying they want to be cared for and how to be cared for, that they are not listened to, that they are not heard. They are saying 'this is what I want. This is what I need.'"

Susanna Howard is associated with "Living Words", an art therapy programme that uses the spoken and written word to help people feel present in their lives, regardless of circumstance.

http://livingwords.org.uk/home.htm

### 23 March: UK poet uses words of people with dementia

Susanna Howard is a poet inspired by people with dementia. She sits with them, notes any words they say and then composes poems with these words.

The result of her work is an individual book that stays with her "subject". The book can be helpful to further bond the person with their carer and help a relative see the identity of their loved one as they are now.

http://livingwords.org.uk/home.htm

### 26 March: New UK report urges parity for mental health

In a recent report, the UK Royal College of Psychiatry (RCP) suggests that mental health should be given the same priority as physical health.

The report is entitled "Whole-person Care: from rhetoric to reality (Achieving parity between mental and physical health)". It explains that people with mental health problems frequently experience stigma and discrimination, not only in the wider community but also from services. This is exemplified in part by lower treatment rates for mental health conditions and an underfunding of mental healthcare relative to the scale and impact of mental health problems.

There is an ambition for the NHS to put mental health on a par with physical health. However, the concept of parity in this context is not always well understood. In this report, an expert working group defines 'parity of esteem' in detail, and examines why parity between mental and physical health does not currently exist and how it might be achieved in practice

Prof Sue Bailey, RCP President, said: "Much has been done to improve mental health in the last 10 years but it still does not receive the same attention as physical health, and the consequences can be serious. People with severe mental illness have a reduced life expectancy of 15 to 20 years yet the majority of reasons for this are avoidable.

"Achieving parity of esteem for mental health is everybody’s business and responsibility. I therefore urge the Government, policy-makers, service commissioners and providers, professionals and the public to always think in terms of the whole person - body and mind - and to apply a 'parity test' to all their activities and to their attitudes."

http://www.rcpsych.ac.uk/usefulresources/publications/collegeports/op/op88.asp

### New Publications & Resources

### 5 March: Eurostat publishes "Healthy life years in 2011"

On 5 March, Eurostat, the statistical office of the European Union, published a report entitled "Healthy life years in 2011". The report shows that women and men in the EU 27 could expect at birth to live 62 years in a healthy condition. At the age of 50, they could expect to live another 18 years
in a healthy condition, while at the age of 65 they could expect to have an additional 9 healthy life years.

Among the Member States, Malta had the highest number of healthy life years at birth in 2011, estimated at 71 years for women and 70 years for men. Other countries with high life expectancy rates are Sweden (70 and 71 years) and Greece, Ireland and Luxembourg (all at 67 and 66 years). The lowest rates are in Slovakia (52 years for both) and Slovenia (54 years for both).


14 March: Adult social care contributes EUR 50 billion to UK economy

A survey conducted by "Skills for Care" in the UK revealed that the adult social care sector is worth £43bn (EUR 50bn) and supports the equivalent of 2.8m full-time jobs in the English economy.

In terms of value, the adult social care sector directly contributes £20bn (EUR 23.1bn) in gross value added, higher than the food and drink service industry (£19bn) and the production and distribution of electricity and gas (£16bn). Gross value added measures the value of goods and services produced in an area, industry or sector of an economy.

In comparison to other sectors, the adult social care sector directly employs 1.5 million people in England, which is more than the construction industry (1.1 million) or all restaurants, cafes, pubs and bars in the food and drink service industry (1.3 million).

A further spend of £22.4bn (EUR 26bn) comes from the indirect effects of spending on goods and services provided by suppliers to the adult social care sector, as well as the induced effect of the wages being spent by workers in the sector. A significant part of this amount will be spent through local suppliers, with the social care setting being the hub of a myriad of services.

These figures are a powerful argument for seeing adult social care providers as not only players in the lives of their communities, but also as key contributors to the prosperity of these same communities.

This report strongly supports the case for continued investment in the adult social care sector. This will ensure that this significant workforce, living and working in every community across the country, is appropriately skilled and capable of provide high quality care and support now and into the future.

The full report can be downloaded from the Skills for Care website.

www.skillsforcare.org.uk/firereport2013

19 March: New report shows the benefits of gardens in care homes

The Fondation Médéric Alzheimer (FMA) has released a report on the benefits of gardens and other outdoor spaces in care homes for people with cognitive disorders.

This report analyses operational features of 21 gardens in care homes and day care centres that are supported by FMA. The results are mainly based on site surveys - including observation, interviews with professionals, residents and families - but also on seminars and reports from field teams.

Results were gathered over several years and show a growing interest in outdoor spaces and their development. There is a huge diversity of practices and examples of creating and maintaining outside spaces that are attractive and lively. It is quite clear that such spaces provide resources and benefits to people with cognitive impairments.

Gardens are often perceived as privileged places, as they are meeting points between the care home and the outside world. They provide a space for pleasant and memorable activities, which help to improve the living environment and quality of life of the residents. In addition, many care home residents are keen gardeners, actively participating in its operation and upkeep. Residents are also routinely consulted on design, landscaping and other future plans for outdoor spaces. In this sense, a garden becomes a living space that residents, care professionals, family members and visitors can all call their own.

The report is available free of charge (in French) on the foundation's website.

www.fondation-mederic-alzheimer.org/Nos-Travaux/Nos-etudes

19 March: US Alzheimer’s Association publishes 2013 report

The US Alzheimer’s Association recently published its "2013 Facts and Figures" report. This contains the latest American data, broken down by state, on dementia prevalence, mortality, caregiving and use and costs of health care services. The report also includes a special report on long-distance caregivers.

- Alzheimer's disease is the sixth leading cause of death in the United States.
- More than 5 million Americans are living with the disease.
- One in three seniors dies with Alzheimer's or another dementia.
- In 2012, 15.4 million caregivers provided more than 17.5 billion hours of unpaid care valued at $216 billion (EUR 167 bill.)
- Nearly 15% of caregivers for people with Alzheimer's or another dementia are long-distance caregivers.
- In 2013, Alzheimer's will cost the nation USD 203 billion (EUR 157 bill.). This number is expected to rise to USD 1.2 trillion (EUR 927 bill.) by 2050.

The report can be downloaded from the association’s website.


Job opportunities

19 March: University of Bradford seeks Lecturer

The University of Bradford is hiring a Lecturer in Dementia Studies for its Bradford Dementia Group.
Ideally, the candidate will be a self-motivated and enthusiastic team player to assist the Group in meeting the unprecedented opportunity for improving the quality of life and quality of care for people with dementia and their families.

His/her main duties include furthering the academic development of dementia studies through publications and externally funded research, in collaboration with people with dementia, family carers, care providers and practitioners.

The post holder will hold a PhD and will contribute to the Group’s portfolio of knowledge transfer including accredited education, short course training, practice development and quality improvement initiatives.

The position is located in Bradford and the closing date for applications is 2 April 2013. Informal enquiries prior to may be made by email to Murna Downes, Professor in Dementia Studies at m.downs@bradford.ac.uk

www.bradford.ac.uk/academic-posts

**AE Calendar 2013**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 April</td>
<td>EMA Scientific Advice Meeting (London, United Kingdom)</td>
<td>Jean</td>
</tr>
<tr>
<td>3 April</td>
<td>Meeting with Maria Carrillo from US Alzheimer’s Association (London, United Kingdom)</td>
<td>Jean</td>
</tr>
<tr>
<td>4 April</td>
<td>Meeting with Piramal (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
<tr>
<td>9 April</td>
<td>EFPIA dinner with Think Tank representatives to discuss pharmaceutical industry transparency (Brussels, Belgium)</td>
<td>Annette</td>
</tr>
<tr>
<td>12 April</td>
<td>EWPWAD meeting (Brussels, Belgium)</td>
<td>Helge &amp; Dianne</td>
</tr>
<tr>
<td>16-20 April</td>
<td>Alzheimer’s Disease International Conference (Taipei, Taiwan)</td>
<td>Jean</td>
</tr>
<tr>
<td>17 April</td>
<td>DECIDE final project review (Rome, Italy)</td>
<td>Alex</td>
</tr>
<tr>
<td>18 April</td>
<td>European Commission conference on “Frailty in old age: a public health concern at EU level” (Brussels, Belgium)</td>
<td>Annette</td>
</tr>
<tr>
<td>23 April</td>
<td>Meeting with Lilly (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
<tr>
<td>26 April</td>
<td>GS Health Advisory Board (London, United Kingdom)</td>
<td>Jean</td>
</tr>
</tbody>
</table>

**Future Conferences**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>11-14 April 2013</td>
<td>The 7th World Congress on Controversies in Neurology (CONy), <a href="http://www.conestymed.com/cony/2013/">www.conestymed.com/cony/2013/</a></td>
<td>Istanbul, Turkey</td>
</tr>
<tr>
<td>4-12 May 2013</td>
<td>Neural Stem Cells in Development and for Brain Repair, <a href="http://www.nnas.it/neural-stem-cells-for-development-and-repair">www.nnas.it/neural-stem-cells-for-development-and-repair</a></td>
<td>Cortona, Italy</td>
</tr>
<tr>
<td>5-6 June 2013</td>
<td>Pioneers in healthcare, <a href="mailto:info@researchmedia.eu">info@researchmedia.eu</a></td>
<td>Brussels, Belgium</td>
</tr>
<tr>
<td>7-8 June 2013</td>
<td>Final PROGRESS project conference: “Alzheimer, intergenerational springboard for social inclusion and employment”, <a href="mailto:ceas.du.var@cegetel.net">ceas.du.var@cegetel.net</a></td>
<td>Toulon, France</td>
</tr>
<tr>
<td>8-11 June 2013</td>
<td>23rd ENS 2013 meeting, <a href="http://www.cangries.com">www.cangries.com</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>13-14 June 2013</td>
<td>EU Summit on active and healthy ageing: An action agenda for European cities and Communities, <a href="http://www.ahaconference2013.ie">www.ahaconference2013.ie</a></td>
<td>Dublin, Ireland</td>
</tr>
<tr>
<td>21-26 September 2013</td>
<td>XII World Congress of Neurology, <a href="http://www.eovnt.at">www.eovnt.at</a></td>
<td>Vienna, Austria</td>
</tr>
<tr>
<td>5-9 October 2013</td>
<td>26th ECNP (European College of Neuropsychopharmacology), <a href="http://www.ecnp-congress.eu">www.ecnp-congress.eu</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>20-22 March 2014</td>
<td>59th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>20-23 March 2014</td>
<td>31st International Congress of Clinical Neurophysiology of the IFCN (CCCN), <a href="http://www.iccn2014.de">www.iccn2014.de</a></td>
<td>Berlin, Germany</td>
</tr>
</tbody>
</table>
The Alzheimer Europe newsletter arises from the 2013 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.