



NEWSLETTER

November 2013

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Editorial

In November, we completed the data collection for the 2013 Dementia in Europe Yearbook and also the European



Dementia Monitor. We are very grateful to the many member associations and other experts that contributed to these publications. We also attended some interesting meetings, including the European Patients' Forum launch of its EU campaign manifesto and a conference on palliative care with Italy's Alzheimer Uniti.

In Brussels, we were pleased to welcome MEP Aldo Patriciello to the European Alzheimer's Alliance. The European Parliament approved the Horizon 2020 (H2020) programme, which is due to launch in January 2014 with a EUR 70.2 billion budget. The Commission is calling for new H2020 experts and we are glad to report that Alzheimer Europe is already in demand as a potential partner in several new projects. The Parliament also approved the overall 2014 EU budget and will likely sign off the new European Health Programme early in the new year.

The Innovative Medicines Initiative (IMI) launched a call for proposals for an Alzheimer's disease prevention programme and the JPND issued a new tool for project partners. At the same time, the EMA is reviewing an unexpectedly large number of comments regarding its new position on access to clinical trial data.

On the research front, there are two new Phase 2 clinical trials for AD: one will test an existing anti-psychotic drug and the other will investigate the beneficial effects of nerve growth factor. In addition the Global CEO Initiative has

launched an open scientific challenge to identify better predictors of AD risk.

In our member countries, Switzerland officially adopted its first national dementia strategy. Poland has made a significant step toward government approval of its own draft dementia plan. This is also the case in Greece, but we are not yet able to provide specific details. Slovenia is working to create its first dementia-friendly city and the UK now has dementia-friendly banks. Finland has inaugurated a working group of people with dementia and we also have a report on the activities of the Scottish Dementia Working Group. France, which still awaits the approval of its fourth dementia plan, has launched a new online carer's guide while Norway has released an iPhone application for carers.

We also report on new learning opportunities, as King's College London and Stirling University have launched new dementia courses. In addition, the Royal College of Nursing released a new guide that aims to improve collaboration between carers and health care workers.

As the year draws to a close, we are planning our activities for 2014. Our first lunch debate will take place in February, featuring IMI's important role in funding research projects for Alzheimer's disease. The next issue of our Dementia in Europe magazine will appear at the same time, including coverage of our 2013 Annual Conference in Malta and insights into the upcoming European elections.

On behalf of all Alzheimer Europe Board and staff members, I would like to wish our readers an enjoyable and restful holiday!

Jean Georges

Executive Director

Alzheimer Europe

30 November: Alzheimer Europe completes collection of project data

Alzheimer Europe would like to thank all the contributors who participated in the 2013 Dementia in Europe Yearbook and European Dementia Monitor projects.

The Yearbook provides detailed information on national policies relating to the care and support of people with dementia and their carers in 28 countries. This includes the provision of care, the training of healthcare professionals and social care staff, and support at home, in the community and in nursing homes. The report also features details on the prevalence of dementia in 33 European countries.

The European Dementia Monitor is a benchmark of national dementia policies in the same 33 countries. The

monitor presents simple information in an easily accessible format, comparing the prevalence of dementia, diagnostic guidelines and infrastructure, availability of medicines and access to clinical trials and care.

European Alzheimer's Alliance

6 November: MEP Patriciello joins the Alliance



On 6 November, Aldo Patriciello, MEP (Italy) joined the European Alzheimer's Alliance. He belongs to the Group of the European People's Party (EPP).

Mr Patriciello sits on the Committee on Budgetary Control and also on the Committee on Industry, Research and Energy.

Alzheimer Europe Networking

On 5 November (Brussels, Belgium), Annette participated in the European Patients' Forum launch of its EU campaign manifesto.

On 13 November (Brussels, Belgium), Annette attended the events "Long-term care – what challenges for Europe?" organised by the European Institute of Health and "Right to live, right to die – euthanasia debate" organised by the Goethe Institute.

On 14 November (Rome, Italy), Jean attended the Anniversary Conference of Fondazione Roma "It is Time to Care".

On 18 November (Brussels, Belgium), Annette met Claudia Kuerzl, assistant of Joseph Cuschieri, MEP (Malta).

On 22 November (London, United Kingdom), Jean attended the GSK Health Advisory Board.

On 25 November (London, United Kingdom), Jean participated in the Scientific Advice Meeting at European Medicines Agency.

On 25 November (Brussels, Belgium), Annette attended the EIP AHA conference of partners, with Grainne McGettrick (Alzheimer Society of Ireland) and Charles Scerri (Malta Dementia Society and Alzheimer's disease Research Group – University of Malta).

On 26 November (Brussels, Belgium), Alex attended a Cardiff University conference on "Basic mechanisms in neurodevelopmental disorders: from research to clinical impact".

On 2-3 December (Brussels, Belgium), AE Board and staff attended the AE Board meeting, EP lunch debate and corporate meeting.

On 5 December (Brussels, Belgium), Annette attended the Eurodiaconia event on "Active ageing for the oldest".

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at 71, representing 23 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:** Demesmaeker Mark (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnoc Milan (ECR), Kohlíček Jaromír (GUE/NGL), 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). **Greece:** Chountis Nikolaos (GUE-NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP). **Ireland:** Aylward Liam (ALDE), Childers Nessa (non-attached), Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP). **Italy:** De Martini Susy (ECR), Panzeri Pier Antonio (S&D), Patriciello Aldo (EPP), Toia Patrizia (S&D). **Lithuania:** Blinkevičiute Vilija (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Malta:** Cuschieri Joseph (S&D). **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), Sârbu Daciana Octavia (S&D), Tanasescu Claudiu Ciprian (S&D). **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP). **Slovenia:** Kleva Kekuš Mojca (S&D), Peterle Alojz (EPP). **Spain:** Badiá i Cutchet Maria (S&D), Estaràs Ferragut Rosa (EPP). **United Kingdom:** Anderson Martina (GUE-NGL), Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), McCarthy Arlene (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 November: AGE Platform Europe launches EU election manifesto

On 5 November, AGE Platform Europe launched its manifesto for the European elections 2014 in the European Parliament. The event was co-hosted by MEPs Claude Moraes and Lambert van Nistelrooij. They are both Vice-Chairs of the Intergroup on ageing and solidarity between generations in the EP and also members of the European Alzheimer's Alliance.

The manifesto suggests concrete actions for candidate MEPs to build a society for all ages, free from discrimination and presents AGE's priorities and recommendations. These include promoting EU citizenship among senior Europeans, encouraging people to vote and highlighting relevant dossiers for older persons to candidate MEPs.

AGE's manifesto is based on the organisation's campaign "Towards an age-friendly EU by 2020", launched on the occasion of the European Year 2012 on ageing and solidarity between generations. It also serves to raise awareness among EU citizens about the concrete role of MEPs in addressing elderly concerns and to encourage EU citizens to vote in large numbers at the elections.

www.age-platform.eu/age-and-the-eu-institutions/european-parliament/ep-elections-2014

13 November: New European Health Programme to be approved in spring 2014

On 13 November, the European Commission presented an update for the 2014-2020 Multiannual Health Programme. The new Health Programme will likely be adopted by the European Parliament in spring 2014.

Following adoption, the Commission will publish the 2014 Annual Work Programme and calls for proposals will be launched by the Executive Agency of Health and Consumers. The new programme will have a budget of EUR 449.4 million over seven years.

The general objectives of the Programme are to complement, support and add value to the policies of the Member States to improve the health of EU citizens and reduce health inequalities by promoting health, encouraging innovation in health, increasing the sustainability of health systems and protecting Union citizens from serious cross-border health threats.

http://ec.europa.eu/health/programme/policy/2014-2020/state_of_play_en.htm
http://ec.europa.eu/health/programme/docs/healthpgm_pres_nov2013_en.pdf
www.eu2013.it/en/news/unions-program-to-reduce-health-inequalities-promote-innovation-in-health-

13 November: EMA reviews comments from consultation on access to clinical trial data



The European Medicines Agency is currently reviewing more than 1,000 comments received during the public consultation on its draft policy on publication and access

to clinical trial data, which ran during June-September 2013.

The Agency is grateful for this exceptional contribution from its stakeholders. The large number of comments received will likely delay the finalisation of the policy initially planned for the end of 2013. An update will be provided following the EMA Management Board meeting on 11-12 December 2013.

The Agency is developing a policy on publication and access to clinical trial data because it believes that the release of data is about establishing trust and confidence in the system. The Agency also believes that availability of data broadens the scientific knowledge base, fosters innovation and encourages investment in the development of medicines and ultimately benefits public health.

www.ema.europa.eu/docs/en_GB/document_library/Press_release/2013/11/WC500154207.pdf



www.alzheimer-europe.org/Donation

19 November: European Parliament approves long-term EU budget

On 19 November, the Parliament approved the EU's budget for 2014-2020, the so-called Multi-annual Financial Framework (MFF). The EU now has an investment plan for the next seven years that includes EUR 960 billion in financial commitments and EUR 908 billion in payments.

The budget includes an additional EUR 2.5 billion for policy priorities that include Horizon 2020, the new EU health programme. The new budget also allows for greater flexibility between budget years and categories, while a mid-term review by 2016 will enable the next Parliament to reassess the EU's budgetary priorities.

The EU ministers will approve the MFF on 2 December 2013.

[www.europarl.europa.eu/news/en/news-room/content/20131118IPR25541/html/European-Parliament-approves-EU%E2%80%99s-long-term-budget-\(MFF\)-2014-2020](http://www.europarl.europa.eu/news/en/news-room/content/20131118IPR25541/html/European-Parliament-approves-EU%E2%80%99s-long-term-budget-(MFF)-2014-2020)

20 November: Structural and Investment Funds will stimulate public and private investments

On 20 November, the European Parliament adopted a legislative package on cohesion policy ensuring a total budget of over EUR 325 billion for the European Regional Development Fund (ERDF), the European Social Fund (ESF) and the Cohesion Fund (CF).

In these times of vast public debt, risk aversion and a severe lack of public spending, European funding aims to stimulate public and private investments and provide means for long-term investments for SMEs, innovation and infrastructure.

The European Structural and Investment Funds deliver major investments in times of economic crisis. Continued funding of important projects in all regions in the European Union plays an extremely important role and

also creates an opportunity for growth and smart improvements.

www.eppgroup.eu/press-release/More-money-for-flexible-investments-across-the-EU

20 November: European Parliament approves 2014 EU budget

On 20 November, the European Parliament approved the 2014 EU budget, which will take effect as planned on 1 January 2014.

The budget has seen an increase of EUR 500 million for payments and also conforms to the EP and Council agreement of 12 November to remedy payments shortfalls in the current fiscal year.

www.europarl.europa.eu/news/en/news-room/content/20131118IPR25540/html/Parliament-approves-EU%E2%80%99s-2014-budget-and-plugs-2013-payment-gaps

21 November: Parliament adopts the Horizon 2020 package

On 21 November, the European Parliament adopted the Horizon 2020 package with a EUR 70.2 billion budget for 2014-2020. The largest budget items are "Societal challenges" (39% of the total budget), "Excellent science" (32%) and "Industrial leadership" (22%). The MEPs approved the following elements of the package:

- Teresa Riera Madurell's (Spain) draft regulation on the establishment of Horizon 2020.
- Maria Da Graça Carvalho's (Portugal) draft regulation on the specific programme implementing Horizon 2020.
- Christian Ehler's (Germany) draft regulation on rules for participation.
- Philippe Lamberts' (Belgium) draft regulation on the European Institute for Innovation and Technology (EIT).
- Marisa Matias' (Portugal) draft regulation on EIT's strategic innovation agenda.

The programme must be formally adopted by the Member States before taking effect on 1 January 2014.

www.europarl.europa.eu/news/en/news-room/content/20131115IPR24730/html/Horizon-2020-research-programme-more-support-for-small-firms-and-new-players

22 November: Commission launches call for Horizon 2020 experts

The European Commission has launched a call for new independent experts to act as peer reviewers in evaluating proposals and reviewing projects within the new Horizon 2020 programme. Their assignments will mainly concern research and technological development, similar to the current FP7 programme.

New applicants are invited to register their profiles, while experts that are already registered for FP7 need to declare their interest in working for Horizon 2020 as well.

<http://ec.europa.eu/research/participants/portal/page/experts>

Members' News

31 October: Norwegian phone app leads to the Dementia Helpline



The Norwegian Health Association has released an iPhone application that provides a direct link to the telephone Dementia Helpline and supplies information about dementia.

The app was developed after research results showed that people often hesitated - sometimes for months - to use the helpline after seeing ads for the service.

The Dementia Helpline is very prominent when the app is opened, but there are also pointers on the earliest signs of dementia, the most common forms of dementia and how to start that difficult conversation when someone in your family is starting to show signs of more than normal forgetfulness.



1 November: Slovenia's Šentjur is becoming a dementia-friendly city



Zlata Felc, head of the regional Šentjur Alzheimer Association, looks back at the 2013 activities that are helping to make Šentjur the first dementia-friendly city in Slovenia.

The activities began in May, with a round-table discussion that generated ideas and practical ways on how Šentjur could be friendlier for people with dementia.

In June, the association formally launched the dementia-friendly project - the first of its kind in Slovenia - in cooperation with the Mayor of the city. The main objective is for Šentjur to be recognised as a dementia-friendly city in 2014, with improvements in the actions of local agencies, businesses and community groups. This includes higher awareness of the needs of people with dementia and their carers, in order to make socialising, shopping, eating out and using public transport and other amenities a more enjoyable experience for everyone.

Finally, in November 2013, the association conducted training sessions for public and private employees as well as social and health workers. These were very popular and the participants returned many positive comments after the sessions.

Zlata and her colleagues are very pleased with the progress of the project, which will help maintain and raise the confidence of people in the earlier stages of dementia, as well as their ability to manage everyday living.



1 November: France Alzheimer releases online guide for caregivers



France Alzheimer has released an online guide for caregivers to help them better understand the specifics of Alzheimer's disease and discover the best practices for daily care. The guide is intended to complement the association's training programmes but also functions as an independent resource.

The new "Guide d'accompagnement en ligne" includes videos that demonstrate the progress of dementia in the brain and a 3D model of a home with a dementia-friendly layout and features. There are also extensive FAQ and documentation sections, including real-life advice and experiences of people with dementia and their caregivers.

The new online guide is freely available on France Alzheimer's website.

<http://guide.francealzheimer.org>

14 November: Alzheimer Uniti and Alzheimer Europe attend AD conference



On 14 November, Dr. Luisa Bartorelli, President of Alzheimer Uniti Onlus (Italy) and Jean Georges, Executive Director of Alzheimer Europe, attended a conference on Alzheimer's disease care in Rome. The "Time to Care" conference was hosted by Fondazione Roma on the occasion of the foundation's 15th year of activities.

The main subjects were the continual care and treatment for people with chronic and progressive diseases such as Alzheimer's disease and amyotrophic lateral sclerosis (ALS) and also palliative care.

Jean Georges gave an overview of the situation regarding dementia in various countries in Europe, highlighting those that make dementia a priority and that have created National Dementia Plans. Dr. Bartorelli gave a presentation on care strategies for people with dementia, including non-pharmacological interventions.



18 November: Bank of Scotland is now dementia-friendly



Bank of Scotland has become Scotland's first official Dementia Friendly Bank, in partnership with Alzheimer Scotland.

The bank and the association have been working closely to deliver awareness-raising and information resources to branch colleagues, which will help them provide a more Dementia Friendly service to people with dementia, their families and carers. The bank has also committed to

further train staff on the issues around dementia and to improve practices on an on-going basis.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: "We are absolutely delighted to be able to work so closely with Bank of Scotland in generating this model of Dementia-Friendly Banking. Managing money is a major concern for people with dementia, their carers, partners and families. It is vital that the financial sector recognises the difficulties involved and is knowledgeable and sympathetic about the help they can provide."

18 November: Finnish working group of people with dementia holds first meeting



The inaugural meeting of the new Finnish working group of people with dementia and their caregivers took place on 18 November in a warm and enthusiastic atmosphere.

The group, chaired by Marja-Leena Alho, will work as an independent expert group of the Alzheimer Society of Finland. Members will comment on topical issues and highlight important themes, ideas and views which could otherwise be overlooked. Raoul Grönqvist and Milja Ahola shared their experiences from the European Working Group of People with Dementia and best practices were adopted in the organisation of the Finnish group.

The first meeting featured lively discussion on various important topics, including the difficulties of recently diagnosed persons in reaching local memory associations and the loneliness of people with dementia. The group members also discussed how voluntary work could be branded and marketed more efficiently.

In December 2013, the group will meet again to comment on the draft law concerning the self-determination of people with dementia, especially with regard to restrictive measures. In 2014, the group is planning to meet at least three times.



21 November: FAI's Gabriella Salvini Porro attends Vatican conference



Dr. Gabriella Salvini Porro, President of Federazione Alzheimer Italia, attended the 28th International Conference of the Pontifical Council for Health Care Workers, which took place during 21-23 November in Vatican City.

The conference was entitled "The Church at the Service of Elderly People: Care for People with Neurodegenerative Pathologies" and was attended by over 700 health professionals from some 60 countries.

Dr. Salvini Porro, a speaker during the panel session "The Elderly Person with Neurodegenerative Illnesses", gave a

presentation about the needs of the family of a person with dementia.

28 November: Alzheimer Portugal attends conference on dementia care



Representatives from Alzheimer Portugal recently attended a conference entitled "Care in Dementia - a Practical and Integrated Approach".

More than 200 delegates, including health professionals and social service advocates, attended the conference. Delegates heard presentations and then held discussions on the following case studies:

1. Early-onset dementia
2. Caregiver overload
3. The need for timely dementia diagnosis
4. People with dementia living in isolation
5. Provision of care-performance limits of family and professionals.

The timeliness and relevance of the case studies contributed to a rich discussion and a sharing of experiences. These included accounts from professionals who encounter - on a daily basis - alarming situations of people with dementia who live alone in unhealthy conditions, without any family support and often without water or light. There were also real-life accounts of the challenges faced by people with dementia when they visit hospital emergency rooms and other vulnerable situations.

People in these situations usually lack any form of protection and are thus at grave risk of being abused or treated arbitrarily, with no one to represent them or defend their best interests. For these people, no legal or social solutions can be appropriate or timely enough.

Alzheimer Portugal is a strong supporter of all initiatives to uphold the rights and improve the quality of life of people with dementia and their caregivers.



30 November: UK banks introduce dementia-friendly policies



The UK Alzheimer's Society, along with Lloyds Banking Group and other partners, has launched a "Dementia-friendly financial services charter" for banks and insurers. The charter aims to make financial institutions more dementia-friendly, thereby allowing people with dementia to retain as much dignity and autonomy as possible where their financial affairs are concerned.

The charter suggests ways in which financial institutions can become more user-friendly for people with dementia and their carers. This includes "Champions" being appointed in branches to lead the initiative and customers

with dementia being given more choice - such as the possibility of informing their bank directly about their diagnosis, to allow for more tailored customer care-provision.

Jeremy Hughes, Chief Executive of the Alzheimer's Society, said: "Lloyds Banking Group has recognised its responsibility to customers affected by dementia and is taking positive steps towards improving the service offered to people with the condition and their carers. Alzheimer's Society would like to see the whole financial services sector signing up to the charter, so that managing money does not add to the list of worries people with dementia and their carers can often face."

30 November: Scottish Dementia Working Group looks back at 2013



This article is a personal account by Peter McLaughlin and David Mackenzie, Vice Chairs of the Scottish Dementia Working Group (SDWG), on the achievements of the group during 2013.

So much has changed in 2013 and we both find that we are now starting to establish ourselves. At first everything we were doing just seemed like a series of disconnected events but through time, we came to see how everything we did connected. All of the groups different activities have the purpose of removing many of the unnecessary hassles faced by people with dementia as we possibly can. We have established a number of priorities in pursuit of that goal. These include early diagnosis, improved nationwide access to post diagnostic support and a well trained workforce.

There have been great improvements in the past year thanks to initiatives from Alzheimer Scotland. The 5 Pillar Model of Post Diagnostic Support is now Scottish Government policy, meaning that anyone diagnosed with dementia in Scotland from April 2013 should receive support from a named link worker to help them come to terms with their diagnosis and plan for the future. The Scottish Dementia Working Group was consulted and had a significant input while this was being formulated.

In addition to this, new posts have been established. The introduction of Dementia Advisors in Scotland is a step forward with huge potential to make life easier for many people.

We are regularly involved in the training of both professionals and volunteers, lecturing to nurses, medical students, allied health professionals, doctors, social workers, post diagnostic link workers, helpline volunteers, hospice staff, care home staff and psychology students.

We get a lot of positive feedback from the students and their lecturers via social media. We are often told that listening to our members gives trainee professionals more insight and information than they could ever get from lectures and books.

We have so many requests for assistance in research that Dot Weaks, one of our co-opted members, has established a sub-group to select those requests that are suitable and in keeping with our own priorities.

We have a Newsletter sub-group to keep members informed about member and staff activities, a Transport sub-group looking into ways which make transport easier for people with dementia to use thereby increasing our independence and an Information Technology group which can help to get us familiar with computers and tablets.

Great things have happened in the last year thanks to Alzheimer Scotland. They have been with the Scottish Dementia Working Group all the way, supporting us and more importantly listening to us as the "independent voice of people with dementia". We believe we can have even more of an impact in 2014 as we grow in confidence and experience.



L-R: David Mackenzie, Peter McLaughlin, Henry Rankin (Chair of SDWG).

www.sdwg.org.uk

Policy Watch

15 November: Polish ombudsman receives draft national dementia plan



On 15 November, representatives of the Polish Alzheimer's Association and the Polish Alzheimer Coalition held a conference at the request of the Office of the Polish Ombudsman.

During the conference, they gave several presentations on the status of people with dementia and their caregivers in Poland. They also presented a conference report and a draft of the national Polish dementia plan to Ombudsman Professor Irena Lipowicz.

Prof Lipowicz will forward the report and the plan to the Minister of Health, along with an official request to take steps enabling adoption and implementation as soon as possible.

21 November: Switzerland adopts national dementia plan



The Swiss federal government and the country's 26 cantons have adopted a national dementia plan for the years 2014-2017.

The plan is based on the premise that dementia affects not only the individual, but also family members and health professionals. It contains nine objectives that include greater awareness, individual care strategies and integrated care pathways. The plan also calls for improvements in early diagnosis and long term care, both in people's homes and in specialised institutions.

The Swiss Alzheimer Association has been very active in the development of the plan since its inception. In a press

release, the association expressed its global approval of the plan and pointed out that each individual canton must now take the appropriate steps to ensure its success.

www.alz.ch/tl_files/PDFs/PDF-F-Gesellschaft%20und%20Politik/MM+Strategie+Demenz_NCD_FR.pdf
www.alz.ch/tl_files/PDFs/PDF-F-Medienmitteilungen/Strategie%20nationale%20Alzheimer%20-%20Association%20Alzheimer.pdf



www.alzheimer-europe.org/Donation

25 November: UK Health Secretary receives letter from AD associations ahead of G8 dementia Summit

The heads of the UK Alzheimer's Society, Alzheimer's Research UK and ADI have presented a letter to UK Health Secretary Jeremy Hunt ahead of the G8 Dementia Summit on 11 December.

The letter calls for a collaborative global action plan on dementia research, a significant increase in funding for that research, and help in attracting, developing and retaining the best scientists, clinicians and care professionals.

This letter follows the similar "St. Julian's Appeal to G8 Dementia Summit" that was adopted by Alzheimer Europe and its member organisations, including the Alzheimer's Society, on 10 October 2013.

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2019
www.alzheimer-europe.org/News/Alzheimer-Europe/Thursday-10-October-2013-Alzheimer-Europe-calls-on-G8-to-step-up-international-research-efforts-on-dementia

Science Watch

3 October: Autophagy mediates the formation of amyloid plaques

A recent Japanese study has shown that a lack of autophagy in neurons prevents the secretion of amyloid beta and the formation of amyloid plaque in the brain.

Autophagy is a cellular cleaning mechanism - similar to a garbage removal system - that clears protein aggregates and other "trash" from neuron interiors. In Alzheimer's disease, autophagy becomes erratic and loses some of its ability to mediate the formation of amyloid plaques.

In this study, researchers blocked autophagy in an Alzheimer mouse model to observe the consequences in amyloid metabolism. The results showed that a complete lack of autophagy within neurons prevents the formation of amyloid plaque outside the cells. However, amyloid accumulated inside the neurons and eventually caused neuronal death.

The research team was led by Dr. Takaomi Saido, Professor of Molecular Psychiatry and Research Scientist Dr. Per Nilsson, both from the RIKEN Brain Science Institute in Japan.

Dr. Nilsson said: "Our study explains how amyloid beta is secreted from the neurons, via autophagy, which wasn't well understood. To control amyloid beta metabolism

including its secretion is a key to control the disease. Autophagy might therefore be a potential drug target for the treatment of Alzheimer's disease."

www.cell.com/cell-reports/retrieve/pii/S2211124713005020?_returnURL=http://linkinghub.elsevier.com/retrieve/pii/S2211124713005020?showall=true

1 November: Phase 2 trial will test pimavanserin for AD psychosis

King's College London (KCL) will conduct a Phase 2 clinical trial to test the drug pimavanserin for treating psychosis in Alzheimer's disease.

Pimavanserin recently completed a successful Phase 3 trial for Parkinson's disease (PD). The trial showed significant improvements of psychotic symptoms and a far better safety profile than any existing antipsychotic drugs. These positive findings were also seen in people with PD and cognitive impairment, indicating a potential benefit to people with Alzheimer's disease and other dementias.

Prof Clive Ballard, Professor of Age-Related Diseases at KCL and lead author of the paper, said: "The results of this study are so promising that we are preparing for a phase II trial with ACADIA Pharmaceuticals to look at the efficacy and safety of pimavanserin for treating psychosis in patients with Alzheimer's disease. Psychotic symptoms are commonly associated with Parkinson's disease, Alzheimer's disease and other neurodegenerative conditions and can cause significant distress to patients and their families and caregivers, so a treatment that can safely and effectively reduce these symptoms has the potential to really improve people's lives."

www.kcl.ac.uk/newsevents/news/newsrecords/2013/11-November/New-drug-for-Parkinsons-shows-promise.aspx
[www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)62106-6/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)62106-6/abstract)

6 November: Bilingual ability may delay onset of dementia

A new Indian cohort study shows that bilingual people did not show signs of Alzheimer's disease, fronto-temporal dementia or vascular dementia for more than four years longer than those who spoke only one language.

The study involved 648 people from the Hyderabad region that were diagnosed between 2006 and 2012. Their records were examined for data on their specific diagnoses, socio-demographic variables, dementia severity and cardiovascular risk factors such as hypertension, smoking status and coronary artery disease. The records also included the languages spoken by the patient prior to the onset of dementia. Of the 648 patients in the study, 257 were monolingual and 391 had two or more languages.

The results showed that the average age of onset of Alzheimer's disease, fronto-temporal dementia or vascular dementia was 61.1 years in those who were monolingual versus 65.6 years in those speaking two or more languages. This difference also applied to individuals who were illiterate and had no formal education at all: those who were monolingual had an average age of dementia onset of 59.0 versus 65.0 years in those speaking two or more languages.

This study was funded by the Indian government.

www.neurology.org/content/early/2013/11/06/01.wnl.0000436620.33155.a4.abstract

7 November: Global CEO Initiative to launch "Big Data Challenge" for AD

The Global CEO Initiative (CEOi) on Alzheimer's Disease has joined forces with Sage Bionetworks and IBM to initiate "AD#1", a computational challenge to identify better predictors of AD risk in pre-clinical populations.

Computational challenges are open contests for scientists to competitively solve a specific problem in a given time period by placing scientific data, tools, scoreboards and the resulting predictive models into a common workspace. This technique is also called "gamifying" and "crowdsourcing" data analysis.

AD#1 will use data from the Alzheimer's disease Neuroimaging Initiative (ADNI), including cognitive, imaging, biological and whole genome sequencing data on cohorts of volunteers with dementia. The best-performing predictive models from the challenge will be evaluated against a similarly structured validation data set. The winning teams will be featured as lead authors in a prominent journal article.

CEOi is an organisation of private-sector leaders who have joined together to provide business leadership in the fight against Alzheimer's disease. The organisation seeks to partner with public leaders to transform the disease from a social, health, and economic crisis into an opportunity for healthy aging and innovation in research and care.

The AD#1 organisers expect the challenge to open in early 2014 with the final scoring of submissions taking place before the summer.

www.synapse.org/#!Synapse:syn2290704
www.ceoalzheimersinitiative.org

7 November: JPND releases a Partnering Tool for researchers

The EU Joint Programme - Neurodegenerative Disease Research (JPND) has released a new tool for the researchers that respond to the upcoming JPND calls in December 2013.

The JPND Partnering Tool allows researchers to present their research group and expertise in a closed forum, tailored for JPND, thus making it easier for research partners to locate each other and collaborate on a proposal.

Researchers can also register a proposal idea and get comments from expert scientists and researchers within the tool. Consortia can then be built around the idea, potentially leading to drafting a proposal on the tool.

It is believed that this tool will especially benefit early-career researchers and research groups not normally included in established consortia. Experienced researchers can potentially use the tool to find specific expertise which may be missing from their pre-existing consortia.

<http://neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/partnering-tool/>
www.alzheimer-europe.org/News/EU-developments/Monday-21-October-2013-JPND-will-launch-two-calls-in-December-2013

8 November: Bristol-Myers Squibb drops neuroscience research

Bristol-Myers Squibb has announced a new research focus that includes discontinuing broad based discovery work in neuroscience, hepatitis C and diabetes. The company will continue to focus on HIV, HBV, heart failure, oncology, immune-science and fibrotic diseases.

www.bms.com/news/features/2013/Pages/Bristol-MyersSquibbEvolvesRDStrategy.aspx

8 November: Luxembourg researcher wins grant for AD research

A team led by Dr. Enrico Glaab, a researcher from the Luxembourg Centre for Systems Biomedicine (LCSB) of the University of Luxembourg, has won the 2013 public scientific challenge of the Geoffrey Beene Foundation. The EUR 37,000 cash award will be used to investigate why women are at greater risk for Alzheimer's disease than men.

Dr. Glaab and his colleagues have identified a gene called USP9 that is much more active in the brains of healthy men than in men with Alzheimer's disease. However, the gene is nearly equally active in the brains of healthy and ill women. The gene also acts as a regulator in many cellular processes associated with Alzheimer's disease. The researchers will investigate whether the elevated activity of the USP9 gene in men provides protection against Alzheimer's disease.

The second prize of the challenge went to Dr. John Quackenbush and Dr. Kimberly Glass from the Harvard School of Public Health. They are examining gender differences in cellular networks and are developing technology to better predict sex-based differences in Alzheimer's disease.

The Geoffrey Beene Foundation Alzheimer's Initiative is a major beneficiary of the Geoffrey Beene Foundation. The organisation has provided funding to advance awareness, diagnosis and research in early stages of Alzheimer's disease since 2007.

http://www.wen.uni.lu/lcsb/news_events/lcsb_wins_global_neurodiscovery_challenge
www.geoffreybeenechallenge.org



11 November: IMI to call for proposal on AD prevention



IMI, the Innovative Medicines Initiative, will launch its 11th call for proposals in late 2013. The call, will likely feature eight topics including EPOC-AD, the "European platform for proof of concept for prevention in Alzheimer's Disease."

EPOC-AD calls for greater cooperation and collaboration between academia, government and industry to enhance the drug development process. The project would create a precompetitive space to enable collaboration for optimising patient selection, clinical trials methodologies and candidate therapies, as well as conducting adaptive

clinical trials that will produce the greatest likelihood of success.

Specific aims of the EPOC-AD project:

- Form the EPOC-AD registry through coordination with existing longitudinal cohorts and physician networks to identify subjects for the registry.
- Maintain a longitudinal natural history cohort of a subset of subjects in the EPOC-AD registry to maintain a "trial-ready cohort" with standardized run-in data.
- Develop criteria and methods for selecting participants from the longitudinal natural history cohort for inclusion in AD prevention adaptive clinical trials.
- Establish an international collaborative group for advancing and conducting adaptive prevention trials for preclinical to early symptomatic AD.
- Develop methods for the design and analysis of adaptive clinical trials for preventing AD that incorporate Bayesian statistical approaches for selecting, introducing and dropping treatments arms, including drug combinations.

www.imi.europa.eu/content/11th-call-2013-8
www.imi.europa.eu/sites/default/files/uploads/documents/11th_Call/11th_Call_indicativetext_20131107.pdf

14 November: Retinal cell changes may be AD biomarkers

A new study has shown that changes to certain cells in the eye's retina could help diagnose and track the progression of Alzheimer's disease.

The researchers were led by Dr Scott Turner, Director of the Georgetown University Memory Disorders Program. They examined the thickness of the retina in mouse models, in two areas that had not previously been investigated: the inner nuclear layer and the retinal ganglion cell layer. Results showed that a loss of thickness occurred only in Alzheimer's mice. The retinal ganglion cell layer had almost halved in size and the inner nuclear layer had decreased by more than a third.

This study builds on existing evidence linking the loss of cells in the eyes to dementia. It is thought that when neurons die in the brain, they also die in the eye, which leads to a thinning of the retina.

Dr Turner said: "The retina is an extension of the brain so it makes sense to see if the same pathologic processes found in an Alzheimer's brain are also found in the eye. This could lead to new ways to diagnose or predict Alzheimer's that could be as simple as looking into the eyes".

These findings were presented at the Neuroscience 2013 conference in San Diego.

www.sfn.org/annual-meeting/neuroscience-2013

15 November: Phase 2 trial tests ability of CERE-110 to increase NGF

A gene therapy for Alzheimer's disease called CERE-110 is being tested in a Phase 2 clinical trial following successful Phase 1 results.

The Phase 1 study showed that surgical delivery of CERE-110 to the brain results in an increase of nerve growth

factor (NGF), a protein that promotes nerve growth and repair and also protects nerves against damage. Results also showed a stabilisation of metabolic activity in neurons, which may reflect a slowing of cell deterioration.

Dr. Paul Aisen, Project Director of the Phase 2 trial and Director of the Alzheimer's Disease Cooperative Study (ADCS) at the University of California San Diego, said: "These early clinical data demonstrate that this therapeutic approach is feasible, well-tolerated and results in appropriate delivery of the therapeutic NGF protein to the intended target cells in the brain."

The Phase 2 trial is being carried out in collaboration with the ADCS and is funded by a grant from the National Institute on Aging (NIA), part of the National Institutes of Health (NIH). The study is fully enrolled and will last until 2015.

These results were presented at the Sixth Clinical Trials on Alzheimer's Disease (CTAD) Meeting in San Diego on 14-16 November 2013.

20 November: Human APOE2 reduces plaque in AD mouse models

A new animal study has shown that injection of the human APOE2 protein into the cerebrospinal fluid (CSF) of mice with established plaque can reduce deposition and retention of beta amyloid.

The APOE4 variant of apolipoprotein E is a known risk factor for late-onset Alzheimer's disease. In humans, carrying two copies of APOE4 increases the risk of developing Alzheimer's disease by 12 times compared to having two copies of the more common APOE3 form. However, inheriting the APOE2 variant appears to cut the risk in half.

In this study, researchers from Massachusetts General Hospital (MGH) tested the APOE2, APOE3 and APOE4 variants in different groups of mice. They used direct CSF injections in adult Alzheimer mouse models with well-established plaques and also maintained a control group.

Results showed that plaques in mice that received APOE4 were more numerous and significantly denser than those of mice receiving APOE2. The growth of plaques in animals receiving APOE3 was in between that of the other two groups and similar to the control group. In addition, beta amyloid levels in the blood of the APOE2 mice were higher than in the other groups, suggesting that this variant increased clearance of beta amyloid from the brain.

Dr. Eloise Hudry, Instructor in Neurology at MGH and lead author said: "This study has allowed us to sort out, in mice, which effects of the different types of APOE were most important to variation in amyloid plaque deposition. Our results imply that APOE-based therapeutic approaches may help to alleviate the progression of Alzheimer's disease."

<http://stm.sciencemag.org/content/5/212/212ra161>

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<http://stm.sciencemag.org/content/5/212/212ra161>

Dementia in Society

13 November: Spanish composer releases new song about dementia

A new Spanish song about dementia has been released on YouTube. "Cordones de mimbre" ("Wicker cord") was composed by Iñaki Alforja and is based on the experiences of a man whose mother has developed dementia. The video portrays many real life situations of people living with dementia in Spain's Navarra region. According to Mr Alforja, "it's a simple story about your feelings when you have a relative with Alzheimer disease."

www.youtube.com/watch?v=SQKZXDIPyTw

New Publications & Resources

9 November: University of Stirling releases a dementia-friendly hospital design

The Dementia Services Development Centre (DSDC) at the University of Stirling has designed a dementia-friendly online virtual hospital. This includes an entrance, wards and a lift that can help people with dementia to feel more in control and more secure. The virtual hospital was funded by the Robert Bosch Stiftung foundation.

<http://dementia.stir.ac.uk/design/virtual-environments/virtual-hospital>

10 November: University of Stirling announces a dementia course

The DSDC is also re-launching its "Improving dementia care" course. The 15 week distance learning course is for health and social care practitioners looking to improve their knowledge and practice in the field of dementia care.

The course aims to improve the knowledge of current approaches to care and support for people with dementia and those who care for them. In addition, participants can develop a better understanding of how to promote change in dementia care and improve outcomes for people with dementia.

The course will start on 31 January 2014 at a cost of EUR 764. Applications are available on the DSDC website.

www.dementia.stir.ac.uk/education/advanced-study/undergraduate

22 November: King's College London launches MSc course for Advanced Care in Dementia

King's College London has developed a master's degree that aims to drive up standards of care for people with dementia. The MSc Advanced Care in Dementia programme can be studied over one year full time or two years part time. Students will explore a biopsychosocial model of dementia care through five taught modules: Measurement and evaluation for healthcare practice; Clinical science of dementia; Evidence-based decision-making in healthcare; Care in dementia; Leadership and change in dementia care. Students must also draw on their learning in dementia care to plan and carry out a relevant research project for their dissertation. Throughout the course, students will develop the knowledge and skills they need to offer person-centred care to people with dementia using evidence-based and reflective approaches.



Geoff Ward, a senior nurse at South London and Maudsley NHS Foundation Trust has just completed the programme. "I wish I had completed this programme years ago," he says. "It is a brilliant opportunity to learn more about dementia, and has also enhanced my understanding of research."

As research into the various forms of dementia adds to our understanding of the condition, the field of dementia care offers a rewarding career for professionals working in all settings. The Advanced Care in Dementia Programme

will equip them to ensure they can respond with skill and compassion to any patients who have dementia.

www.kcl.ac.uk/prospectus/graduate/acid

27 November: Royal College of Nursing releases dementia care guide

A guide to improve the care of people with dementia by ensuring support and involvement of their carers has been published by the Royal College of Nursing (RCN) and Carers Trust.

The "Triangle of Care" contains six key standards that aim to improve collaboration between carers and health care workers:

1. Carers and their essential role are identified as soon as possible.
2. Staff is "carer aware" and trained to engage with and understand carers' needs.
3. Policy and practice regarding confidentiality and sharing information are in place.
4. Defined posts responsible for carers are in place.
5. A carer introduction to the service and staff is available.
6. A range of carer support services are available.

Dr. Peter Carter, Chief Executive and General Secretary of the RCN said: "Carers often have their own needs and should be offered information and support. They also have a lot to offer health care staff, as they are often the ones who know the person best. No one is better placed to advise on a person's needs and how their dementia affects them than a carer who has known them for years. Carers and staff are working towards the same goal and it is better for everyone if they can work together to achieve this."

www.nursingpractice.com/article/rcn-calls-improved-links-dementia-carers

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AE Calendar 2013

Date	Meeting	AE representative
10 December	Glasgow site inspection for 2014 AE conference (Glasgow, UK)	Gwladys
10-11 December	EMA Training Session for patient organisations and the EMA Patient and Consumer Working Party (London, United Kingdom)	Jean
11 December	3 rd NILVAD Steering Committee meeting (London, UK)	Alex
11-12 December	G8 Dementia Summit and the CEO Initiative on Dementia (London, UK)	Heike
12-13 December	DANDEC project application kick off meeting (Prague, Czech Republic)	Dianne
12-13 December	EMIF project - 2 nd AD General Assembly (Amsterdam, the Netherlands)	Alex
13 December	EFPIA Think Tank (Brussels, Belgium)	Annette
16 December	Meeting with EPEMED European Personalised Medicine association (Luxembourg, Luxembourg)	Jean
17 December	European Parliament Interest Group on Mental health, Well-being and Brain Disorders (Brussels, Belgium)	Jean

Future Conferences

Date	Meeting	Place
8-9 December 2013	2 nd Middle East and North Africa Conference of Alzheimer's Disease International, www.adidubai2013.org	Dubai, UAE
11-14 December 2013	The 16 th Asia Pacific regional Conference of Alzheimer's disease international, www.aprc2013-hongkong-macau.com	Hong Kong & Macau, China
20-22 March 2014	58 th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), www.dgkn-kongress.de	Berlin, Germany
20-23 March 2014	30 th International Congress of Clinical Neurophysiology of the IFCN (ICCN), www.iccn2014.de	Berlin, Germany
26-29 March 2014	13th Int. Geneva/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Geneva, Switzerland
1-4 May 2014	29 th ADI Conference, www.adi2014.org	San Juan, Porto Rico
8-11 May 2014	8th World Congress on Controversies in Neurology (CONy), www.comtecmed.com/cony/2014/	Berlin, Germany
31 May-3 June 2014	EFNS-ENS Joint Congress of European Neurology, http://www.jointcongressofeuropeanneurology.org	Istanbul, Turkey
11-14 June 2014	12ème Réunion francophone sur la maladie d'Alzheimer et les syndromes apparentés	Montpellier, France
26-27 June 2014	International Dementia Conference, "Risky Business 2 – this time it's personal!", http://www.dementiaconference.com/call-for-papers	Sydney, Australia
5-9 July 2014	9 th FENS Forum of Neuroscience, http://forum.fens.org/2014	Milan, Italy
20-22 October 2014	24th Alzheimer Europe Conference "Dignity and autonomy in dementia", www.alzheimer-europe.org/Conferences	Glasgow, United Kingdom
23-25 October 2014	9 th International Conference on Frontotemporal Dementias, www.ubccpd.ca	Vancouver, Canada

24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014

Mark the dates!

www.alzheimer-europe.org/conferences



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.