Editorial

December 2013 already seems like a distant memory to me, yet there were quite a few activities at the end of the year, notably the G8 Dementia Summit. This remarkable event has shown us how far we have come in addressing the challenges that face people with dementia and their families.

In December, we also held a lunch debate in Brussels. This was hosted by Maltese MEP Joseph Cuschieri and allowed us to present our new European Dementia Monitor.

After the end-of-year break, we welcomed our new colleagues Ana, Kate and Stefanie – and also bid farewell to Julie Fraser, who is unfortunately no longer with us. While we are still settling into our new offices, we are glad to announce that the Alzheimer Europe Foundation is now officially established and operational. The foundation will support many of our activities, such as involving people with dementia in European conferences and projects.

In January we also attended launch meetings of two new EU projects - AETIONOMY and ACTIFCare - and we will continue to represent the interests of our members in all our project work during the year.

We are grateful to the first seven MEPs that have already signed our European Dementia Pledge; we expect that many more will join them in committing to make dementia a priority in the new Parliament. In other EU news, Greece has taken over the EU presidency and Horizon 2020 has been approved by the Member States. The first calls have already gone out and the JPND has also launched two calls - along with a new report on its ongoing cohort research.

In our member countries, Greece has begun work on a national dementia strategy. Italy is also making progress and Norway has launched an ambitious dementia research programme. Our member associations in Germany, the Netherlands and the UK are also funding research projects and the UK’s Dementia Friends campaign continues its successful course.

We have reports of several new drug trials, including three Phase 3 trials and also a clinical assessment of a gaming platform as a biomarker. In Europe, the EMA approved a new rivastigmine patch and an imaging agent while a new American project called YODA will provide access to clinical trial data.

Our next lunch debate will take place on 18 February in Brussels, where we will explore the current and future projects of the Innovative Medicines Initiative with IMI Executive Director Michel Goldman. On the same day, we will also be releasing three new publications: the latest issue of our Dementia in Europe Magazine, the 2013 Ethics report and the 2013 Dementia in Europe Yearbook.

The Ethics report examines the issues linked to the perceptions and portrayal of dementia, while the Yearbook includes detailed information on national policies relating to the care and support of people with dementia and their carers in 28 countries.

We wish all our readers a successful year and look forward to seeing many of you at an Alzheimer Europe event very soon.

Jean Georges
Executive Director
2 December: Alzheimer Europe holds Board meeting

Alzheimer Europe held a Board meeting on 2-3 December in Brussels that was attended by seven Board members. Amongst other items, they reviewed the outcomes of AE’s successful 2013 Annual Conference in Malta and the progress of the upcoming Dementia in Europe Yearbook. The Board members also reviewed financial forecasts for 2013 and adopted the 2014 work plan and budget.

The next AE Board meeting will take place on 17 February.

3 December: AE holds a lunch debate on the European Dementia Monitor

On 3 December, Joseph Cuschieri, MEP (Malta) and member of the European Alzheimer’s Alliance, hosted an Alzheimer Europe lunch debate dedicated to the development of AE’s European Dementia Monitor.

Mr. Cuschieri welcomed the participants and pointed out that dementia is a challenge for all EU Member States: over seven million Europeans live with dementia and there are some 21 million informal carers. He also said that it is imperative to address both the stigma associated with the disease and the fact that the treatment and care of people with dementia differs between EU Member States.

MEP Cuschieri was followed by Jean Georges, Executive Director of Alzheimer Europe. Mr. Georges gave a presentation on AE’s European Dementia Monitor (EDM), which is a benchmark of national dementia policies in 33 European countries. The monitor presents simple information in an easily accessible format, comparing the prevalence of dementia, diagnostic guidelines and infrastructure, availability of medicines, access to clinical trials and care availability.

The EDM is based on data from existing and trustworthy sources, mainly Alzheimer Europe member associations. The comparison of data from different countries is often challenging but the EDM overcomes this by using a point system to present results in a simple and clear table. Preliminary results show a wide range of differences between European countries, meaning that shortcomings can be identified. Mr. Georges said that this would be a priority for Alzheimer Europe in 2014 and that the findings will be published in a scientific journal.

There were 40 participants at the lunch debate, including MEPs Anneli Jäätteenmäki (Finland) and Marina Yannakoudakis (UK), while Sirpa Pietikäinen (Finland) was represented by her assistant. Other participants included representatives from the European Commission, the pharmaceutical industry and eight member associations of Alzheimer Europe.

3 December: Alzheimer Europe holds a corporate meeting

Following the lunch debate, Alzheimer Europe held a meeting with corporate sponsors that featured a presentation on sponsorship opportunities for 2014. Jean Georges described AE’s 2014 activities and described the various mechanisms that are available for existing and new corporate sponsors.

These include the existing gold, silver and bronze packages, but AE will now present its activities in smaller packages than in the past. This will allow companies with fewer resources to participate as well. Conference sponsorship will also become more accessible and there will also be new advertising options.

According to Mr Georges, the new options provide “à la carte” sponsorship opportunities in a clear and straightforward manner.

10 December: Alzheimer Europe joins the PredictND project

Alzheimer Europe has joined PredictND, a project within the Seventh Framework Programme (FP7) that aims to provide an objective and systematic ICT-based approach for the diagnosis of neurodegenerative diseases.

One of the main objectives is to show that a clinical protocol based on the use of modern computer-based models enables objective earlier diagnostics compared to current clinical procedures. The second main objective of PredictND is to improve cost-efficiency of early diagnostics by developing a low-cost and simple-to-use battery of measurements that could be used to detect persons at high risk for dementia.

The PredictND project will be coordinated by VTT Technical Research Centre of Finland. AE will be a partner in dissemination and outreach activities and the other partners are shown below:

- Danish Dementia Research Centre (Denmark)
- University of Eastern Finland
- University of Perugia (Italy)
- VU University Medical Center (The Netherlands)
- GE Healthcare Life Sciences (Sweden)
- Imperial College of London (UK)

2 January 2014: Alzheimer Europe presents new colleagues

Alzheimer Europe is pleased to welcome three new colleagues to its Luxembourg office:

Ana Diaz, Project Officer: Ana will collaborate with AE’s member associations in the development of national reports on care pathways. She will also develop and maintain databases on clinical trials and diagnostic and treatment guidelines in Europe. In addition, Ana will support the development of project applications towards EU programmes and support the dissemination of EU funded research projects. Ana is currently finalising her PhD thesis entitled “Quality of life and anti-dementia medication: An exploration of the experiences of people living with dementia and their care-partners” from Trinity College Dublin. She can be reached at ana.diaz@alzheimer-europe.org

Kate Ellis, Communications Officer: Kate has been with AE on a part-time basis since 1 January 2013. In her new full-time position, she will take over the production of the
Kate can be reached at katherine.ellis@alzheimer-europe.org

Stefanie Peulen, Finance Officer: Stefanie will be working on a part-time basis to prepare monthly and annual financial reports as well as developing annual budgets. She will also prepare budgets and monitor the accounts of EU projects and support the development of new fundraising activities. Stefanie can be reached at stefanie.peulen@alzheimer-europe.org

In addition, AE has named Dianne Gove as Director for Projects and Alex Teligadas as Director for Communication. Dianne will continue to lead AE’s research efforts, including the ethics and incontinence working groups. Alex will update AE’s communication strategy and will take over as editor of the Dementia in Europe magazine. He will also continue to represent AE in a number of EU research projects.

Finally, AE regrets to announce the departure of Julie Fraser. Julie joined Alzheimer Europe in December 2007 and served as Communications Officer until September 2011, when she became the Editor of the Dementia in Europe magazine. We would like to thank her for her outstanding contribution and wish her every success in the future.

www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-staff

The AEF Board was established in 2011 and is chaired by Maria do Rosário Zincke dos Reis, who is also Honorary Treasurer of AE. Heike von Lützau-Hohlbein and Iva Holmerová (respectively Chair and Vice-Chair of AE) were named as Board members at that time. They were joined in 2013 by Marc Schaefer, a member of the Luxembourg Alzheimer’s Association and former AE Board member.

The AEF Board will be further expanded and all Board members are appointed for three year terms.

10 January: AE finalises the set-up of the Alzheimer Europe Foundation

AE is pleased to announce that the Alzheimer Europe Foundation (AEF) is now officially established and operational. The final step was taken on 10 January, when the Foundation was formally approved by Grand-Ducal Decree. The AEF aims to:

- support the networking activities of national Alzheimer associations in the framework of Alzheimer Europe.
- encourage the involvement of people with dementia in European conferences, meetings and projects.
- promote European dialogue on legal and ethical issues in dementia.
- support the exchange of information and good practices on national dementia strategies and Alzheimer’s plans.

The AEF Board was established in 2011 and is chaired by Maria do Rosário Zincke dos Reis, who is also Honorary Treasurer of AE. Heike von Lützau-Hohlbein and Iva Holmerová (respectively Chair and Vice-Chair of AE) were named as Board members at that time. They were joined in 2013 by Marc Schaefer, a member of the Luxembourg Alzheimer’s Association and former AE Board member.

The AEF Board will be further expanded and all Board members are appointed for three year terms.

Impressions from the lunch debate

Joseph Cuschieri, MEP (Malta) and host of the lunch debate

Elisabetta Vaudano, [IMI], Anneli Jäätteenmäki, MEP (Finland), Heike von Lützau-Hohlbein (Germany), Alicja Sadowska (Poland)

Jean Georges (AE), Heike von Lützau-Hohlbein, MEP Cuschieri and Charles Scerri (Malta)

Maurice O’Connell (Ireland) and Gráinne Crowley (Lilly)

Annette Dumas [Alzheimer Europe] with Maria do Rosário Zincke dos Reis (Portugal)
which enable an optimum quality of life despite cognitive impairment. The project is funded by the German Ministry of Education and Research.

12 December: EMIF holds 2nd General Assembly of the Alzheimer's disease partners

The EMIF-AD partners held their second General Assembly during 12-13 December in Amsterdam. The assembly included work package updates and a poster presentation. The sessions were mainly led by Pieter Jelle Fischer and Johannes Streffer, who are heading the AD work topics.

EMIF has now reached the end of its first year. During that time, the 56 project partners have clarified many scientific issues and issued their first papers. In addition, the first AD cohorts have been successfully loaded onto the tranSMART platform.

Bart Vannieuwenhuyse and Simon Lovestone, co-coordinators of the project, were pleased with the year’s work. According to Bart, “the hard preparation work is done. Now we can start to deliver.” Simon added that “the EMIF project brings size; we will have access to more data and samples than I could ever generate from conventional collaboration. Because of the nature of the information, we can address different questions from before. There are cohorts with five years or more of data, up to ten in some instances. Then electronic health records bring in primary care data, not only from the ‘at risk’ age group. We can search for significant indications even back to childhood.”

EMIF is part of the broader European Innovative Medicines Initiative (IMI) and aims to create an environment that allows for efficient re-use of existing health data.

9 January 2014: AETIONOMY project holds launch meeting

On 9-10 January, the AETIONOMY project partners held their first meeting in Brussels. The five-year project aims to improve the classification and diagnosis of neurodegenerative disease by collecting, curating and organising all the publicly available knowledge about disease mechanisms in order to improve drug development and therapy.

More specifically, the project partners will develop new taxonomies, or classifications, of Alzheimer’s and Parkinson’s diseases based on specific disease mechanisms. They will also validate these taxonomies with a clinical study, in order to identify patient subgroups based on the new taxonomy. This will hopefully lead to earlier and more accurate diagnoses and also improved drug development.

AETIONOMY will be led by Prof Duncan McHale, Vice President of Global Exploratory Development at UCB and Prof Martin Hofmann-Apitius, Head of Bioinformatics at Fraunhofer. Together they will coordinate the efforts of 17 project partners working in five work packages.

Alzheimer Europe is a partner in work package 4 - Ethical and Legal Governance - along with UCB, Leibniz
Universität Hannover, Erasmus Medical Center and the European Brain Council. This group will initially provide input to ensure that patient perspectives and interests are considered in the project’s legal framework.

AETIONOMY receives support from the Innovative Medicines Initiative Joint Undertaking (IMI-JU) under grant agreement n° 115568.

AETIONOMY project partners

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<th>Institution</th>
<th>Partner</th>
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<td>Alzheimer Europe (Luxembourg)</td>
<td>Luxembourg Centre for Systems Biology (Luxembourg)</td>
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<td>Boehringer Ingelheim (Germany)</td>
<td>NeuroRad (Romania)</td>
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<td>Erasmus Medical Center (The Netherlands)</td>
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<td>European Brain Council (Belgium)</td>
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<td>Fraunhofer Institute SCAI (Germany)</td>
<td>Sanofi (France)</td>
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<td>ICM - Institut du Cerveau et de la Moelle épinière (France)</td>
<td>UCB Pharma (Belgium)</td>
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<td>IDIBAPS - Institut d'Investigaciones Biomédicas August Pi i Sunyer (Spain)</td>
<td>Universitätsklinikum Bonn (Germany)</td>
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<td>Karolinska Institutet (Sweden)</td>
<td>University College London (UK)</td>
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<td>Leibniz Universität Hannover (Germany)</td>
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In addition, costs, consequences and novel specific outcome measures will be evaluated. This will lead to the identification of best-practice pathways to formal care. Alzheimer Europe is a member of the consumer board on this project.

ACTIFCare is a three year project supported by JPND, the EU Joint Programme for Neurodegenerative Disease Research.

European Alzheimer’s Alliance

28 January: MEP van Nistelrooij addresses dementia question to the European Commission

Mr Lambert van Nistelrooij, MEP (Netherlands) and member of the European Alzheimer’s Alliance, recently addressed the following written question to the European Commission:

Subject: Eradicating dementia by 2025

On 11 December 2013 the group of the eight largest industrialised countries in the world, the G8, made a commitment to develop a medicine to cure dementia, or control it more effectively, by 2025. This is an important initiative as it is estimated that 135 million people worldwide will suffer from dementia in 2050 if no action is taken. According to the World Health Organisation, the global cost of dementia in 2010 was USD 604 billion.

In the light of the above:

- Has the Commission pledged its support for the G8 commitment?
- What research and innovation resources under the Horizon 2020 programme is the Commission making available for age-related diseases (both for fundamental research into the causes and for treatments for the various stages of these diseases)?
- Will the Commission make an additional financial contribution to the G8 initiative, either directly or indirectly?

The Commission is expected to reply within eight weeks and AE will publish the response in a future newsletter.

30 January: Jim Higgins joins the European Alzheimer’s Alliance

The European Alzheimer’s Alliance is pleased to welcome Jim Higgins, MEP (Ireland) and member of the Group of the European People’s Party (EPP). Mr Higgins sits on the Committee on Transport and Tourism and is also a Quaestor in the Parliament Bureau.

31 January: Seven MEPs sign the European Dementia Pledge

Alzheimer Europe wishes to thank the first seven MEPs to sign the European Dementia Pledge:

- Austria - Heinz Becker and Angelika Werthmann
- Ireland - Jim Higgins
- Slovenia - Mojka Kleva Kekuš and Ivo Vajgl
• United Kingdom - Claude Moraes

The Pledge is a simple commitment by European Parliament candidates to support our campaign to make dementia a priority:

"On my election to the European Parliament, I will...

• Join the European Alzheimer’s Alliance comprised of Members of the European Parliament committed to making dementia a European priority and

• Make myself available to my national Alzheimer’s society and people with dementia from my country."

We invite all our readers to contact their MEP candidates and make them aware of the European Dementia Pledge.

www.alzheimer-europe.org/Policy-in-Practice2/European-Dementia-Pledge

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**Alzheimer Europe Networking 2013**

On 2-3 December, Jean and the staff attended the AE Board meeting and Lunch debate on the findings of the European Dementia Monitor (Brussels, Belgium).

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

On 10 December, Gwladys conducted a site inspection for the 2014 AE conference (Glasgow, UK).

On 10-11 December, Alex attended an EMA training session and the 3rd NILVAD Steering Committee meeting (London, UK).

On 12-13 December, Dianne attended the DANDEC project application kick off meeting (Prague, Czech Republic).

On 12-13 December, Alex went to the 2nd EMIF-AD General Assembly (Amsterdam, the Netherlands).

On 13 December, Annette attended the EFPIA Think Tank (Brussels, Belgium).

On 16 December, Annette participated in the WHO Europe Regional meeting on “Implementing policies for healthy ageing in the WHO region” (Utrecht, the Netherlands).

On 23 December, Julie and Alex attended an Editorial meeting with Binsfeld (Luxembourg, Luxembourg).

On 9-10 January, Alex attended the AETIONOMY launch meeting (Brussels, Belgium).

On 14 January, Jean met with European Personalised Medicine Association (Luxembourg, Luxembourg).

On 16-17 January, 2014 Dianne attended the kick-off meeting of the ACTIFCare project (Maastricht, the Netherlands).

On 27 January, Alex attended the PharmaCog Steering Committee meeting (Lille, France).

On 27 January, Dianne attended the JPND-AAL meeting (Amsterdam, the Netherlands).

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**Members of the European Alzheimer’s Alliance**

Currently, the total number of MEPs in the Alliance stands at 72, 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 (NL). _Belgium:_ Demeersmaeker Mark (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tanabell Marc (S&D). _Bulgaria:_ Panvarova Antoniya (ALDE). _Cyprus:_ Trantaphyllides Kyriacos (GUE-NGL). _Czech Republic:_ Cabenoch Milan (ECR), Kohlincek Jaromir (GUE-NGL), Roithova Zuzana (EPP). _Denmark:_ Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). _Finland:_ Ikkala Janniskari Liisa (S&D), Jäätteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP). _France:_ Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Juvin Philippe (EPP), Morin-Charter Elisabeth (EPP), Pargneaux Gilles (S&D). _Germany:_ Niебler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Uller Thomas (EPP). _Greece:_ Chountis Nikolaos (GUE-NGL), Koppa Maria Elena (S&D), Kratza-Tasarapoulou Rodi (EPP). _Ireland:_ Aylward Liam (ALDE), Childers Nessa (non-attached), Crowley Brian (ALDE), Higgins Jim (EPP). _Italy:_ Guineas Mairead (EPP), Mitchell Gay (EPP). _Ireland:_ McAvan Linda (S&D). _Luxembourg:_ Auwyer Linnien (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Juvin Philippe (EPP), Morin-Charter Elisabeth (EPP), Pargneaux Gilles (S&D). _Lithuania:_ Blinkevičiaite Vilija (S&D). _Luxembourg:_ Engel Frank (EPP), Lulling Astrid (EPP). _Malta:_ Cucinelli Joseph (S&D). _Netherlands:_ De Lange Esther (EPP), van Nistelrooij Lambert (S&D). _Poland:_ Łukacijewskaja Eliza (EPP). _Portugal:_ Carvalho Maria da Graça (EPP), Coelho Carlos (EPP). _Romania:_ Anoncescu Elena Oana (EPP), Sârbu Daciana Octavia (S&D), Tanasescu Claudia (S&D). _Slovakia:_ Molnářik Mia (EPP). _Slovenia:_ Klevčičučle Vilija (S&D). _United Kingdom:_ 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).
a selection of INGOs, taking into account the need for a balanced representation of the different fields concerned.

22 January: EP committee meets the Greek Minister of Health

On 22 January, the European Parliament Committee on the Environment, Public Health and Food Safety (ENVI) held a meeting with Spyridon-Adonis Georgiadis, Greek Minister of Health. The meeting was an exchange of views on Greece’s Council Presidency programme.

In the field of health, the Greek Presidency sees good health as a prerequisite for growth. As such, more effective health systems and better health must be a priority. Minister Georgiadis welcomed the agreements on clinical trials and said that medical devices and patient safety remain on the agenda.

Greece, along with other EU countries, is currently reforming its frontline healthcare system. The Presidency would like to look at best practices and put together a package of measures that could be used by all.

Minister Georgiadis explained that there will be a particular emphasis on innovation in electronic health and also cited diet and physical exercise as important priorities of the Presidency. He concluded by saying that those innovations that can reform healthcare and help patients will be set as a priority.

The ENVI Committee includes the following MEPs who are also members of the European Alzheimer’s Alliance: Dagmar Roth-Berendt (Germany), Alojz Peterle (Slovenia) and Marina Yannakoudakis (UK).

Members’ News

10 December: Launch of Human Rights and Older People Policy Paper

On 10 December, World Human Rights Day, the Alzheimer Society of Ireland launched its “Human Rights and Older People in Ireland” policy paper. This was authored by The Human Rights and Older People Working Group, with ASI at its helm.

The paper describes stigma and ageism as major barriers within the current framework in Ireland, preventing older people from realising their human rights.

Speaking at the launch, Senator Feargal Quinn gave insight into some of the major issues covered by the paper, including “the stigma surrounding diseases such as dementia and indeed how we need to look completely differently at the relationship between ageing and disability.”

He also gave assurance that “the paper provides concrete ways in which older people can realise their basic human rights.”

The paper makes five recommendations, identified as critical factors to the realisation of Human Rights for Older People:

- access to appropriate and timely information
- choice
- allocation of resources
having a voice
access to redress

Professor Gerard Quinn from the Centre of Disability Law & Policy at NUI Galway, also speaking at the launch, hailed the paper as marking “a watershed in the evolution of thinking about older people and their rights in Ireland…by helping to re-frame age from a human rights perspective you have done a great service. It will strike many as unfamiliar. But this unfamiliarity is itself a striking illustration of the reality that universal human rights have yet to be made genuinely universal.”


1 January 2014: Federazione Alzheimer Italia launches annual awareness campaign

As every year since 2009, Federazione Alzheimer Italia (FAI) will launch an SMS campaign to raise awareness and funds. The campaign will run during 2-16 February 2014 to support "Pronto Alzheimer", the first Alzheimer helpline in Italy to give practical help to family members. It will be supported the video "The memory room", which will air on national and local television networks throughout the campaign.

"Pronto Alzheimer" was launched 21 years ago to respond to the questions and worries of family members of people with Alzheimer’s disease. Today, service represents 30% of FAI’s activities and has become the national reference point - both for families and for all professionals who are involved with Alzheimer’s disease. The helpline provides information, support, psychological help and advice relating to legal, social security, psychological and social aspects and also provides contacts to the best available local services.

"Pronto Alzheimer" has responded to over 135,000 requests for help since it began in 1993. During 2013, service operators recorded 4,576 contacts from all over Italy in a dedicated database.

Among these, 2,627 contacts were from patients’ family members. The most frequent requests were for information on disease and patient management, research, diagnostic centres and local services and legal and fiscal problems. Other popular requests dealt with explanatory documentation and books, psychological and legal support, social support and occupational therapy – the latest service offering from Federazione Alzheimer Italia.

6 January: German Alzheimer Society will fund dementia research

The German Alzheimer Society has announced that it will fund dementia research for up to EUR 200,000 during 2014.

Research projects should aim to improve the situation of people with dementia and their families. Projects that have a specific focus on the use of technical support for dementia are especially welcome.

Heike von Lützau-Hohlbein, First Chair of the Society, said: "We are very pleased to be able to provide funding for research in 2014. This year, we intend to concentrate on projects that will bring technical solutions to the practical problems that confront people with dementia and their families every day of their lives.”

Applications can be submitted until 30 April 2014 and all proposals will be evaluated by the technical advisory board of the German Alzheimer Society.


10 January: Alzheimer Nederland to improve treatment of depression

Together with the Dutch Mental Health Fund, Alzheimer Nederland is co-funding a research project to improve the treatment of people with Alzheimer’s disease who also suffer from depression.

It is estimated that 20-25% of people with Alzheimer’s disease also suffer from depression. On average, depression has a bad prognosis and is very difficult to treat. The current standardised treatment for depression could be one of the reasons for the lack of its success. If this is the case, treatment can be improved by tailoring it on a case by case basis.

The researchers will seek to identify individual causes of depression by daily digital questionnaires about the severity of depression symptoms and the occurrence of known risk factors. After identification of the most important risk factor(s), a personalised treatment program will be put together. This may consist of an exercise programme for people who have little activity, light therapy for people with sleep disorders or cognitive behavioural therapy for people who are worried about their memory complaints.

www.alzheimer-europe.org/Donation

14 January: Alzheimer Uniti Italy attends national dementia strategy meeting

On 14 January, representatives from Alzheimer Uniti Italy attended a meeting hosted by the Italian Ministry of Health for the drafting of a national dementia strategy. The meeting was also attended by delegates from the other national dementia organisations and representatives from the country’s regional authorities.

This group includes all the relevant players that would implement a national dementia strategy. It is hoped that the group can achieve rapid progress toward establishing a chain of rational services, rooted properly in the entire country, which will respond to the needs and expectations of people with dementia and their caregivers.
15 January: Belgium’s LINAL provides guidelines for missing persons

Ligue Nationale Alzheimer Liga (LINAL) has released a new brochure in its ongoing campaign to develop Dementia Friendly Cities in Belgium. The brochure provides guidelines on what to do if a person with dementia disappears from his/her home or place of residence.

The brochure explains the various types of collaboration that exist between municipal authorities, the police and local chapters of the association to locate missing people. This collaboration is based on the four principles of prevention, quick intervention, collaboration and information.

The new brochure also includes a legal point of view, a practical guide and a “To Do” list for families and caregivers.

15 January: Thirty more UK MPs and Peers become Dementia Friends

On 15 January, an information session was held at the UK Houses of Parliament in London to recruit a cross-party group of thirty MPs and Peers to the ever-increasing ranks of Dementia Friends throughout England and Wales.

The session, held at the Houses of Parliament, helped Parliamentarians understand the impact that dementia has on people’s lives and the things that can be done to help people with dementia to live well.

Dementia Friends is a national initiative, launched in February 2013 by the UK Alzheimer’s Society. It aims to help people understand what it might be like to live with dementia and turn that understanding into action. Alzheimer’s Society is aiming to have one million Dementia Friends by 2015, to help make the UK more dementia-friendly and improve the lives of the 650,000 people currently living nationwide with the condition.

The thirty participating MPs and Peers were also asked to pledge an action in order to help make their community more dementia-friendly.

Jeremy Hughes, Chief Executive at Alzheimer’s Society said: “Most people don’t know enough about dementia. Dementia Friends is the perfect opportunity to be able to invite everyone to improve their knowledge. We are pleased to have been able to engage 30 MPs and peers in one day. They have a huge influence in their local communities and we hope they will use this opportunity to take action and improve lives.”

The Alzheimer Society estimates that there are now almost 100 MPs and Peers who are Dementia Friends. This includes those who attended one of two sessions in parliament (the first session was held on 13 September 2013) as well as those who have attended sessions locally in their constituencies.

www.dementiafriends.org.uk

31 January: Norway launches national dementia research programme

In October 2013, the Norwegian National Broadcaster (NRK) selected the Norwegian Health Association as the organisation that would benefit from its traditional annual fundraising event.

The event raised EUR ten million, which will be used to create and run a national coordinated research programme focusing on causes, prevention, diagnostics and treatment of dementia. It will also be used to fund a national research network amongst dementia researchers in Norway.

The network approach aims to stimulate collaboration among scientists in basic research, clinical research and epidemiology. The ultimate goal for the association is to take a large step forward in curing, preventing or postponing the development of dementia, as well as securing the best quality of life for persons with dementia and their caregivers.

The Norwegian Dementia Research programme issued its first annual call just before Christmas 2013 and has already received 62 applications. The proposals will be evaluated and assessed by a panel according to their focus (causes, prevention, diagnostics and treatment of dementia), feasibility, novelty and originality, and collaborative intentions. Following this, an independent international panel will assess the remaining proposals with a focus on scientific quality. Successful projects will be funded for three years, with the possibility to apply for an extension up to five years.

The Norwegian Health Association is aiming to raise more money during the first years of the programme in order to establish the research programme as a permanent national fixture for Norwegian dementia research.

Policy Watch

11 December: G8 countries hold dementia summit

On 11 December, the G8 group of countries held the dementia summit in London. The summit gave leaders from the G8 nations (Canada, France, Germany, Italy, Japan, Russia, UK, USA) the opportunity to discuss new strategies for the fight against dementia on a global scale.

The programme included medical and social aspects of dementia, including prevention, the quality of life and care of people with dementia and social adaptation to dementia. The delegates followed presentations and discussions led by experts from research establishments, the pharmaceutical industry and dementia organisations – including Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

The summit concluded with a declaration that set the ambitious goal of developing a cure or treatment for dementia by 2025. The G8 Ministers also committed to improve the lives of people living with the condition and to reduce social stigma, even if no particular timeframe was assigned for these objectives.

Innovation, greater international cooperation and higher funding were all highlighted as key requirements to meet...
The current economic and financial crisis has led the Greek Presidency to deal with recession and unemployment, safeguarding the common currency, deepening the Economic and Monetary Union (EMU) and dealing with migration issues.

In this context, the Presidency will work on the full and effective implementation of the Compact for Growth and Jobs with specific actions promoting development, tackling youth unemployment, promoting labour market mobility and taking action to address the social impact of the crisis.

In the health field, the Greek Presidency will advance legislative proposals for tobacco products, clinical trials, pharmaco-vigilance fees, transparency directive and legislative proposals for tobacco products, clinical trials, medical devices. Non-legislative work will aim at promoting initiatives for more efficient health care systems and better public health. This includes the impact of the economic crisis on healthcare and health systems, migration and public health, nutrition and physical activity, eHealth and health innovation.

1 January 2014: Greece takes over EU Presidency

On 1 January, Greece took over the Presidency of the EU Council from Lithuania and will hold the office until 30 June 2014.

The Greek Alzheimer associations are very active, to look after them. Alzheimer Report 2013 shows that there are 200,000 people with dementia in Greece and 400,000 family carers. In contrast, ADI's World Alzheimer's Association and also includes professors of neurology, psychiatry and law as well as health economists and carers.

There are currently very few specialised services for people with dementia in Greece. These include 15 memory clinics, 13 day care centres and three respite care facilities that serve more than 5,000 people with dementia and their carers. In contrast, ADI's World Alzheimer Report 2013 shows that there are 200,000 people with dementia in Greece and 400,000 family carers to look after them.

The Greek Alzheimer associations are very active, organising awareness campaigns, seminars for health professionals, screening programs for the public, educational programs for carers and also scientific research. The associations will continue to be closely involved in the development and implementation of the national dementia strategy.

17 January: Record Alzheimer's disease funding bill passed in the US

A bill, increasing funding for Alzheimer’s research, education, outreach and caregiver support by USD 122 million, was signed into law on 17 January by President Barack Obama for his 2014 budget.

Currently, research figures show that for every USD 27,000 spent on healthcare for individuals with Alzheimer’s disease in the US, the National Institutes of Health (NIH) spends only USD 100 on research.

The US Alzheimer’s Association, which backed the passing of the bill, congratulated the Obama administration as well as Congress for providing funding to enable the continued implementation of the National Plan to Address Alzheimer’s Disease, which aims to prevent and effectively treat Alzheimer’s disease by 2025.

“The Alzheimer’s Association celebrates this significant milestone with our more than 600,000 advocates who have been relentless in their efforts given the current fiscal climate. Their determination and passion are second to none,” said Harry Johns, President and CEO of the Alzheimer’s Association.

Science Watch

26 November: Memories dulled by lack of NMDA receptors

Decoding brain activity patterns to better understand learning and memory represents a huge challenge for scientists working in the area of Neurobiology. Progress in this area could be extremely useful in understanding the dementia-affected brain, and the process of memory recall decline.

A recent mouse study at the Medical College of Georgia, investigating memory code in N-methyl-D-aspartate (NMDA) in the hippocampus has led to some progress in ‘mapping’ some of these codes.

“We have begun to crack the neural code, which allows us to look in real time at how thoughts happen and how memories are made”, said Dr Joe Tsien, corresponding author of the study in the journal PLOS ONE, neuroscientist at the Medical College of Georgia.

Using Pavlovian techniques, the team played a tone to groups of mouse models (some normal and some lacking the NMDA receptor), followed 20 seconds later by a mild foot shock. The normal mouse models quickly made the
On 29 November the largest ever study and clinical trial in ulcers, and kidney problems. Medical and research professionals have, however, repeatedly warned of the significant side-effects risks of the long-term use of NSAIDs (including stomach bleeding, ulcers, and kidney problems).

On 29 November the largest ever study and clinical trial in Australia, ASPREE (ASPirin in Reducing Events in the Elderly) was announced: ASPREE is a study of 15,000 people (to date) aged over 70 in Australia and the US, on the use of aspirin to prevent disease in the elderly. The recruitment drive continues until July 2014, with the hope of reaching 19,000 participants.

ASPRE study executive officer Dr Robyn Woods commented, "Because of the power provided by the number and the targeted age range of participants, the results of this trial will offer us more insight than any other study into the benefits of aspirin for older people".

Research team leader Professor Mark Nelson, from Hobart’s Menzies Research Institute in Tasmania, says that the ASPREE study and clinical trial will examine whether the potential primary prevention benefits of low dose aspirin outweigh the risks linked to its use, in particular in older, healthy individuals.

Dr Simon Ridley of Alzheimer’s Research UK said: "Systematic reviews of previous aspirin trials have so far showed no evidence that the drugs can benefit people with dementia, but the studies done to date have been relatively small. Large-scale controlled trials could provide more conclusive evidence".

www.ncbi.nlm.nih.gov/pubmed/24113028

29 November: Large-scale clinical trial and study into preventative effects of aspirin on dementia

The effects of low-dosage aspirin (as well as some other non-steroidal anti-inflammatory drugs or NSAIDs), taken over an extended period of time have long been of interest in the area of Alzheimer’s disease and dementia research.

Medical and research professionals have, however, repeatedly warned of the significant side-effects risks of the long-term use of NSAIDs (including stomach bleeding, ulcers, and kidney problems).

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www.ncbi.nlm.nih.gov/pubmed/24113028

2 December: JPND launches two calls for neurodegenerative diseases

JPND (the EU Joint Programme – Neurodegenerative Disease Research) has launched two calls for proposals aimed at investigating cross-disease pathways in neurodegenerative diseases (including dementia) and to identify new preventive strategies. The programme will disburse some EUR 23 million to applicants from 18 European countries.

Call 1: Cross-Disease Analysis of Pathways

This call is for proposals to perform network analyses in different neurodegenerative and other chronic diseases to elucidate the underlying mechanisms involved. The combined analysis of diseases across traditional clinical boundaries may lead to a re-definition of clinical phenotypes and new approaches in the treatment of neurodegenerative diseases.

JPND Countries participating in this call: Belgium, Canada, Finland, France, Germany, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Portugal, Slovak Republic, Spain, Sweden, Turkey. Interested applicants are invited to present a pre-proposal submission by 18 February 2014.

Call 2: Pilot Studies on Preventive Strategies

This call aims to encourage interdisciplinary “pilot” studies for the design of preventive strategies that may modify both the risk of developing neurodegenerative diseases and of symptom progression.

JPND Countries participating in this call: Austria, Belgium, Denmark, Finland, France, Germany, Ireland, Italy, Luxembourg, the Netherlands, Norway, Poland, Portugal, Spain, Sweden, Turkey. Interested applicants are invited to present a pre-proposal submission by 20 February 2014.

3 December: Amlodipine to undergo a clinical trial for vascular dementia

The UK Alzheimer’s Society and the British Heart Foundation (BHF) have announced a clinical trial of the existing drug amlodipine for the treatment of vascular dementia.

The four-year trial will involve 600 people with a specific type of vascular dementia called subcortical ischaemic vascular dementia (SIVD). Researchers will begin recruitment in early 2014 and will be led by Dr Peter Passmore, Professor of Ageing and Geriatric Medicine at Queen’s University in Belfast. They hope to show that a daily 10mg dose of the drug can significantly improve memory and cognitive health.

Amlodipine is currently used to treat high blood pressure, which is a major risk factor for vascular dementia. It is known to enter the brain and researchers think it might work by protecting neurons from damage when blood supply to the brain is restricted.

www.qub.ac.uk/home/cwac/News/Title,425013,en.html
10 December: Merck launches clinical trials for its BACE inhibitor

Merck has announced two new Phase 3 trials of its MK-8931 compound for Alzheimer’s disease. This follows a successful mid-stage trial of 200 patients who had been treated with MK-8931 for at least three months. The first trial is called EPOCH and will involve up to 1,960 participants with mild to moderate Alzheimer’s disease over 18 months. The second trial (APECS) will test the same drug in people with mild cognitive impairment and biomarkers for Alzheimer’s disease over a two-year period.

MK-8931 is a BACE inhibitor, i.e. it blocks the activity of an enzyme called beta secretase that is involved in the production of beta amyloid. In 2012, a different BACE inhibitor trial was stopped due to safety concerns. In this case, an independent monitoring board was given access to the data of Merck’s early trial and concluded that the Phase 3 trials could proceed safely.

www.allforum.org/therapeutic/mk-8931

14 December: Roche moves molecules across blood brain barrier

Roche has demonstrated a new method to deliver large antibody molecules through the blood brain barrier (BBB). The BBB acts as a roadblock that prevents unwanted toxins - but also medicines - from reaching the central nervous system and the brain.

The Roche “brain shuttle” essentially fools an existing natural transport mechanism called receptor-mediated transcytosis into allowing large molecules to enter. More specifically, the shuttle activates the natural transferrin receptor (TfR) in a specific mode that triggers the production of beta amyloid. In 2012, a different BACE inhibitor trial was stopped due to safety concerns. This is normally used to transfer proteins within the brain but is now suborned to bring in external bodies as well.

The new technique showed a significant reduction of amyloid load when tested in Alzheimer mouse models. According to Luca Santarelli, Head of Neuroscience, Ophthalmology and Rare Diseases at Roche: “The target engagement of investigational antibodies in the brain in a preclinical model was increased by over 50-fold compared to the parent antibody.”

Roche will continue to investigate the shuttle’s potential, including the transport of growth factors, antibodies, peptides and oligonucleotides across the BBB.

www.cell.com/neuron/retrieve/pii/S0896627313010350

19 December: Post-menopausal heart patients are more prone to dementia

A new study shows that post-menopausal women with heart disease are nearly a third more likely to develop dementia.

The researchers were led by Dr Bernhard Haring, a Clinical Fellow at the University of Würzburg in Germany. They studied nearly 6,500 women between the ages of 65 and 79 who had healthy brain function at the start of the study and came to the following conclusions:

• Postmenopausal women with heart disease or vascular disease were 29 % more likely to experience cognitive decline over time compared with women without heart disease.
• The risk for cognitive decline was approximately double among women who had a heart attack compared with those who had not had a heart attack.
• Women who had heart bypass surgery, carotid endarterectomy (surgical removal of a blockage in a neck artery) or peripheral artery disease were at greater risk for cognitive decline.
• Risk factors such as high blood pressure and diabetes increased risk for cognitive decline over time.
• Obesity did not significantly increase cognitive decline in elderly women.

http://circ.ahajournals.org/cgi/content/meeting_abstract/127/12_MeetingAbstracts/AABSTRACTS/AAM2571sid=6bf9ff4a-6ff1-4eb2-9355-6b683b3babab

20 December: NAD moves back ageing indicators in mouse models

Researchers from Harvard University and the University of New South Wales (Australia) have discovered a way of restoring the efficiency of cells and thus reversing the ageing process in muscles.

The research was conducted on mouse models and focused on an area of energy-producing cells called mitochondria. Over time, the communication between this area and the cell nuclei degrades, leading to the ageing process.

The scientists injected two-year old mice with nicotinamide adenine dinucleotide (NAD) over one week. This is a naturally occurring compound in humans that reduces with human age. The results showed that key indicators of ageing moved back to that of a six-month-old mouse, or the equivalent of making a 60-year-old person feel like a 20-year-old.

Dr Nigel Turner, senior research fellow at UNSW and co-author of the study, said: “We know that this cell...
communication breaks down in diseases such as dementia, cancer and type-two diabetes. This research focused on muscles, but it could benefit multiple organs and delay and prevent a lot of these diseases occurring."

20 December: Novartis withdraws EMA extension for rivastigmine

On 20 December, the European Medicine Agency announced the withdrawal of an application by Novartis to extend the use of its rivastigmine patches to people with severe Alzheimer’s disease.

Novartis has seen two types of its transdermal patches authorised for use in the EU since 1998, for the treatment of patients with mild to moderately severe Alzheimer’s disease. The company wished to extend their use to people with severe Alzheimer’s disease, but the EMA concluded that this would create more risks than benefits for patients.

In particular, the reviewers were concerned that several side effects (including falls, vomiting and diarrhoea, dehydration, loss of appetite and psychiatric disorders) seemed to be more common and more severe in patients with severe Alzheimer’s dementia. This could have more serious consequences in patients with severe disease, which is of concern in this more vulnerable population.


23 December: Study shows AD origin in the lateral entorhinal cortex

An American research team has shown that Alzheimer’s disease originates in the lateral entorhinal cortex (LEC), a small region of the brain linked to the hippocampus.

The study also shows how the effects of AD spread from this area to other regions of the cerebral cortex. One region especially targeted is the parietal cortex, whose functions including spatial orientation and navigation.

The scientists were led by Professor Scott Small, director of the Alzheimer’s Disease Research Centre at Columbia University in New York. They conducted MRI brain scans of 96 healthy adults over the age of 65. The results showed reduced LEC activity in 12 people who later developed symptoms of AD, compared to normal activity in those who did not.

Professor Small said: “This study is the first to show in living patients that it begins specifically in the LEC. The LEC is considered to be a gateway to the hippocampus, which, among other functions, plays a key role in the consolidation of long-term memory. If the LEC is affected, other aspects of the hippocampus will also be affected.

“Now we’ve pinpointed where Alzheimer’s starts, and shown that those changes are observable, we may be able to detect Alzheimer’s at its earliest preclinical stage.”

www.nature.com/neuro/doi/10.1038/neuro.17.021486.1301237

30 December: Cholesterol levels may affect onset of Alzheimer’s disease

A study investigating the associations between serum cholesterol levels and cerebral amyloidosis, which can be an early indicator of Alzheimer’s disease, was published in JAMA Neurology journal on 30 December.

The study involved 74 male and female participants with an average age of 78 and included three people with mild dementia, 33 who were cognitively normal and 38 who had mild cognitive impairment.

The participants’ amyloid levels were obtained using PET scans, in combination with a tracer that binds with amyloid plaques. Higher fasting levels of LDL cholesterol and lower levels of HDL cholesterol were both correlated with lower levels of amyloid plaque deposition in the brain. This is a pattern that mirrors the relationship between HDL and LDL cholesterol in cardiovascular disease, according to lead researcher Professor Bruce Reed, an associate director of University of California Davis’ Alzheimer’s Disease Center.

A word of caution from Reed and his co-authors, however, was that the study does not prove cholesterol is directly affecting amyloid deposition. Unhealthy cholesterol levels could be linked to vascular damage, such as small strokes, and those micro-injuries could be the reason for the protein deposits.

Dr Laura Phipps of Alzheimer’s Research UK warned that there was still insufficient evidence to recommend that cholesterol-lowering drugs such as statins should be used to treat Alzheimer’s disease. "While this study did not investigate the mechanism behind the link, the findings add to existing evidence that cholesterol could play a role in the Alzheimer’s disease process”, she said.


1 January 2014: Vitamin E may slow functional decline in mild to moderate Alzheimer’s disease

A study published in the January 1 issue of JAMA found that a daily, high dose of alpha tocopherol (fat-soluble vitamin E) given to patients with mild to moderate Alzheimer’s disease was effective in slowing functional decline by about six months during an average follow-up time of two years.

The study was carried out by Dr Maurice Dysken and his colleagues at the Minneapolis VA Medical Center. They examined the effects and safety of alpha tocopherol, memantine and the combination of the two on patients with mild to moderate AD who were also taking an acetylcholinesterase inhibitor. They performed a randomised clinical trial involving 613 patients with mild to moderate AD, between 2007 and 2012 at 14 Veterans Affairs medical centres in the U.S.

The researchers noted that the placebo group lost approximately three units more on the ADCS-ADL (Alzheimer’s Disease Cooperative Study-Activities of Daily Living) inventory than the alpha tocopherol group. Caregiver time in assisting patients was shown to be reduced by about two hours per day in the alpha tocopherol group.
Neither memantine nor the combination of vitamin E and memantine showed clinical benefit in this trial. Vitamin E did not delay cognitive or memory deterioration. The study had a high drop-out rate, which may have affected the results. A second limitation was the small number of women who took part.

Dr Eric Karran, director of research at Alzheimer’s Research UK, said the trial suggested vitamin E may modestly slow the decline in day-to-day functioning in people with mild to moderate Alzheimer’s, but without having an effect on memory and thinking skills. He said it was too early to recommend vitamin E as a treatment.


6 January: Recoding GP records may improve dementia diagnosis

A new UK study shows that a review of patient records by GPs could significantly increase the number of dementia diagnoses.

The researchers were led by Dr Sube Banerjee, Professor of Dementia at the University of Sussex. They examined the records of 23 GP practices across 19 London boroughs. The results show that a coding review could increase the UK national diagnosis rate of dementia to 55%. The miscoding of dementia was mainly due to the current coding system or unclear information from health care facilities.

According to the authors, these results demonstrate the potential of a simple primary care coding exercise - requiring no specific training - to increase the dementia identification rate. Implementing this exercise appears to be a simple and effective way to improve recognition rates in primary care.

http://bmjopen.bmj.com/content/3/12/e004023.full

14 January: Pfizer to conduct clinical trial on game platform

Pfizer has announced plans to assess a gaming platform as a biomarker or cognitive endpoint for people at risk of Alzheimer’s disease.

“Project Evo” is a product of Akili, a US-based company that develops mobile video games as potential therapeutics for neurological disorders or as tools for remote monitoring of core cognition. The platform is designed to quantify and improve the ability of individuals to deal with cognitive interference affecting their ability to pay attention, plan or make decisions.

The trial will involve some 100 healthy elderly subjects, some of whose brains show the presence of amyloid, as determined by Positron Emission Tomography (PET) imaging. The participants’ cognitive abilities will be measured at baseline and over the course of one month’s game play.

http://newspharmatimes.com/article/14-01-14/Pfizer_to_assess_Akili_game_as_Alzheimer’s_biomarker.aspx

21 January: Redesigned yeast protein unravels misfolded proteins

A new study shows how the Hsp104 yeast protein may provide a way to “unravel” the misfolded proteins that are associated with neurodegenerative diseases. Hsp104 is known as a chaperone protein, as it assists in the development and functioning of other protein structures. It is not naturally present in humans, but scientists developed a re-programmed version that suppresses the toxicity associated with misfolding.

The researchers were led Dr James Shorter, Associate Professor of Biochemistry and Biophysics at the Perelman School of Medicine, University of Pennsylvania. They had already determined that the natural version of Hsp104 is active against neurodegenerative proteins.

In this study, they sought to increase that activity by conducting a screening of numerous Hsp104 variants. Dr Shorter said: "Luckily several variants came out of our screen that could suppress the toxicity associated with misfolded and clumped FUS, TDP-43 and alpha-synuclein disease proteins in yeast, while also enhancing proper protein function."

The study was carried out on worm models and the researchers plan to move on to mouse models. Dr Shorter pointed out that this is not yet a cure or practical treatment for neurodegenerative disease, but a major first step toward that ultimate goal. "We’ve defined that it is possible to achieve clot-busting activity in a simple model system. The challenge is to move it forward from there."

www.sciencedirect.com/science/article/pii/S0092867413015432

22 January: EnVivo announces Phase 3 clinical trial for encenicline

EnVivo Pharmaceuticals recently announced the launch of COGNIITIV AD, a Phase 3 clinical trial to evaluate encenicline-hydrochloride (EVP-6124) in people with Alzheimer’s disease.

The trial programme consists of two randomized, double-blind, placebo-controlled trials, with approximately 1,600 patients at sites in the United States and other countries. Patients will be randomized to receive one of two doses of encenicline once daily or placebo.

In addition to assessing the safety and tolerability of encenicline, efficacy will be evaluated by two co-primary endpoints. These are the Alzheimer’s Disease Assessment Scale-Cognitive Subscale (ADAS-Cog) as a measure of cognition and the Clinical Dementia Rating Sum of Boxes (CDR-SB) as a measure of clinical function.

EnVivo is also testing encenicline in people with cognitive impairment associated with schizophrenia.

www.clinicaltrial.gov/ct2/show/NCT02004392?term=EVP-6124&rank=4
www.clinicaltrial.gov/ct2/show/NCT00766363?term=EVP-6124&rank=1

23 January: EMA approves rivastigmine patch

On 23 January, the European Medicines Agency’s Committee for Medicinal Products for Human Use (CHMP) adopted a positive opinion, recommending the granting of a marketing authorisation for the medicinal product Rivastigmine in the form of transdermal patches. These
are intended for symptomatic treatment of mild to moderately severe Alzheimer’s dementia. The applicant for this medicinal product is 3M Health Care Limited.

d127

24 January: New global partnership launches call for dementia research

The UK’s Alzheimer’s Society and the Alzheimer’s Drug Discovery Foundation (ADDF) have launched a call for new research projects with potential to speed up the development of treatments for Alzheimer’s disease and other types of dementia.

Together, the organisations are offering up to EUR 1.1 million for each project that either tests promising drugs in people in clinical trials or in preclinical animal models, advancing them towards testing in humans. The call is open for research looking at all forms of dementia including Alzheimer’s disease.

Research proposals will be accepted until 5 June 5, 2014.

www.alzheimers.org.uk/drugdiscoverycall

30 January: Johnson & Johnson will share clinical trial data

Johnson & Johnson (J&J) has announced an agreement to share data from clinical trials with the Yale School of Medicine’s Open Data Access Project (YODA). Under this agreement, YODA will serve as an independent body to review requests from investigators and physicians seeking access to clinical trial data from Janssen (a J&J company) and will make decisions on sharing data.

Jane Griffiths, Company Group Chairman, Janssen Europe, Middle East & Africa, said: “We support the overall PHRMA-EFPIA principles of greater clinical trial data transparency and sharing, including registration and disclosure of clinical trial results in external registries, publication of results in peer reviewed journals, and sharing of Clinical Study Reports (CSRs).

“We believe it sets a new industry standard in ensuring all requests for clinical data are reviewed in a systematic and objective way that protects patient privacy and confidentiality.”

http://medicine.yale.edu/core/projects/yodap/index.aspx

Dementia in Society

26 November: Triple Oscar winner Saul Zaentz passes away

Independent film producer and music executive Saul Zaentz passed away on 5 January in San Francisco. He was 92 years old and, according to his nephew, died due to complications from Alzheimer’s disease.


In recognition of the quality of his work and career achievements, Mr. Zaentz was also awarded the prestigious Irving G. Thalberg Award (1997) from the Academy of Motion Picture Arts and Sciences, the Producers Guild of America's Motion Picture Producer of the Year Award (1997) and in 2003 received a BAFTA (British Academy of Film and Television Arts) Academy Fellowship.

Other internationally acclaimed films produced by Zaentz include “The Mosquito Coast”, “The unbearable lightness of being” and “At play in the fields of the Lord”. His last and most recently produced movie was “Goya’s Ghosts” (2006).

13 January 2014: Inspector Wallander pursues his last case

Inspector Karl Wallander, the Swedish police investigator from the popular books and TV series, announced in a recent episode that he is retiring because he is developing symptoms of Alzheimer’s disease.

In the episode “Farewell”, the veteran officer displays various signs of memory loss, such as forgetting how to make a tie knot and forgetting to feed his dog. He continually checks to see that the kitchen hot plates are off and omits to tie his shoelaces before going to work. His colleagues try to cover when he becomes confused during an interrogation, but inevitably he admits that he can no longer function as an investigator.

Karl Wallander was created by writer Henning Mankell. He is the main character of several mystery novels set in and around the town of Ystad in southern Sweden. Wallander has been portrayed on screen by the actors Rolf Lassgård, Krister Henriksson (pictured) and Kenneth Branagh.

21 January: Alzheimer Nederland conducts awareness campaign

Alzheimer Nederland has launched a new Facebook campaign to promote dementia awareness among younger people. The idea is based on one of your Facebook friends tagging you in a manipulated photo.

In this photo - which will appear on your timeline - it appears that you were present at a non-existent event. You will see yourself attending an event, but you know you weren’t there at all. Nevertheless...there you are in the photo.

In this very contemporary way, people get to experience for themselves the confusion that Alzheimer’s patients face on a daily basis, and thus the impact that the disease can have. To make the campaign more credible, Alzheimer Nederland is collaborating with existing event organisations. The video link below provides an explanation, including English subtitles.

www.youtube.com/watch?v=H967wH153PU
25 January: Documentary on music and memory wins Sundance award

The 2014 Sundance film festival in Utah (USA) announced its official category winners on 25 January. Among them was the feature-length documentary film “Alive Inside: A Story of Music & Memory”, which received the Audience Award in the category of U.S. Documentary.

“Alive Inside” follows the efforts of social worker Dan Cohen - founder of the non-profit organisation Music and Memory - to demonstrate the therapeutic benefits of music for people with dementia. The documentary centres around nursing home patients in the advanced stages of dementia, many of whom do not normally engage much with the world around them.

Cohen meets with caregivers, families and friends to create a playlist of favourite songs and then plays these songs to the patient. The film shows patients begin to talk, smile, sing and sometimes dance. It seems that the effect of the music continues for a short time after listening. Footage of one particular patient, Henry, shows that when his headphones are removed and he is asked questions concerning his favourite music, he is able to respond confidently and with excitement about his preferences. He recalls lyrics, singers and song titles and is able to elaborate quite eloquently about his emotions concerning music and what it represents to him.

Professor Oliver Sacks of the neurology department at the NYU School of Medicine comments: “He has been restored to himself. He has remembered who he is. He has reacquired his identity for a while, through the power of music.”

Cohen said that, while the use of music is certainly not a cure, “We hope that our film will inspire and educate...and create a grassroots demand for this kind of low-cost treatment, which could help not only patients but also caregivers across the globe”.

Peggy Woolley in radio drama “The Archers” since the show began in 1950, has been honoured with a Lifetime Achievement award. Amid praise for the Archers’ long-running Alzheimer’s disease storyline, the actress received the award at the BBC Audio Drama Awards ceremony, at Broadcasting House in London on 26 January.

The plot, which saw Peggy struggling to come to terms with her husband’s dementia, resonated with millions of listeners, and has helped bring the disease into the spotlight in the UK.

Arnold Peters, the actor who played her husband, Jack suffered from dementia himself and Spencer’s real-life husband Roger lived with Alzheimer’s disease for five years before a fatal stroke in 2001.

The actress said: “I am absolutely thrilled and overwhelmed to receive this. Alzheimer’s disease used to be swept under the carpet, and charities say this storyline has made an enormous difference in helping people understand more.”

New Publications & Resources

9 December: JPND releases report on longitudinal cohort studies

A JPND Action Group has published a report that brings together, for the first time, the wealth of cohort opportunities for neurodegeneration research across the JPND countries.

The report is part of an ongoing study of potential actions for both disease-based and population-based longitudinal cohort studies. It is intended to identify areas that can be expanded or better exploited and also identify new activities.

The new report spans general population-based, targeted (preclinical) and disease-focused cohorts, including the following:

- analyses of longitudinal and disease cohort studies
- an analysis of imaging studies
- a cohort reference list with web links

Based on the conclusions of the report (see link below), the JPND Management Board will announce priorities for action in 2014.

http://www.neurodegenerationresearch.eu/initiatives/jpnd-alignment-actions/longitudinal-cohorts

17 January 2014: NHS analysis suggests over-prescription of AD medicines

A new analysis of 2012 NHS data shows that prescription rates of donepezil, galantamine, rivastigmine and memantine were 50% higher than expected when compared with AD prevalence rates.

The data was published as part of an analysis of the use of NICE-approved medicines by the Health and Social Care Information Centre. The analysis takes into account a 2011 NICE recommendation that people with mild forms of Alzheimer’s disease be prescribed dementia drugs.

Professor Steve Illife, a GP and professor of primary care for older people at University College London, said the study was based on old estimates of dementia prevalence: “The authors of the report have used Alzheimer’s Society estimates from six years ago, and the situation is different now. My guess is that two-thirds to three-quarters of people with Alzheimer’s disease are known, and that under-diagnosis occurs more often with vascular dementia.
"Then there is the tendency to describe some people with dementia as "mixed type" with Alzheimer’s features, and of course some individuals with apparent Lewy body dementia also receive cholinesterase inhibitors."

NICE - the National Institute for Health and Clinical Excellence - is an independent agency that develops standards and performance metrics for those providing commissioning health, public health and social care services.


17 January: Joseph Rowntree Foundation publishes "Dementia Friendly Yorkshire"

On 17 January, the Joseph Rowntree Foundation released a publication bringing together twenty short case-studies of dementia-friendly projects taking place in communities across Yorkshire, where the foundation is based. Featured project locations included various places of religious worship, shops and cafes, as well as public services such as transport, museums, hospitals, schools, libraries and sports centres, among others.

Project Leader, Philly Hare said “I am delighted that the idea of the dementia-friendly community is taking off around the UK. Five years ago the concept of the dementia-friendly community was almost unheard of. Things started to move more quickly when the Prime Minister launched his Challenge in March 2012, and there are now over 50 communities across the UK on the way to becoming dementia-friendly. I hope we can all draw inspiration from these case studies, and each play our role in making our own community or organisation a welcoming and supportive place for people with dementia.”

“Dementia Friendly Yorkshire” is available in electronic format or in hard copy.

Contact Alzheimer Europe:
Alzheimer Europe, 14 rue Dicks, L-1417, Luxembourg info@alzheimer-europe.org, www.alzheimer-europe.org

Alzheimer Europe Board
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Future Conferences

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<tr>
<td>20-22 March</td>
<td>58th Annual meeting of the German society for clinical neurophysiology and functional imaging (DIGN), <a href="http://www.dgnikongress.de">www.dgnikongress.de</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>20-23 March</td>
<td>30th International Congress of Clinical Neurophysiology of the IFCN (CCN), <a href="http://www.iccn2014.de">www.iccn2014.de</a></td>
<td>Berlin, Germany</td>
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<td>8-11 May</td>
<td>8th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtcmed.com/cony2014/">www.comtcmed.com/cony2014/</a></td>
<td>Berlin, Germany</td>
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<td>16-17 May</td>
<td>The Alzheimer’s Show, <a href="http://alzheimershow.co.uk/">http://alzheimershow.co.uk/</a></td>
<td>London, UK</td>
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<td>31 May-3 June</td>
<td>EFNS-ENS joint Congress of European Neurology, <a href="http://www.jointcongressofeuropeannurology.org">http://www.jointcongressofeuropeannurology.org</a></td>
<td>Istanbul, Turkey</td>
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<tr>
<td>11-14 June</td>
<td>12ème Réunion francophone sur la maladie d’Alzheimer et les syndromes apparentés</td>
<td>Montpellier, France</td>
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<td>26-27 June</td>
<td>International Dementia Conference, &quot;Risky Business 2 – this time it's personal&quot;, <a href="http://www.dementiaconference.com/call-for-papers">http://www.dementiaconference.com/call-for-papers</a></td>
<td>Sydney, Australia</td>
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<td>3-9 July</td>
<td>5th EFNS Forum of Neuroscience, <a href="http://forum.fens.org/2014">http://forum.fens.org/2014</a></td>
<td>Milan, Italy</td>
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<td>20-22 October</td>
<td>24th Alzheimer Europe Conference &quot;Dignity and autonomy in dementia&quot;, <a href="http://www.alzheimer-europe.org/Conferences">www.alzheimer-europe.org/Conferences</a></td>
<td>Glasgow, United Kingdom</td>
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<tr>
<td>23-25 October</td>
<td>9th International Conference on Frontotemporal Dementias, <a href="http://www.ucdpd.ca">www.ucdpd.ca</a></td>
<td>Vancouver, Canada</td>
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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.