



# NEWSLETTER

June 2014

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## Editorial



Welcome!

This month has seen the AE team travelling all over Europe for a variety of meetings

including a series of workshops and meetings for EU projects we are involved in, such as EMIF, AFE Innovnet, NILVAD and IMPACT. We were also represented in Geneva at the "Alzheimer University" of Alzheimer's Disease International.

We also participated in two high level policy events in June with Annette attending the Global Dementia Legacy Event in London and Alex participating in the first international dementia conference organised by the Scottish Government. The importance of these events was aptly summarised by Geoff Huggins, Scotland's Acting Director of Health and Social Care Integration saying that "dementia is too big for any one nation". It is heartening to see the international community following the example of the European Union in promoting greater collaboration on dementia.

Human rights, in particular those of older people, have been another hot topic, with World Elder Abuse Awareness Day being observed on 15 June. UN Secretary-General Ban Ki-Moon called for more effective prevention strategies and further interest has been gathering for a possible UN convention on the human rights of older people.

On the EU front, the European Medicines Agency has agreed a modified clinical trial data policy, in response to questions from the EU Ombudsman regarding a previous draft. We will also shortly be reaching out to all elected and re-elected Members of the European Parliament to discuss

their involvement in our European Alzheimer's Alliance. We were very grateful to Marina Yannakoudakis who contacted us to discuss a continuing collaboration with AE, despite not having been re-elected. We look forward to continuing working with her.

In the UK, the "Dementia Friends" programme has now been extended to Scotland thanks to funding from Alzheimer Scotland. As a new and very welcome development in this area, the UK Parliament pledged to become the first dementia-friendly parliament in the world!

In the scientific field, a form of cocoa extract has been in the news this month as a possible dietary supplement to help ward off dementia, further studies pending. A new therapeutic target may also have been found in the form of a compound that is claimed to prevent blood clots in the brain.

We are enjoying a warm, Luxembourgish summer, preparing for a series of meetings here in July and for our Conference in Glasgow in October. The early bird fee is no longer available, but you can register with the normal fee via our website. The detailed conference programme is now available on our website too, in the conference section. Judging by the registrations so far, we are looking at record numbers of attendees this year.

Issue 17 of our DIE magazine just come out and is available for purchase, also on our website in the publications section.

Finally, our friends at the Bradford Dementia group are looking for a Head of Practice Development and Training. Applications for the position close on 15 July.

Wishing you a fantastic summer!

**Jean Georges**  
Executive Director



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## Alzheimer Europe

### 2 June: AE issues call for EWGPWD candidates



On 2 June a call was issued to all of Alzheimer Europe's member organisations to nominate new members for its European Working Group of People with Dementia (EWGPWD) as well as candidates for the next Board.

The working group came into being in 2012 and the current Board was elected in October 2012 to serve for two years. The group's next meeting will be held in October, just prior to AE's AGM and 24<sup>th</sup> annual conference in Glasgow, Scotland and will include the election of the new Board. The new Chairperson of the EWGPWD will also sit on the Board of Alzheimer Europe.

### 12 June: Former MEP Marina Yannakoudakis meets with AE to discuss continuing collaboration



On 12 June 2014 Alzheimer Europe's Annette Dumas met former MEP Marina Yannakoudakis in Brussels to discuss future collaboration on dementia issues.

Ms Yannakoudakis has been a keen and dedicated dementia advocate as member and Vice-Chair of the European Alzheimer's Alliance in the European Parliament. She wishes to continue supporting Alzheimer Europe in keeping dementia as a European priority and dedicate some of her time to help the organisation.

The Global Fight against Dementia initiated by UK Prime Minister D. Cameron has been identified as an area where we could work together.

### 27 June: EWGPWD's Daphne Wallace reports on activities in UK this year



Since this time last year a lot of things have happened in UK with regards to dementia. In December there was a G8 Summit Meeting and dementia was a topic that came up for discussion.

At the end of February 2014 David Cameron, Prime Minister of the UK announced the plans in UK to tackle the issues identified at the G8 meeting. He announced a £90 million package to improve dementia diagnosis and care. This was intended to help solve a problem with diagnosis in UK: diagnosis can take up to 25 weeks (or more) for some while other people receive a diagnosis in 6 weeks.

David Cameron also announced the appointment of a World Dementia Envoy to raise funds for research towards a cure (Dr Dennis Gillings, CBE, PH.D.). This followed a landmark agreement by the G8 countries following the summit in London in December 2013.

The marked difference in rate of diagnosis by GPs between France and UK (more GPs than relatives initiate diagnosis in France, the opposite is true in UK) has been looked at by the Health Secretary who visited France in February this year to learn how this has been achieved.

Throughout the UK in the last 6 months an increasing number of people from all walks of life in UK have become "Dementia Friends". This means that they have had some basic instruction with regard to dementia and its effects on day to day life for those with the diagnosis and their carers. Basic knowledge includes the fact that not all dementias are the same, both in their effects and the problems they cause. At the same time four major businesses in UK have pledged all staff to become Dementia Friends and ensured understanding in dealing with any problems that arise. It is hoped that over the next 12 months an increasing number will become sensitive in this way to the problems of those with dementia and their carers over day to day things and how to make a difference.

As an Ambassador for the Society and a person with dementia I am always glad to hear of these developments and pleased that now people with dementia are given a voice and can influence how things can be improved.

### 30 June: Dementia in Europe magazine issue 17 published



Alzheimer Europe's Dementia in Europe magazine, issue 17 was published on 30 June and is available on our website.

This issue contains articles on:

- IMI's Michel Goldman at Alzheimer Europe's lunch debate.
- MEP Marina Yannakoudakis exploring the effects of EU initiatives on Alzheimer's disease.
- AE's plans to re-launch the EAA and the Europe-wide pre-election campaigns that took place to recruit the new parliamentary members.
- A new Care Pathways research project.
- AETIONOMY project coordinators outlining the aims of a new IMI research project.
- The EWGPWD preparing for the 2014 AE Conference.
- AE launching a clinical trial database.
- Switzerland's new national dementia strategy.
- Italy preparing for its EU Presidency.
- Greece working towards a new national dementia strategy.
- Finland introducing economic austerity measures.
- The AAL JP programme harnessing ICT to improve the quality of life of people with dementia.
- AMPA Monaco providing care for all people with dementia.
- Jean-Pierre Frognet describing his recent trial run of a day care centre.
- A Czech soap opera portraying dementia in its storyline.

The price of the magazine, including postage is EUR 5.20.

[www.alzheimer-europe.org/Publications/Dementia-in-Europe-Magazines](http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Magazines)

### 30 June: 24<sup>th</sup> Annual AE Conference programme is available online


Alzheimer Europe's 24<sup>th</sup> annual conference is to be held this year in Glasgow from 20 to 22 October. The detailed programme for the full conference is now available on the AE website:

[www.alzheimer-europe.org/Conferences/2014-Glasgow/Detailed-Programme-and-abstracts](http://www.alzheimer-europe.org/Conferences/2014-Glasgow/Detailed-Programme-and-abstracts)



## EU Projects

### 27 May: NILVAD partners attend Brain Health Awareness Day



On 27 May, a Brain Health Awareness Day was organised at St James's Hospital in Dublin, Ireland. This event was aimed at members of the general public who were visiting the hospital.

A stand in the foyer contained information and leaflets about how to maintain a healthy brain and promoted the "Hello Brain" campaign – see link below. The stand also displayed short "bite-size" animated films about memory loss and brain health, which can be viewed online at <http://freedemliving.com/>.

The stand was manned by members of the NILVAD team, as well as research assistants from Trinity College Institute for Neuroscience. During the day, the staff spoke to members of the public about the various research projects underway within Trinity College and St James's Hospital in the field of brain health, for example Destress, Relate, NEIL, Dempath, and NILVAD, thereby raising awareness of the study among a larger demographic of people within Dublin.

More information and photos are available on the NILVAD website.

[www.nilvad.eu/dissemination/news](http://www.nilvad.eu/dissemination/news)  
[www.tcd.ie/Neuroscience/neil/interventions/hello-brain.php](http://www.tcd.ie/Neuroscience/neil/interventions/hello-brain.php)

### 3 June: EMA-PCWP-HCPWP organise joint meeting

On 3<sup>rd</sup> June, the European Medicines Agency (EMA) Human Scientific Committees' Working Parties with Patients' and Consumers' Organisations (PCWP) and Healthcare Professionals' Organisations (HCPWP) held a joint meeting in London.

An update on the Agency's policy on publication of clinical trial data and an overview of the new clinical trials regulation (Regulation EU No.536/2014), were provided to meeting delegates. In addition, four National Medicines Agencies (MHRA, UK; ASNM, France; MPA, Sweden; MEB, Netherlands) presented their experiences of involving patients and healthcare professionals in regulatory decisions.

Other topics discussed during the day included a study on off-label use of medicines that the European Commission will be conducting in 2014, an update on Risk

Management Plan summaries, and information about the new headquarters of the EMA. Ana Diaz attended for AE.


### 4 June: IMPACT meeting takes place in Spain

On 4 June, an IMPACT project meeting was held in Lleida, Spain. The meeting consisted mainly of progress reports by the work package leaders and discussing the dissemination of the findings as well as the final conference (Towards integration of palliative care in an age-friendly EU) on 15 October 2014 in Brussels where they will present their findings. This is by invitation only.

The overall aim of the IMPACT project is to develop optimal improvement strategies to improve the organisation of palliative cancer and dementia care in Europe and to study factors influencing the effectiveness of the strategies. Dianne Gove was there, from AE.

If you are interested in attending the October conference, please see: [www.palliativecare2020.eu](http://www.palliativecare2020.eu)

### 11 June: EFPIA delivers webinar on 'Patient Understanding of Benefit Risk'



On 11 June a webinar was delivered by the European Federation of Pharmaceutical Industries and Associations (EFPIA) on 'Patient Understanding of Benefit Risk'. This webinar was organised to follow-up on discussions that took place at the last EFPIA Think Tank. Because the views of patients on the benefit and risk of a medicine can differ from those of other stakeholders, the webinar sought to explore how benefit risk preferences should be weighed by patients and practitioners when evaluating new accelerated pathways.

The webinar was moderated by Alastair Kent (Genetic Alliance UK). Some presentations were made by Andrea Beyer (European Medicines Agency), Yann Le Cam (EURORDIS), Pat Furlong (Parent Project Muscular Dystrophy) and Donald Singer (European Association of Clinical Pharmacology and Therapeutics).

The converging views were that patients with a specific disease are well-placed to state their expectations from a treatment, their appreciation of the benefits and acceptance of the risks that can outweigh the plight of having a progressive, debilitating and sometimes deadly disease. There was a common agreement that both EMA and the FDA were receptive to the patients' perspectives and valued their input. Annette Dumas participated.

### 17 June: EMIF holds 2<sup>nd</sup> Business Modelling Workshop



The EMIF partners held their second business modelling workshop on 17 June in Barcelona. The delegates continued their work to study different sustainability scenarios for the long-term maintenance and development of the service. The event was chaired by EMIF Coordinator Bart Vannieuwenhuysse and attended by some 30 delegates. The next business modelling workshop will take place in November 2014.

Alex Teligadas represented AE at the meeting.

## 25 June: AFE INNOVNET holds webinar on age-friendly communities



On 25 June, the AFE INNOVNET project partners broadcast the second of a series of webinars that present ongoing project work.

From the onset of the financial and economic crisis, national governments across Europe have adopted measures to curb its effects. Reduced budgetary income in contrast with aggravated expenses due to citizen's demands for specific public services, have led to significant constraints in local and regional finances. Local and regional authorities only had a limited number of possible responses to make savings without reducing services.

This webinar was dedicated to local and regional authorities that have seen the current situation as an opportunity to implement age-friendly initiatives in order to address some shortfalls.

- Valencia province (Spain): Irene Monsonis Payá, Project Manager at Polibienestar, presented "Alzheimer: intergenerational springboard of social and professional inclusion".
- Fredericia municipality (Denmark): Helle Juhl, Project Manager at the local Health and Care Department, showed "Life Long Living".
- Udine municipality (Italy): Mayor Furio Honsell described the many activities undertaken to earn the city its "Dementia Friendly Community" status.
- Bulgaria: Dimitar Pehlivanov, International Cooperation Expert at the National Association of Municipalities in Bulgaria, spoke about the challenges but also the rewards of creating age-friendly communities all across the country.

All of these presentations will soon be available on the project website. The next AFE INNOVNET webinar will take place on 22 September.

Alex Teligadas participated in the webinar.

[www.afeinnovnet.eu](http://www.afeinnovnet.eu)

## 25 June: JPND palliative care expert workshop takes place in Amsterdam

On 25 June a JPND palliative care expert workshop took place in Amsterdam, Netherlands. JPND is the EU Joint Programme on Neurodegenerative Disease Research.

Jenny van der Steen provided an overview of the EAPC White Paper, which AE was involved in developing and David Oliver gave a lecture on palliative care for patients with progressive neurological diseases.

The organisers emphasised that the focus of the workshop was on palliative care research priorities for people with neurodegenerative diseases, not just dementia. Participants split up into two groups to discuss research priority areas and the development of proposed actions and these were presented at the end of the meeting.

JPND will consider these ideas in relation to its future research priorities for palliative care of people with neurodegenerative diseases and it is therefore not known at this point which they will take on board. Some of the points raised included: the need for multi-methods approaches, systematic reviews, Delphi studies and to recognise public, patient, policy and existing research evidence, the need for qualitative studies which should be evaluated according to relevant criteria rather than on the basis of criteria developed for quantitative studies which are inappropriate.

The White Paper was seen as a starting point for discussion. There is a need to increase research funding (especially for social care) and to target specific conditions; there is a need to break down barriers/resistance to the implementation of research priorities and to incentivise patient involvement and interdisciplinary research; protection of research subjects should be balanced with respect for autonomy and with the equal right to participate in research despite cognitive impairment.

Dianne Gove took part in the workshop, representing AE.



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## Alzheimer Europe Networking

On 3 June (London, UK) Ana attended the European Medicines Agency (EMA) Human Scientific Committees' Working Parties with Patients' and Consumers' Organisations (PCWP) and Healthcare Professionals' Organisations (HCPWP) joint meeting.

On 4 June (Lleida, Spain) Dianne took part in the IMPACT project meeting.

On 3 and 4 June (Stockholm, Sweden) Jean attended an Advisory Board meeting of Lilly.

On 6 June (Erl Wood, UK) Jean attended a working group meeting of Lilly.

On 9-10 June (Edinburgh, UK) Alex attended the Scottish government's first International Dementia Conference.

On 10 June (Brussels, Belgium) Annette attended the EPF Public Affairs meeting.

On 11 June 2014 (Brussels, Belgium) Annette participated in the webinar organised by EFPIA on 'Patient Understanding of Benefit Risk'.

On 12 June 2014 (Brussels, Belgium) Annette met Marina Yannakoudakis to discuss future collaboration on dementia issues.

On 17 June (Barcelona, Spain) Alex attended the 2nd EMIF Business Modelling Workshop.

On 18 June (Brussels, Belgium) Dianne attended the conference "Frailty in old age, identifying priorities for EU policy", organised by the Directorate General for Health and Consumers (DG SANCO)

On 18-19 June (Glasgow, UK) Gwladys met with conference suppliers.

On 19 June 2014 (London, UK), Annette attended the first Global Dementia Legacy Event organised by the UK Department of Health.

On 23-26 June 2014 (Geneva, Switzerland), Annette participated in ADI Alzheimer University. This year's theme was "Campaigning for change".

On 25 June (Amsterdam, the Netherlands) Dianne took part in the JPND palliative care expert workshop.

On 27 June (Copenhagen, Denmark) Jean participated in a patient advocacy meeting organised by Lundbeck.

## EU Developments

### 31 May: EPF calls for volunteers for working group

Following the European Patients' Forum (EPF) AGM on 12 May, a call has been made for volunteers to join a working group "on what constitutes a bona fide patients' organisation – setting out the basic objectives of the group". Meetings will be held by telephone.

If interested in joining or for more information, please contact [camille.bullot@eu-patient.eu](mailto:camille.bullot@eu-patient.eu)

### 12 June: EMA agrees to make its new policy on clinical trial data more user-friendly


On 12 June the European Medicines Agency (EMA) agreed its new policy on publication of clinical trial data, together with amendments proposed by Executive Director Guido Rasi. An earlier incarnation of the policy had led to questions and concerns from the European Ombudsman, so Mr Rasi suggested some modifications to clarify the EMA's intentions with this new policy and to make it more "user-friendly".

The EMA said that the new policy "will not only allow the Agency to proactively publish clinical trial data that are submitted as part of marketing authorisation applications, but also give the possibility to download, save and print the trial data for academic and non-commercial research purposes."

Having been finalised with a view to its adoption by EMA's Board through written procedure by mid-July 2014, the new policy will be effective from 1 October 2014.

[www.ema.europa.eu/ema/index.jsp?curl=pages/news\\_and\\_events/news/2014/06/news\\_detail\\_002124.jsp&mid=WC0b01ac058004d5c1](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2014/06/news_detail_002124.jsp&mid=WC0b01ac058004d5c1)

### 18 June: DG SANCO organises "frailty" conference

 On 18 June in Brussels, Belgium a conference on "Frailty in old age, identifying priorities for EU policy" was organised by the Directorate General for Health and Consumers (DG SANCO).

The highlights of the conference were two presentations by Kenneth Rockwood and Bruno Vellas on an integrated approach to prevent and treat frailty.

Prof. Kenneth Rockwood defined frailty as an elevated state of risk compared to people of the same age and highlighted that frailty is not necessarily disability. He described two approaches: 1. frailty as a syndrome (based on people experiencing a constellation of signs and symptoms) and 2. frailty as a state (based on the accumulation of deficits - 'the more things individuals have wrong with them, the higher the likelihood they will be frail'). He provided examples of different large scales studies whereby frailty indices comprising different

variables and applied to different populations increase with age and correlate strongly with mortality. His conclusion was that frail older people are like the canaries in the coal mines (i.e. may be the first indicator that something is wrong), emphasising in relation to frailty policy the need to make routine care less hazardous, less ageist and more person centred (i.e. rather than limiting certain care and treatment on the grounds that someone is too frail).

Prof. Bruno Vellas followed on with a speech on the same topic and he emphasised hospitalisation-associated disability, namely overuse of diapers and transurethral urinary catheters, excessive bed rest and lack of assistance with mobility.

Subsequent speakers emphasised that frailty is a social and medical condition but not inevitable, there is a need to take decisive action, there are implications for employment and public finances and the need to scale up innovative solutions to address frailty, it is important to think what can be done for frail older people before starting to screen, there is a need for awareness raising amongst professionals and the general public and if screening is carried out, who should do it. Dianne Gove attended for AE.



### 23 June: CoE, EC and AGE Platform hold joint event on Human rights of older persons



Older persons in need of care and assistance are particularly vulnerable to human rights breaches. They are more exposed to the risk of elder abuse because of their specific situation of

social isolation, health problems, frailty, or financial limitations. On the occasion of the World Awareness Day against elder abuse, AGE Platform Europe together with the Council of Europe and the European Commission Directorate-General on Employment and Social Affairs co-organised an event on 'Human Rights of Older persons: Who cares?' focused on the rights of older persons in need of care and assistance. The event aimed at discussing the human rights approach applied to the field of care for older persons by promoting firstly, the Council of Europe Recommendation on the promotion of rights of older persons, and secondly, the recently adopted Report on long-term care, prepared by the Social Protection Committee Working Group on Ageing.

The event started with an introduction from Ambassador Torbjørn Frøysnes, Head of the Brussels Office of the Council of Europe to the EU, followed by an introduction

of both initiatives of the Council of Europe (Mathias Kloth) and of the Social Protection Committee working group on Ageing (Niclas Jacobson). A panel discussion gathering representatives from the Human rights field (Jan Jarab from OCHCR), from the care field (Sarah Mahon from the Health Service Executive in Ireland and Geert Roggeman from the European Social Network) and from older persons organisations (Liz Mestheneos, 50+ Hellas in Greece) complemented the presentations of the initiatives.

The event hoped to raise awareness regarding the rights of older persons and discuss how the implementation of these rights can be taken into account into the Commission's work on long-term care and the fight against elder abuse. Testimonies from the panelists and from the floor emphasised the challenges and opportunities of applying a rights-based approach in the care field, especially in a period of economic and social crisis. A lot was said on the protection of older people's rights in international instruments, existing gaps and the need for more knowledge on elder abuse and on the rights of older people at a European level. The discussions also focused on how to balance an objective of cost-efficient policies with the need to ensure high-quality care services in Europe as well as respecting older persons' fundamental rights and dignity. It looked at the importance of taking the needs of professional carers and migrant workers into account. The importance of empowering older persons needing care and of empowering their families was discussed, as was the means for achieving this empowerment through the use of European and national policies as catalysts, thus enforcing human rights and making more sustainable care systems a reality. The European Charter for the rights and responsibilities for older people in need of care and assistance is an example of European initiatives helping to build some steps on that direction.

A more detailed report of the event and of the expert workshop organised in the afternoon will be soon available on the AGE website:

[www.age-platform.eu/age-work/age-policy-work/dignified-ageing/age-work/2143-save-the-date-human-rights-for-older-persons-in-europe-who-cares](http://www.age-platform.eu/age-work/age-policy-work/dignified-ageing/age-work/2143-save-the-date-human-rights-for-older-persons-in-europe-who-cares).

## Members' News

### 15 May: FAAS elects new chairman



The national Alzheimer's association of Iceland, FAAS appointed a new Chairman, Árni Sveinsson on 15 May.

Mr Sveinsson has been working in Iceland's health sector since 1980. During this time he spent 31 years as CEO of St Joseph's Hospital in the Icelandic port city of Hafnarfjörður. In 2006 he also became CEO of a nursing home and began to take an active interest in Alzheimer's disease and other dementias. In 2010, his father was diagnosed with Lewy Body dementia.

He has been on the Board of FAAS for one year already and when he was asked to run for the position of Chairman earlier this year, he jumped at the chance.

Mr Sveinsson is 61 years old, married with four children (all girls, all now grown up) and has a degree from the Commercial College of Iceland. In 2008 he took an AMP (Advanced Management Program) at the University of Reykjavík, Iceland and the IECE, Barcelona, Spain.

He is very much looking forward to this new challenge at the helm of FAAS.

### 26 May: Polish Alzheimer Association launches new website

The Polish Alzheimer Association, Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimerą launched its new website in May:



[www.alzheimer-waw.pl/](http://www.alzheimer-waw.pl/)

### 2 June: Dementia Friends programme stretches north with support of Alzheimer Scotland



Just prior to Scotland's Dementia Awareness Week from 2 to 8 June, Alzheimer Scotland confirmed that the Dementia Friends scheme, which has been so successful in England, would be launched north of the border.

Henry Simmons, Chief Executive, Alzheimer Scotland explained that Dementia Friends training would be delivered both locally by Alzheimer Scotland Dementia Advisors and online. It is to be managed at national level through a dedicated Dementia Friends Programme Manager.

"Dementia Friends will tie closely with the already outstanding work being carried out locally and nationally in Scotland; linking with our growing network of Alzheimer Scotland Dementia Resource Centres and with our development of Dementia Friendly Communities. Motherwell, Scotland's first Dementia Friendly Town, has already influenced practice in Norway and Sweden and recently won a European Foundations' Initiative on Dementia award for exemplary practice." The Dementia Friends programme in Scotland is being funded by Alzheimer Scotland.

[www.scottishdementiafriends.org](http://www.scottishdementiafriends.org)

### 6 June: Alzheimer Hellas hosts workshops for children



The Greek Association of Alzheimer's disease has held a series of three workshops over the course of two months within the framework of a project called "Who am I, grandpa?" aimed at children and adolescents. The workshops were designed by three psychologists specialised in the field of dementia who work at the association's daycare centre, to try to help young people understand more about dementia and help them feel less confused if a family member is affected.

As the number of people with dementia increases, more and more children have grandparents or even parents living with dementia. Alzheimer Hellas wanted to give them the opportunity to understand the symptoms, causes and prognosis and also to learn new ways of

interacting with their grandparent or other family member.

Alzheimer Hellas says that parents rarely explain these things to their children, as they don't have the time or worry about not being able to cope with their child's emotions and questions. Moreover, there is a belief in some families that young people should be protected and not come into contact with health issues, which might make them feel sad or scared. Children, therefore, rarely have the opportunity to express their feelings and any questions they might have concerning their loved one.

Prejudices and stereotypes about dementia and about people living with dementia were discussed during the workshops, through the use of group play. The children expressed themselves by making collages and painting, as well as during targeted discussions that took place under the guidance of the psychologists. A fairytale was also used to grab the children's attention and to help them process further information and discussion.

The grandchildren of patients at the daycare centre were invited to the workshops, as well as a random selection of children from the general population. A total of 46 children and young people attended.

The project won the runner-up award in the ADI-MetLife Foundation Awards 2014 at the recent ADI conference in Puerto Rico.

### 15 June: Spanish Alzheimer organisation introduces new blog



Confederacion Espanola de Familiares de Enfermos de Alzheimer (CEAFA) in Spain launched its new blog this June, seeking to increase its online social media presence.

The blog will feature the latest local and international news and opinions in Spanish.

Visitors to the blog are invited to share their thoughts on the issues covered, such as research, pharmacology and the work CEAFA is doing: [www.ceafa.es/alzheimer-blog/](http://www.ceafa.es/alzheimer-blog/)

### 18 June: Alzheimer Society of Ireland advocates more financial support for dementia care



On 18 June the Alzheimer Society of Ireland (ASI) announced that it will be advocating that the Irish government provide more adequate support for community care for people with dementia

and carers. This comes in light of the run up to the Irish Budget 2015

ASI says Ireland's government "is not doing enough for people with dementia living at home and the Budget 2015 must change this. Resourcing community supports and services is critical to support carers to care for longer in the home and to support people with dementia to live well in their communities."

ASI's pre-Budget submission can be found here:

[www.alzheimer.ie/Alzheimer/media/SiteMedia/Fundraising/Camino/2014/PS-BS-web.pdf](http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Fundraising/Camino/2014/PS-BS-web.pdf)

## Policy Watch

### 30 May: World Dementia Envoy releases first monthly newsletter

Recently appointed World Dementia Envoy, Dr Dennis Gillings released his first monthly newsletter on 30 May. The newsletter is available in six different languages.

In this first edition of the newsletter, Dr Gillings talks about his role as envoy and the work of the World Dementia Council, including meetings attended, policies in progress and updates on the status of the Council main aim: to identify a cure or disease modifying therapy by 2025.

[www.dementiachallenge.dh.gov.uk/2014/05/30/newsletter1/](http://www.dementiachallenge.dh.gov.uk/2014/05/30/newsletter1/)

By clicking the link below, you can subscribe to this and other UK Department of Health newsletters and campaign newsfeeds:

<https://public.govdelivery.com/accounts/UKDH/subscriber/new>

### 9 June: Scottish government holds international dementia conference



On 9-10 June, the Scottish government hosted its first international dementia conference in Edinburgh as part of the increasing worldwide collaboration to tackle dementia in all its forms.

The two-day event aimed to inform international delegates about Scotland's approach to improving the quality of care for people with dementia and their carers. Coincidentally, Scottish stakeholders learned about various international activities stemming from the G8 Dementia Summit in December 2013. They also heard about EU actions to support dementia research and care, as well as individual countries' efforts to deal with these burdens. The conference was chaired by Geoff Huggins, Scotland's Acting Director of Health and Social Care Integration, with support from Alzheimer Scotland.

The first day consisted of a series of presentations paired with round table discussions on Scotland's initiatives to improve service performance, re-design and outcomes in three focus areas: diagnosis, post-diagnostic support and care management. The discussions clearly showed that dementia is one of the foremost public health challenges worldwide, with Mr Huggins aptly remarking that "dementia is too big for any one nation." The delegates also agreed on the importance of a timely and accurate diagnosis, as well as access to a range of effective, safe and person-centred services that recognise and promote the human rights of the person with dementia.

On day two, the delegates were greeted by Alex Neil, Scotland's Cabinet Secretary for Health and Wellbeing and former carer of his father, who lived with dementia. Mr

Neil thanked all the participants for their presence, including the international visitors from Ireland, Japan, Luxembourg, New Zealand, South Korea, and the United States. He said that dementia is not just a health problem, but also a societal challenge and affirmed that "Scotland aims to be a beacon of best practices for caring for people with dementia."

The programme continued with three panel sessions that focused on "Dementia in Scotland", "European Perspectives" and "Country Perspectives". Each panel member - starting with Ms Agnes Houston, who is living with dementia - gave a short presentation and these were followed by lively discussion periods. These sessions were particularly interesting, as the audience represented a considerable variety of countries, backgrounds and occupations.

Mr Huggins ended the session with a summary of the days' events, including a list of opportunities for future international collaboration. There was unanimous agreement to prioritise this list and to continue working together. Mr Huggins thanked the delegates for their active participation and closed the conference.

Alex Teligadas represented AE at the conference.

### 15 June: World Elder Abuse Awareness day serves as platform to call for new UN convention



It is estimated by the World Health Organisation (WHO) that between four and 6% of the world's older population (defined as persons over 65) is subject to some form of abuse. Since 2006 the International Network for the Prevention of Elder Abuse (INPEA) has named 15 June as World Elder Abuse Awareness Day (WEAAD) and since 2012 it has been officially recognised and observed by the UN.

On 15 June this year, United Nations Secretary-General Ban Ki-moon called upon "governments and all concerned actors to design and carry out more effective prevention strategies and stronger laws and policies to address all aspects of elder abuse".

Help Age International, a global movement for the rights of older people, says that a UN convention on the rights of older people, setting standards that currently do not exist in international human rights law would prohibit such abuse and ensure access to the justice system for victims.

Help Age used World Elder Abuse Awareness Day as a platform to promote its Age Demands Action campaign, which includes a petition aiming to collect 300,000 signatures, of which 204,649 had already been collected at the time of writing.

A UN working group on ageing will meet in July to gather information and evidence on the need for a convention.

[www.undesadspd.org/Ageing/WorldElderAbuseAwarenessDay.aspx](http://www.undesadspd.org/Ageing/WorldElderAbuseAwarenessDay.aspx)  
[www.helpage.org/get-involved/sign-the-ada-petition/](http://www.helpage.org/get-involved/sign-the-ada-petition/)



### 19 June: UK Department of Health hosts Global Dementia Legacy event in London

On 19 June the first Global Dementia Legacy Event organised by the UK Department of Health took place in London. The aim of the meeting was to introduce the work of Dr Dennis Gillings, the newly-appointed World Dementia Envoy and to hear from international experts how to stimulate innovation and coordinate international efforts to attract new sources of finance.

The first session provided an overview of the global challenge of dementia and presented the ambition of the G7 Governments and the work of Dr Gillings. Martin Prince, Kings' College London, gave an insight into the global challenge of dementia. Dementia is more prevalent in the world's richest and most demographically aged countries. The assumption that the age-specific prevalence of dementia would be constant is currently being challenged: dementia has declined in high income countries but has increased in China, where exposure to cardiovascular risk factors has increased. 60% of people with dementia live in low and middle income countries. By 2050, the bulk of the increase is expected to occur in middle income countries where the population is ageing at an unprecedented rate. Prof. Prince also warned that attempts to improve people's health with physical activity, smoking and diabetes prevention campaigns may not necessarily prevent dementia in 90% of the cases and that we needed to be realistic about prevention.

'Care today, cure tomorrow' was illustrated by Dr Shekhar Saxena, WHO. Funding dementia research must be increased. Improved coordination of research, investment tracking will reduce duplication and open access to what is being done, while creating knowledge transfer and ensure effective use of funds. Regarding prevention, the WHO programme on non-communicable diseases prevention should include dementia. The use of information and communication technology are useful tools to use.

Jeremy Hunt, UK Secretary of State for Health, showed some optimism in the sense that illnesses like cholera, polio, TB, cancer and HIV AIDS now have some treatment. Dementia needs to be the next one. This will only be possible if a real big push is given to dementia research, alongside the removal of barriers and the creation of incentives. He reminded the UK engagement in the fight against dementia and the need for new flow in dementia research. If a treatment were available, the onset of dementia could be delayed by 36 months and £ 5 billion could be saved. He mentioned the Medical Research Council, the world's largest group of research that will allow identification of biomarkers, develop more precise selection process for participation in clinical trials and study how existing drugs for other conditions may have an impact on dementia. Alzheimer's Research UK announced on 19 June the funding of a £ 100 million programme that will occupy 800 extra British scientists.

Dr Gillings, the World Dementia Envoy regretted progress on research has been achingly low and that a cure would be impossible without a shift in approach. Research must become attractive to pharmaceutical companies. It is necessary to free up regulation in order to test ground-breaking drugs and explore how market exclusivity can be



extended. He identified three priorities: identification and elimination of barriers, stimulation of innovation through incentives, new financial structures and harnessing the power of social media and data to energise research. Dr Gillings, working directly with the UK, will also commit to looking at ways of bringing forward a global fund that could draw billions in private and public investment specifically focussed on dementia.



UK Prime Minister, David Cameron, also insisted it is time to address market failure on dementia research and drug development, which had seen global spending on dementia at five

times below research on cancer, with only three drugs making it onto the market in the last 15 years. He identified four key challenges: market failures undermine research, it takes far too long to reach patent stage, collaboration needs to be streamlined and there is a need for more investment. A lot is already happening with the UK doubling funding for dementia by 2015 and the Medical Research Council using the event to announce the creation of the world's biggest study group for dementia, involving two million people, alongside a EUR 126 (£100 million) research pledge from Alzheimer's Research UK. The UK will bring forward specific proposals on patent extensions, earlier access to new drugs for patients, greater research collaboration and facilitating much high-levels of investment, by October this year.

John Rouse, Department of Health, UK, presented the next steps. The specific actions will evolve around the urgency for investment, both economic and social; shaking things up through collaboration, a better regulatory framework and incentives; the support of health conveners like WHO, the necessity to stretch beyond G7, need to stretch beyond health ministries and include finance, trade and international ministries; address the barriers and involve all actors (people with dementia, carers, philanthropists...).

Representatives from Canada, France, Japan and the US gave a snapshot of their plans for future global legacy events. Annette Dumas attended on behalf of AE.

**28 June: Australian government backpedals on dementia care package**



Australian Prime Minister, Tony Abbott and his government are facing criticism over their perceived lack of commitment to making dementia a public health priority, largely due to an unexpected decision to abolish a key funding package; the "dementia and severe behaviours supplement".

Glenn Rees, CEO of Alzheimer's Australia said this about-face on funds targeted at specialised care for the most severely affected patients raised questions about the government's commitment to improving quality of care.

"It's not encouraging and we also don't know much about what the government's plans are to roll out some of the other elements...like the money for timely diagnosis of dementia and making hospitals safer", he added.

The government has also been criticised for delaying elderly care reform and for not taking any action on the issue of Australian nursing home residents being prescribed anti-psychotic drugs. Alzheimer's Australia estimates that 80 per cent of dementia patients in care in Australia are on same kind of anti-psychotic, but that only 20 per cent actually get any benefit from these. The association believes that a number of premature deaths, strokes and side effects could be avoided if their use were limited.

**30 June: UK Parliament pledges to become the first dementia-friendly parliament in the world**

On 30 June, the UK Parliament launched an organisation-wide effort, together with Alzheimer's Society, to become the first ever dementia-friendly parliament in the world.



The society is supporting the initiative, which aims to see all members, staff and the wider parliamentary community improve their understanding of dementia and take action to support those living with the condition.

The initiative calls for Parliament to work towards:

- Making dementia awareness part of all newly elected MPs' inductions.

- Delivering "Dementia Friends" awareness sessions to all public-facing staff so they can support external visitors living with dementia.

- Providing MPs and Peers with information and knowledge about dementia to help them assist constituents affected by dementia.

- Informing staff with caring responsibilities for people with dementia about the help available from Alzheimer's Society.

The Rt Hon John Bercow MP, Speaker of the House of Commons said:

"It is my hope that the House of Commons leads by example in becoming dementia-friendly, so that people with the condition are respected, welcomed and supported in Parliament and beyond."

The Rt Hon Baroness D'Souza CMG, Speaker of the House of Lords said:

"The new measures will ensure that all parliamentarians and staff throughout Westminster grasp the realities of living with dementia and are better equipped to support those living with the condition."

George McNamara, Head of Policy and Public Affairs at Alzheimer's Society, said:

"UK Parliament is taking the leading role in supporting people with dementia, setting an example to other nations. In an open democracy the least we can do is make Parliament accessible to all."

[www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=2076](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2076)

## Science Watch

### 25 April: Yoga may benefit people with dementia and their carers



A small UK-based study, published online on 25 April in the *Journal of Bodywork and Movement Therapies*, says that holistic exercise could have psychological and physical benefits for people with dementia and their carers.

With support from the Alzheimer's Society, study authors designed and implemented a programme of holistic exercise aimed specifically at people with dementia and their carers. The programme, called "Happy Antics" included a combination of group discussion, stretching, bending, breathing exercises, tai chi, yoga, meditation, qigong and dance. Movement was accompanied by music and was described as "non-strenuous" and usually occurred while seated.

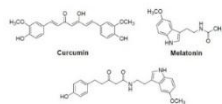
"This is an activity that caregivers and patients can do together," said study lead author Dr Yvonne J-Lyn Khoo, a researcher with the Health and Social Care Institute at Teesside University in Middlesbrough, UK. "Because everyone is doing the program together, caregivers have peace of mind to at least allow themselves to 'let go' and do some exercise."

The small-scale study involved eight patients with dementia, five of their caregivers, and two research volunteers. Participants ranged between 52 and 86 years of age when the study launched in 2013, and over the course of six weeks 70% of the group completed all six 45-minute sessions.

In post-program interviews all of the patients and caregivers had positive feedback about "Happy Antics", saying it helped them be more social. Pain relief was cited as an added benefit by some of the participants, as was a feeling of empowerment. The presence of caregivers was said to help people with dementia involved to feel safe and at ease as well.

[www.bodyworkmovementtherapies.com/article/S1360-8592%2814%2900015-1/abstract](http://www.bodyworkmovementtherapies.com/article/S1360-8592%2814%2900015-1/abstract)

### 22 May: Chemists combine two compounds to help against AD



Chemical researchers at Virginia Commonwealth University in the US and at the Instituto de Química Médica in Madrid, Spain have

blended together two compounds using a carbonyl found in both, in a bid to create a possible supplement to help prevent and alleviate the effects of Alzheimer's disease.

The team hybridised two compounds that have previously shown promise in this area individually: curcumin and melatonin.

The researchers tested their hybrid on human neuroblastoma cells genetically tweaked to produce high levels of amyloid- $\beta$  peptides and eventually die. They found that their compound prevented cell death at

concentrations that were 1% of those needed for curcumin or melatonin alone or together.

The mechanism behind the hybrid's apparently far superior effectiveness is unknown at the moment, but the team's early tests suggest it scavenges free radicals in the cells' mitochondria.

The latest version of the hybrid can cross the blood-brain barrier in mice and is now being tested on AD mouse models.

[www.pubs.acs.org/doi/abs/10.1021/cn500081s](http://www.pubs.acs.org/doi/abs/10.1021/cn500081s)

### 28 May: Cynics may be more prone to dementia

A report published online in the journal *Neurology* on 28 May claims people with high levels of cynical distrust may be more likely to develop dementia. The research was completed at University of Eastern Finland, Kuopio.

Cynical distrust (the belief that others are mainly motivated by selfish concerns) has previously been associated with health problems such as heart disease but this is the first study to look at a possible link with dementia.

For the study, 1449 people with an average age of 71 were given a cognitive test for dementia as well as a questionnaire measuring their level of cynical distrust. The latter was based on the Cook-Medley Hostility Scale.

622 of the participants also completed a second test for dementia an average of eight years after the study began. During that time, 46 participants were diagnosed with dementia. After adjustments to allow for other factors that could affect dementia risk, such as high blood pressure, high cholesterol and smoking, the research team concluded that people with high levels of cynical distrust appeared to be three times more likely to develop dementia than people with low levels.

Dr Doug Brown of Alzheimer's Society, commented that far too few people were studied that actually developed dementia to be able to draw any firm conclusions.

"We acknowledge the need for larger replication studies", the report concluded.

[www.neurology.org/content/early/2014/05/28/WNL.0000000000000528](http://www.neurology.org/content/early/2014/05/28/WNL.0000000000000528)

### 2 June: Learning a second language may help cognition and slow dementia

A study, published in *Annals of Neurology* on 2 June, suggests that not only could learning a second language have a positive impact on cognition and delay the onset of dementia as previous studies have suggested, but that it may not matter whether this second language is learned in childhood or later in life.



Researchers at the University of Edinburgh, Scotland, studied 853 participants whose cognitive skills were first tested in 1947 (aged 11 years). The researchers tested this group of people again in 2008–2010 (now aged in their 70s) to see how their cognitive abilities had changed. All participants said they were able to communicate in at least one language other than English at the time of the

second test, about 25% of them having learned their second language after the age of 18.

Researchers were surprised by a positive difference of some considerable ilk between the results they would have expected from the second tests, considering the baseline cognitive skills of the bilingual participants and the results actually achieved. The greatest impact was seen in the areas of general intelligence and reading levels. These improved cognitive scores were achieved by participants who acquired their second languages in adulthood and childhood alike.

Dr Thomas Bak, from the Centre for Cognitive Ageing and Cognitive Epidemiology at the University of Edinburgh, who led the study, said that he and his team had shown that "bilingualism, even when acquired in adulthood, may benefit the ageing brain."

He added that further studies needed to be conducted, particularly to see whether learning yet more languages could potentially benefit the brain even further.

[www.onlinelibrary.wiley.com/doi/10.1002/ana.24158/abstract;jsessionid=4D9B2E06D1CE61597E50F1BB6589413B.F03t04](http://www.onlinelibrary.wiley.com/doi/10.1002/ana.24158/abstract;jsessionid=4D9B2E06D1CE61597E50F1BB6589413B.F03t04)

## 2 June: Study links lack of sleep to higher levels of amyloid-beta



Lack of sleep leads to an increased level of the protein amyloid-beta in the human brain, a new study claims. High levels of amyloid-beta have previously been identified as a risk factor for Alzheimer's disease (AD).

Researchers at Radboud University Medical Center in Nijmegen, Netherlands, used a study group of 26 middle-aged men who reported normal sleeping habits. Half of the participants were randomly assigned to the "sleeping group" and the rest remained awake for an entire night.

Catheters were inserted into the spines of all participants to measure the levels of amyloid-beta protein present before and after the night session.

The sleeping group had amyloid-beta levels that were 6% lower than the levels measured at the baseline. The protein levels in the men who stayed awake remained the same. The team also found that the men who reported higher quality of sleep had greater reductions in their amyloid-beta levels.

Senior author of the study, Dr Jurgen Claassen concluded that "normal healthy sleep helps reduce the amount of [amyloid] beta in the brain and if your sleep is disturbed this decrease is prevented...We think the beta is cleared from the brain or less produced during sleep...Based on this and other studies, it would be good to have people look at their sleep behaviors."

The study concludes that chronic sleep deprivation increases cerebral amyloid-beta levels, which could mean an elevated risk of AD however more research would be required to understand the link between sleep deprivation and AD.

[www.archneur.jamanetwork.com/article.aspx?articleid=1875833](http://www.archneur.jamanetwork.com/article.aspx?articleid=1875833)

## 4 June: US study links memory impairments in adults to poor health and lifestyle factors

A study carried out by the University of California, Los Angeles (UCLA) has found that health factors believed to increase the risk of dementia in later life may also increase the likelihood of "subjective memory impairments" (SMI), across all adult age groups, including young adults aged from 18 to 39.

The study, led by Professor Gary Small, UCLA's Parlow-Solomon Professor on Aging and director of the UCLA Longevity Center, was published online in the journal PLOS ONE on 4 June.

Researchers polled 18,552 individuals in the US, aged between 18 and 99, about their memory skills and a variety of lifestyle and health factors. They focused on those factors believed to increase the risk of Alzheimer's disease such as depression, diabetes, lower education levels, obesity and smoking.

The findings seemed to show that many of these risk factors increased the incidence of SMI among all age groups. Of those polled, 20% were found to have SMI, including 14% of young adults (ages 18-39), 22% of middle-aged adults (ages 40-59) and 26% of older adults (ages 60-99).

The study concludes that the risk factors most likely to increase SMI at any age are depression, low levels of education, physical inactivity and high blood pressure. The strongest single risk factor they found across all ages for SMI was depression.

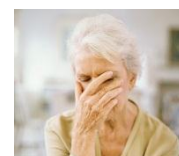
Researchers noted that young adults might suffer from different memory issues to those afflicting older individuals. They identified that stress and multi-tasking brought on by the continual presence of technology (the Internet and wireless devices) could have a greater impact on the attention spans of young adults, making it more difficult for them to focus and remember things.

The study concludes "whether modifying these risk factors reduces SMI and the eventual incidence of AD and other dementias later in life remains to be determined."

[www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0098630](http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0098630)

## 7 June: Study says depression speeds up dementia

A study, unveiled at the 61st Annual Meeting of the Society of Nuclear Medicine and Molecular Imaging on 7 June in the US and subsequently published in the Journal of Nuclear Medicine on 9 June, has used molecular imaging to show that late-life depression may cause beta-amyloid plaque to build up in the brain, hastening the development of dementia.



Many people develop depression in the later stages of life and the researchers, led by Dr Axel Rominger of the Department of Nuclear Medicine, University of Munich, Germany say that late-life depression could therefore become a major risk factor:

"The combination of elevated amyloid-levels and coexisting depressive symptoms constitute a patient

population with a high risk for faster progression to Alzheimer's disease" said Dr Rominger.

The study involved 371 patients with mild cognitive impairment who underwent PET imaging with the radiotracer F-18 florbetapir and magnetic resonance imaging (MRI) chosen retrospectively from the Alzheimer's Disease Neuroimaging Initiative (ADNI) database, which includes data from at least 55 research centres across the US and Canada.

[www.jnumedmtg.snmjournals.org/cgi/content/meeting\\_abstract/55/1\\_MeetingAbstracts/87](http://www.jnumedmtg.snmjournals.org/cgi/content/meeting_abstract/55/1_MeetingAbstracts/87)



### 20 June: Potential AD drug may prevent blood clots in the brain



One of the causes of Alzheimer's disease (AD) is believed to be the frequent blood clots that form in brains affected by the condition, which contribute to memory loss, confusion and cognitive decline.

Scientists at Rockefeller University, New York say they have identified a compound that might stop the progression of AD by interfering with the role played by amyloid-beta in forming blood clots.

By targeting the amyloid-beta protein's ability to bind to a clotting agent in blood, the work done in the Strickland lab at Rockefeller University offers a possible new strategy.

The compound, known as RU-505, emerged from among 93,716 candidates selected from libraries of compounds, the researchers write on 20 June, in the *Journal of Experimental Medicine*. Because RU-505 binds to amyloid- $\beta$  and only prevents abnormal blood clot formation, it does not interfere with normal clotting. It is also capable of passing through the blood-brain barrier.

"We tested RU-505 in mouse models of Alzheimer's disease that over-express amyloid- $\beta$  and have a relatively early onset of disease. Because Alzheimer's disease is a long-term, progressive disease, these treatments lasted for three months," Dr Ahn, a member of the research team says. "Afterward, we found evidence of improvement both at the cellular and the behavioural levels."

The brains of the treated AD mouse models had less of the chronic and harmful inflammation associated with the disease and blood flow in their brains was closer to normal than that of untreated ones. The RU-505-treated mice also did better when placed in a maze to see whether their cognitive functions would allow them to get out within a normal time-frame. AD mouse models have trouble exiting the maze, but after these mice were treated with RU-505, they performed much better, according to the report.

The researchers have begun the next steps toward developing a human treatment.

[www.nature.com/nrd/journal/v13/n7/full/nrd4370.html](http://www.nature.com/nrd/journal/v13/n7/full/nrd4370.html)

### 23 June: Cocoa extract may help counter AD



Insights into mechanisms behind the potential benefits of cocoa may lead to new treatments or dietary regimens for people with Alzheimer's

disease, says a study conducted at the Icahn School of Medicine at Mount Sinai, New York. It was published on 20 June in the *Journal of Alzheimer's Disease* (JAD).

The research team, led by Giulio Maria Pasinetti, Professor of Neurology at the Icahn School of Medicine, tested the effects of extracts from Dutched, Natural, and Lavado cocoa on AD mouse models. Each of these cocoa extracts contains different levels of polyphenols, antioxidants also found in fruits and vegetables and which past studies have found help prevent degenerative brain diseases.

Each cocoa type was evaluated for its ability to reduce the formation of amyloid-beta ( $A\beta$ ) oligomers and to rescue synaptic function. Lavado extract, which has the highest polyphenol content and anti-inflammatory activity among the three, was also the most effective in reducing the formation of these oligomers as well as reversing damage to synapses.

According to Prof. Pasinetti the results suggest that "Lavado cocoa extract prevents the abnormal formation of  $A\beta$  into clumped oligomeric structures, to prevent synaptic insult and eventually cognitive decline".

Because loss of synaptic function may have a greater role in memory loss than the loss of nerve cells, rescue of synaptic function may serve as a more reliable target for an effective Alzheimer's disease drug, he concluded.

Dr James Pickett, Head of Research at Alzheimer's Society in the UK commented: "It would be fantastic if the next treatment for dementia was found in a naturally occurring product like cocoa, but clearly more research is needed. Before focusing all our attention on chocolate, it's worth noting that research indicates that the best way to reduce your risk of developing dementia is to eat a healthy diet, exercise regularly and not to smoke."

[www.iospress.metapress.com/content/t547816182146gg8/?issue=2&genre=article&spage=643&issn=1387-2877&volume=41](http://www.iospress.metapress.com/content/t547816182146gg8/?issue=2&genre=article&spage=643&issn=1387-2877&volume=41)

### 30 June: GE gets positive opinion from EMA on PET Imaging Agent

On 30 June, GE Healthcare announced receipt of a positive opinion from the European Medicines Agency (EMA) concerning a proposed flutemetamol F-18 injection for PET imaging.

The opinion, given by EMA's Committee for Medicinal Products for Human Use (CHMP), recommends the granting of a marketing authorisation for the radiopharmaceutical medicinal product.

Flutemetamol F-18 is indicated for Positron Emission Tomography (PET) imaging of beta amyloid neuritic plaque density in the brains of adult patients with cognitive impairment. The agent would be used for diagnostic purposes only, in conjunction with a clinical evaluation for Alzheimer's disease (AD), as well as other neurological disorders.

## Dementia in Society

### 12 June: FIFA World Cup could help unlock precious memories

The world's most watched sporting event, the quadrennial FIFA World Cup, began on 12 June in Brazil and will conclude on 13 July. The previous world cup, held in South Africa in 2010 attracted 3.2 billion viewers globally.



The football World Cup was first organised in 1930 and has attracted steadily increasing interest since its beginnings. Other popular sporting events which have stood the test of time and attract global interest include the Olympic Games (1894), Wimbledon (1877) and the Tour de France (1903). The fact that these events have been taking place regularly for so many decades and that they evoke such emotion in fans, means that they hold a special significance for many.

Popular, longstanding sporting events such as these can help unlock precious memories for people with dementia and may help some of those who feel isolated as a result of their dementia to feel more engaged, according to organisations such as Sporting Memories Network and Care UK.

### 16 June: Channel 4 News broaches sex and dementia in care homes

UK television's Channel 4 News recently aired a series of ten minute episodes called "Love and Sex when we're over 60". Broadcast during the week of 16 June, the mini-series culminated in an episode tackling the rarely-broached topic of sex and dementia in care homes.

Speaking during this episode, Dr David Sheard from dementia consultancy, Dementia Care Matters said that many care homes see sexual behaviour "as a problem to be suppressed". His belief, however, is that people living with dementia should be allowed to enjoy loving relationships "in their moment, in their reality", whether they are resident in a care home or not. One care home staff member interviewed also comments that this behaviour would be seen as normal in the community, so why should it be any different in a care home?

"The problem is that care homes aren't designed with people's individual needs in mind, especially their sexual ones", comments Channel 4 News.

A care home manager interviewed says of residents with dementia, that she doesn't want to "wrap them up in cotton wool" and that they should be allowed to live their own lives and "be human beings". One resident, in the advanced stages of dementia, comments to her husband during the programme "I'm your wife, remember? I'm your wife, I'm not a child."

Channel 4 concludes the episode by commenting that the challenge for families and for care home staff alike is to recognise the needs of people with dementia.

### 23-26 June: "Alzheimer University" held in Geneva

On 23-26 June 2014 Alzheimer's Disease International (ADI) held its annual "Alzheimer University" in Geneva,

Switzerland. This year's theme was 'Campaigning for change'. The purpose of the event was to provide participants with tools to make Alzheimer's disease a government priority. The courses were articulated around several themes: policy advocacy, building relationships, strategy building and national plans. At the end of the event, the participant were invited to jot down ideas for a draft national dementia strategy and follow-up with ADI staff over the next months to refine their plan.

Johanna Ralston, CEO of the World Health Federation talked about the Non-Communicable Diseases Alliance (NCDs). The Alliance was founded by four international NGO federations representing four main NCDs (cardiovascular disease, diabetes, cancer and chronic respiratory disease). It unites civil organisations of all over the world. Its mission is to put health at the centre of all policies and ensure NCDs are recognised as a global emergency.

Mr Tursan d'Espaignet, WHO, presented a fact sheet on 'Tobacco use and dementia' that was going to be presented to the public within the next few days. This fact sheet is a collaborative work between WHO and ADI. It reviews a series of studies that reveal that smoking is associated with the risk of developing dementia. This greatly contradicts the studies sponsored by the tobacco industry that claim that tobacco has a protective factor.

WHO now calls upon all stakeholders to largely disseminate the findings of this fact sheet when it comes out and promote tobacco control.

Annette Dumas from AE was attending and presented the basics of building relationships with policy makers and participated in the panel discussion on the role of patients in promoting and supporting life-changing and life-saving research into treatment or cures.

### 27 June: Soul legend Bobby Womack dies with Alzheimer's disease

American singer-songwriter and musician Bobby Womack has died on 27 June, aged 70. The cause of his death was not announced, but he had been diagnosed with Alzheimer's disease two years previously and had a history of other health issues including prostate cancer and drug addiction issues.



Most noted for his soul music and his "signature soul scream", Mr Womack's recording career began in the early 1960s and spanned more than 5 decades. From 1970-90 he charted 36 singles including "Lookin' For a Love", "That's The Way I Feel About Cha" and "Across 110th Street". He was inducted into the Rock and Roll Hall of Fame in 2009.

Many fellow musicians have paid tribute to the soul legend on Twitter, including Ronnie Wood, Damon Albarn, Peter Gabriel, De la Soul and MC Hammer.



### 27 June: BBC television drama, *Holby City* takes on dementia storyline



BBC television's medical drama series, *Holby City* has decided to include a dementia storyline for its characters, Adrienne and Serena Campbell. The latter, played by Catherine Russell, is one of the series' major characters. Serena was informed during the episode aired on 27 May that her mother, Adrienne may have dementia.

Alzheimer's Society was consulted in the writing of the script and advised on everything from symptoms to the types of issues faced by people living with dementia and their carers.

Sandra Voe, who plays the part of Adrienne also visited an Alzheimer's Society day support centre at Edgware Hospital in North London to help her get a better understanding of the condition for her role.

Alzheimer's Society commented that it was pleased to see awareness of dementia being raised in *Holby City*'s storyline. It said that some of the issues tackled in the storyline such as recognising symptoms, obtaining a diagnosis and putting plans in place for care were "all key parts of a family's journey when affected by dementia."

### 30 June: Thomson Reuters predicts dementia will decline by 2025

Analysts for Thomson Reuters in New York have made ten innovation predictions for the year 2025, in a report released on 30 June. One of their predictions is that, due to an expected increase in understanding of the human genome and in access to scientific funding, dementia will be on the decline.

The report, entitled "The World in 2025: 10 Predictions of Innovation" also includes predictions about many more people holding pilot licenses; functionality of quantum teleportation; preventability of type I diabetes; total digitalisation of our daily lives; vast expansion of solar power and the normalisation of DNA mapping at birth.

To conduct the study, researchers identified the top 10 emerging scientific areas based on an analysis of popular topics using Thomson Reuters Web of Science.

How many of the predictions come to fruition remains to be seen, but the analysts say that their purpose is to provoke debate among the research community and the world at large.

[www.sciencewatch.com/tags/2025](http://www.sciencewatch.com/tags/2025)

## New Publications & Resources

### 20 May: RCN publishes report on dementia care in UK hospitals



The Royal College of Nursing (RCN) has published a report containing the results of a year-long programme looking into innovative ways to improve dementia care in hospitals. It was launched at the Transforming Dementia Care in Hospitals conference on

20 May at RCN headquarters and includes a number of examples of strategies.

An independent evaluation of the programme was carried out by the Association for Dementia Studies at the University of Worcester, showing that the two main points integral to achieving improvements in dementia care are:

- Commitment and leadership from Trust boards.
- Investing in dedicated dementia nurse specialists.

The full report is available here: <http://goo.gl/KX2k4h>

### 6 June: NHS Education for Scotland report welcomed by Alzheimer Scotland



An NHS Education for Scotland report, "Evaluating the impact of the Alzheimer Scotland Dementia Nurse Consultants/Specialists & Dementia Champions in bringing about improvements to dementia care in acute general hospitals", was published on 6 June, receiving a hearty welcome from Alzheimer Scotland.

The report points out that "Improving experiences and outcomes for people with dementia care in acute general hospitals is recognised in Scotland's Dementia Strategies as requiring significant cultural change and service development...despite the enormity of the task and the relative small scale and immaturity of the initiatives, a significant amount of change and improvement work has been initiated by the two roles, and would likely not have happened without them."

Scottish Cabinet Secretary for Health and Wellbeing, Alex Neil said, "This report shows that both Dementia Nurses and Dementia Champions have an invaluable role in helping people with dementia and their families, in hospital and care settings."

Henry Simmons, Chief Executive of Alzheimer Scotland said, "This report clearly demonstrates the right formula for improving care for people with dementia in hospitals: enabling Alzheimer Scotland Dementia Nurses to take a strategic lead within their NHS board, assisting Dementia Champions to deliver frontline change through supportive managers (and regular contact with their Dementia Nurse and fellow Champions) and a commitment at board level to the 10 point action plan in Scotland's Dementia Strategy. This formula allows us to make measurable and meaningful improvements in the delivery of care."

The full NHS Education for Scotland report is available here:

[www.nes.scot.nhs.uk/media/2711493/impact\\_evaluation\\_-\\_final\\_report.pdf](http://www.nes.scot.nhs.uk/media/2711493/impact_evaluation_-_final_report.pdf)

### 15 June: Alzheimer's Society helps create "Cataracts and dementia" factsheet



Cataracts are a very common eye condition in older people. Most people with cataracts are over the age of 60 and they become more common as people age. Dementia is also a condition that mainly affects people over the age of 65 and becomes more common as people get older. A

significant number of people are therefore affected by both dementia and sight loss. Because of this many people may face having a cataract operation while also dealing with dementia.

Alzheimer's Society has lent its support to the "Vision 2020 UK" programme in producing a factsheet on cataracts and dementia. While it is mainly aimed at UK residents, much of the content is universally applicable.

The factsheet covers:

- What a cataract is and its effect on vision.
- How to tell if you or someone you care for has a cataract.
- Cataract surgery and the difference it can make to a person's quality of life.
- How to prepare for surgery.
- How to help someone with dementia cope with surgery.
- What happens after surgery.

[www.rnib.org.uk/sites/default/files/Cataracts\\_and\\_dementia\\_factsheet.pdf](http://www.rnib.org.uk/sites/default/files/Cataracts_and_dementia_factsheet.pdf)

### 30 June: IMI to hold six information sessions for the IMI 2 programme



The members of IMI's States Representatives Group are organising six national information sessions on the new IMI 2 programme:

**The Netherlands** - 3 July - Session on IMI during the info day "Research & Innovation for a Healthy Europe" in The Hague. [www.rvo.nl/actueel/evenementen/info-day-research-innovation-healthy-europe](http://www.rvo.nl/actueel/evenementen/info-day-research-innovation-healthy-europe)

**Germany** - 10 July - IMI 2 Info Day in Frankfurt. <http://events.dechema.de/IMI2.html>

**Spain** - 10 July - Session on IMI during JTI launch day in Madrid.

[www.cdti.es/index.asp?MP=9&MS=37&MN=2&TR=&IDR=0&accion=si&texto=&idprograma=0&fecha=01/07/2014&filtrodia=0&fechadesde=&fechahasta=&tipo=&id=2503&xtrmc=&xtrcr=3](http://www.cdti.es/index.asp?MP=9&MS=37&MN=2&TR=&IDR=0&accion=si&texto=&idprograma=0&fecha=01/07/2014&filtrodia=0&fechadesde=&fechahasta=&tipo=&id=2503&xtrmc=&xtrcr=3)

**Austria** - 16 July - Info session on IMI 2. [www.ffg.at/veranstaltungen/imi2\\_2014-07-16](http://www.ffg.at/veranstaltungen/imi2_2014-07-16)

**Finland** - 26 August - IMI 2 Info Day in Helsinki. <https://tapahumat.tekes.fi/event/imi2infoday>

**Denmark & Sweden** - 28 August - IMI launch event in Copenhagen. [www.mva.org/danish-swedish-launch-event-innovative-medicines-initiative](http://www.mva.org/danish-swedish-launch-event-innovative-medicines-initiative)

Further info days in other countries are also planned. Once details are confirmed, the information will be added to the IMI web page shown below.

[www.imi.europa.eu/events/2014/06/27/national-info-days-imi-2](http://www.imi.europa.eu/events/2014/06/27/national-info-days-imi-2)

## Job opportunities

### 1 June: Bradford Dementia Group seeks Head of Practice Development and Training

Bradford Dementia Group's School of Health Studies is looking to fill the position of Head of Practice Development and Training (senior lecturer grade 10).

The main focus of the role is to provide strategic, academic and operational leadership of Bradford Dementia Group's evidence-based practice development and training activities. These include: customer service, generation of new business, delivery excellence, research and development, and line management in line with financial and work load models.

The successful candidate will:

- Lead high quality applied research and development projects in improving quality of care for people affected by dementia.
- Lead the Bradford Dementia Group in ensuring high quality practice development consultancy and short courses in dementia care.
- Manage a multi-disciplinary and multi-professional team of expert practitioners developing and delivering our portfolio of short courses and consultancy in improving quality of care.
- Closing date for applications is 15 July.

<http://jobs.bradford.ac.uk/Upload/vacancies/files/751/AH55149.pdf>

### Contact Alzheimer Europe:

Alzheimer Europe, 14 rue Dicks, L-1417, Luxembourg [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org), [www.alzheimer-europe.org](http://www.alzheimer-europe.org)

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## AE Calendar 2014

| Date       | Meeting   | AE representative                        |
|------------|---|--|
| 1 July     | EFPIA Think Tank Brussels, Belgium)   | Annette                                  |
| 3 July     | Meeting with Natalie Turner, Senior Policy Advisor, AARP International office (Brussels, Belgium)                     | Annette                                  |
| 7-9 July   | AE Board, Corporate Round Table and AE Public Affairs Meeting   | AE Board, member organisations and staff |
| 21-22 July | Second meeting of Alzheimer Europe's working group on ethical dilemmas faced by people with dementia and their carers | Dianne                                   |

## Future Conferences

| Date            | Meeting   | Place                  |
|-----------------|---|------------------------|
| 5-9 July        | 9th FENS Forum of Neuroscience, <a href="http://forum.fens.org/2014">http://forum.fens.org/2014</a>   | Milan, Italy           |
| 12-17 July      | AAIC Conference 2014, <a href="http://www.alz.org/aaic">www.alz.org/aaic</a>  | Copenhagen, Denmark    |
| 18-19 September | 6th International conference "Senior's training and nonpharmacological interventions for Alzheimer's disease", <a href="http://www.alzheimer.sk/slovenska-alzheimerova-spolocnost/akcie/konferencia2014.aspx">http://www.alzheimer.sk/slovenska-alzheimerova-spolocnost/akcie/konferencia2014.aspx</a>  | Bratislava, Slovakia   |
| 18-20 September | 4 <sup>th</sup> International CAA Conference - Cerebral Amyloid Angiopathy and related disorders, <a href="http://internationalcaaassociation.org">http://internationalcaaassociation.org</a>   | London, UK             |
| 25-26 September | Innovation in Ageing Services-Pathways to the Future, <a href="http://uniproject.nl/eahsa/home">http://uniproject.nl/eahsa/home</a>   | Amsterdam, Netherlands |
| 30 September    | 'A Life Worth Living – young onset dementia services and supports', <a href="http://www.youngdementiauk.org/yduk-national-events">http://www.youngdementiauk.org/yduk-national-events</a>   | Oxford, UK             |
| 20-22 October   | 24th Alzheimer Europe Conference "Dignity and autonomy in dementia", <a href="http://www.alzheimer-europe.org/Conferences">www.alzheimer-europe.org/Conferences</a>   | Glasgow, UK            |
| 23-25 October   | 9th International Conference on Frontotemporal Dementias, <a href="http://ubccpd.ca/course/FTD2014">http://ubccpd.ca/course/FTD2014</a>   | Vancouver, Canada      |
| 23-25 October   | 8. Kongress der Deutschen Alzheimer Gesellschaft "Demenz - jeder kann etwas tun", <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a>  | Gütersloh, Germany     |
| 7-9 November    | 17th Asia Pacific Regional Conference of Alzheimer's Disease International, <a href="http://www.aprc2014-india.com/">http://www.aprc2014-india.com/</a>   | New Delhi, India       |
| 24-25 November  | EMA workshop on the clinical investigation of medicines for the treatment of Alzheimer's disease, <a href="http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2014/04/event_detail_000932.jsp&amp;mid=WC0b01ac058004d5c3">http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2014/04/event_detail_000932.jsp&amp;mid=WC0b01ac058004d5c3</a> | London, UK             |
| 20-23 June 2015 | 1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/berlin2015">www.eaneurology.org/berlin2015</a>   | Berlin, Germany        |



# 24<sup>th</sup> Alzheimer Europe Conference

## Dignity and autonomy in dementia

### Glasgow, Scotland, UK

### 20-22 October 2014

Register now!

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)



The Alzheimer Europe newsletter arises from the 2014 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.