Welcome and Happy New Year!

First of all, I would like to extend our deepest condolences to Jerome H. Stone’s family, friends and colleagues. Mr Stone, Founding President and Honorary Chair of the US Alzheimer’s Association and Founder and Honorary President of Alzheimer’s Disease International (ADI), passed away on 1 January.

On a contrasting note, I’d like to congratulate our friends at the Alzheimer Society of Ireland (ASI), whose hard work on Ireland’s National Dementia Strategy has come to fruition, with its launch finally taking place on 17 December. CEO, Gerry Martin welcomed the publication of the report and the funding which has been made available for three priority areas: intensive home care supports, GP education and training and dementia awareness.

I’d also like to congratulate Alzheimer Europe (AE) Chairperson, Heike on a medal she recently received for her commitment to voluntary work and to congratulate the European Working Group of People with Dementia (EWGPWD) Chairperson, Helga on her recent “commitment award” (Deutscher Engagementpreis 2014). As a final congratulations for this month, I’d also like to wish the German Alzheimer Society (DAzG) a happy 25th anniversary!

In the early part of December, the first meeting of AE’s recently elected Board members took place in Brussels. This was followed by the final lunch debate of 2014, this time hosted by MEP Keith Taylor (UK), Vice-Chairperson of the European Alzheimer’s Alliance. The event focused on dementia prevention. Presenting on this subject was Dr Miia Kivipelto, Professor of Clinical Geriatric Epidemiology at Sweden’s Karolinska Institute and Senior Geriatrician at Karolinska University Hospital. Our 2014 publications – the year book, the ethics report and the incontinence report – were distributed to the participants and are also available for free download on our website.

On the EU front this month, the Innovative Medicines initiative (IMI) parted ways with Executive Director, Michel Goldman, mid-month and named a new Acting Executive Director. Our Honorary Secretary, Charles Scerri reports on the Italian EU Presidency dementia conference in this issue also. The conference preceded the end of Italy’s EU Presidency term, with the mantle having passed to Latvia on 1 January. It will, in turn, pass to Luxembourg on 1 July.

Finally, we have decided to run a short survey about our newsletter for the first time. I would be most grateful if you could take the time to complete it, as it will help us understand what we are doing well and where we might need to make change for the future.

Speaking of the future, I wish you all the very best for a new and successful 2015!

Jean Georges
Executive Director
Alzheimer Europe

19 November: Heike von Lützau-Hohlbain receives medal for her work

Alzheimer Europe (AE) Chairperson, Heike von Lützau-Hohlbain, has been honoured, in Germany, for her voluntary work.

Ms von Lützau-Hohlbain received a medal on 19 November 2014, praising her longstanding commitment as a founding member and the first President of the German Alzheimer Society (DAlzG) and as Chairperson of AE.

Ms von Lützau-Hohlbain is pictured here, receiving her award from Minister Huml.

24-25 November: AE Honorary Secretary reports on EMA Workshop

On 24 and 25 November, Alzheimer Europe (AE) Honorary Secretary, Dr Charles Scerri attended a European Medicines Agency (EMA) Workshop on Alzheimer’s disease, in London, UK. Dr Scerri reported back:

The aim of this two-day workshop was to provide the opportunity for different stakeholders (pharmaceutical industry, independent experts, patient representatives and regulators) to come together and discuss key scientific issues in the Alzheimer’s disease field.

Alzheimer Europe was represented by Iva Holmerova, Mary-Frances Morris, Helga Rohra, and Charles Scerri. Helga Rohra opened the workshop with a presentation on the role of patient organisations together with giving her outlook on different aspect of dementia from the patient point of view. Iva Holmerova stressed on the need to continue developing and supporting solutions, in collaboration with national Alzheimer associations in every EU country. Mr Taylor then introduced Dr Kivipelto, the featured speaker for the debate.

Dr Miia Kivipelto, Professor of Clinical Geriatric Epidemiology at Sweden’s Karolinska Institute and Senior Geriatrician at Karolinska University Hospital, presented “Prevention of Dementia: Why & How”. Her presentation, based on the outcomes of the FINGER study, showed that cognitive decline can be slowed down or even prevented by addressing multiple risk factors simultaneously. This approach clearly contrasts with current research practice, where clinical trials tend to focus on a single risk factor.

The FINGER study (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability), led by Dr Kivipelto, began in 2009 with a group of 1,260 Finnish people aged 60-77. The study included nutrition, exercise, cognitive training and social activity, as well as monitoring of metabolic and vascular risk factors over two years. The intervention period ended in February 2014 and the final study results are expected within the next few months. These results will show that multidomain intervention is effective in reducing or preventing cognitive decline. Dr Kivipelto said that she would like to pool her results with those of similar studies in other countries, in the hope of identifying more people with dementia risk factors.

Dr Kivipelto was followed by Heike von Lützau-Hohlbain, Chair of Alzheimer Europe, who presented two recently published AE publications. The 2014 Dementia in Europe Yearbook is a comparative report on national policies and practices. It addresses different aspects of the timely diagnosis of dementia and of the post-diagnostic care and support available to individuals living with dementia in 30 European countries. The other new report is about the ethical dilemmas sometimes faced by people with dementia and their carers. In addressing ethical dilemmas, the authors focus on some of the more problematic aspects of living with dementia but with the positive aim of trying to make such issues less of a problem.

Newsletter: December 2014

Board discussed various financial and operational matters, including initial preparations for the 25th Alzheimer Europe Conference that will take place in Slovenia in September 2015. The next Board meeting will take place on 23 February in Luxembourg.

2 December: AE holds a lunch debate on dementia prevention

Keith Taylor, MEP (UK) and Vice-Chairperson of the European Alzheimer’s Alliance, hosted AE’s latest lunch debate in Brussels on 2 December.

Mr Taylor welcomed the delegates and opened the debate by saying that dementia is a challenge for every EU country but also for the EU as a whole. He noted that we cannot be complacent about dealing with the growing societal challenge that is dementia. He also stressed the need to continue developing and supporting solutions, in collaboration with national Alzheimer associations in every EU country. Mr Taylor then introduced Dr Kivipelto, the featured speaker for the debate.

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Impressions from the lunch debate

Ms von Lützau-Hohlbein also presented the Glasgow Declaration, which was launched at the Alzheimer Europe Conference in October 2014. In broad terms, the Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Mr Taylor joined Ms von Lützau-Hohlbein in thanking Dr Kivipelto and all the delegates for their participation and support.

Delegates at the lunch debate included MEPs Biljana Borzan from Croatia, Irish MEPs Nessa Childers, Deirdre Clune and Marian Harkin as well as Sirpa Pietikäinen from Finland. Other participants included representatives from the European Commission, the pharmaceutical industry and representatives from 11 Alzheimer Europe member associations.

Alzheimer Europe’s next lunch debate will take place in June 2015 at the European Parliament.

3 December: European Patients Forum hosts first meeting of the Access Working Group

The objectives of the meeting were to adopt the terms of reference of this group, confirm the working group and steering group members (Juan Fuertes (Pulmonary Hypertension Association Europe, Baiba Ziemele (European Hemophilia Consortium) and Geoffrey Henning (EuropaColon), agree on the 2015 work plan. A brainstorming session was organised to draft a definition of access from a patient’s perspective and how to input into EPF’s future work in the area of discrimination. Finally, an update on the Multistakeholder Access Partnership (MAP) was given.

The Access Working Group was set up by EPF in 2014 to discuss and overcome the barriers that patients experience in access to care, treatment and support in the Member States.

AE’s Annette Dumas, who is making the link between EPF’s Policy Affairs Groups and the Access Working Group, participated in the meeting.

4 December: Dianne Gove and Helga Rohra essay on dementia stigma published

The International Longevity Centre-UK (ILC) – an independent think tank on longevity and demographic change – has published a compendium of essays, called “New perspectives and approaches to understanding dementia and stigma”.

The collection, which examines the social stigma surrounding dementia, includes an essay on “Empowering people with dementia”, by Alzheimer Europe’s Director for Projects, Dianne Gove and the Chairperson of the European Working Group of People with Dementia (EWGPWD), Helga Rohra.
4 December: AE board member presents 2015 activities in Slovenia

Alzheimer Europe (AE) Board member, Štefanič Zlobec was a speaker at 45th Annual Congress of the Geriatric Association of Slovenia (Gerontološko društvo Slovenije, or GDS) on 4 December. Ms Zlobec, President of the Alzheimer Association of Slovenia (Spominčica), talked about AE’s activities and presented our 25th annual conference, which will be co-hosted by Spominčica in Ljubljana, Slovenia from 2 to 4 September, 2015. Delegates at the Slovenian congress were invited to submit abstracts for AE’s conference once the process opens in early 2015.

7 December: Helga Rohra awarded 2014 German commitment award

Helga Rohra, Chairperson of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) has received an award for national and international campaigning in the field of dementia: the German “commitment award” (Deutscher Engagementpreis 2014).

The agenda was rather busy, with Thomas Heynisch (European Commission – DG Enterprise and Industry) giving a report of the European Commission multi-stakeholder workshop held in Rome in October and giving an overview of the Commission’s working paper on sector strategy. He also provided the Commission perspective on the patient role in shaping industry policy.

An update on the IMI proposal on risk-benefit and an update on the EFPIA’s work on the lay person summary requested by the new Clinical Trials Regulation were presented and discussed. The question of patient access to congresses was also discussed by the group.

A report of the healthcare summit organised by EFPIA in October was presented and the repetition of such an event next year was debated.

EPF gave a short report on the progress of the IMI-funded project EUPATI (European Patients’ Academy on Therapeutic Innovation). EFPIA gave an insight into the Think Tank areas for discussion during 2015 for the group to discuss.

Finally, the launch of a European Coalition on Prevention was presented.

AE’s Annette Dumas participated in the meeting.

18 December: AE 2014 publications available online

On 18 December, Alzheimer Europe made its 2014 publications available for free download on the AE website.

The Dementia in Europe Yearbook 2014 is a comparative report on care pathways for people with dementia living at home in Europe. It can be downloaded here: http://alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks

AE’s reports on “Improving continence care for people with dementia living at home” and on “Ethical dilemmas faced by carers and people with dementia” can be downloaded here: http://alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Alzheimer Europe Networking

On 1 December (Brussels, Belgium) Dianne attended the EIP AHA 3rd partners’ conference of partners: “Taking stock and focusing on delivery”.

On 1-2 December (Brussels, Belgium) AE staff and Board members attended an AE Board meeting and a Lunch Debate on dementia prevention.

On 5 December (Lille, France) Ana took part in the working day “People with dementia experiences of participating in the NILVAD clinical trial”.

On 8-9 December (Geneva, Switzerland) AE Honorary Secretary, Charles Scerri attended a workshop on “The diagnosis of Alzheimer’s disease with biomarkers: Now despite no cure, or later ‘only if’?”

On 9-12 December (Barcelona, Spain) Alex attended a series of meetings for the EMIF project and the EMIF Colloquium.

On 10 December (Brussels, Belgium) Annette attended this year’s last EFPIA Think Tank.

On 10 December (Barcelona, Spain) AE Board member, Jesús Rodrigo gave a presentation on AE activities at the EMIF Colloquium.

On 10 December 2014 (Brussels, Belgium) Dianne took part in a workshop to develop the AAL challenge-led call for proposals 2015.

On 18 December (Luxembourg, Luxembourg) Jean met with representatives of Roche.
In memoriam Jerome H. Stone, 1913 - 2015

Jerome H. Stone, Founding President and Honorary Chair of the US Alzheimer’s Association and Founder and Honorary President of Alzheimer’s Disease International (ADI), sadly passed away on 1 January, aged 101.

The Alzheimer’s Association released the following statement:

“The Alzheimer’s Association has lost our Founding President and Honorary Chair, Jerome H. Stone. He was not only a longtime board member, volunteer and advocate, but also a philanthropist who led by example and believed deeply in giving to transform our cause.

Mr. Stone was a true visionary in the Alzheimer’s movement. When his wife, Evelyn, was diagnosed with the disease in 1970, he recognized the need for a leader in the field that would unite caregivers, provide support to those facing Alzheimer’s, and advance research toward treatment, prevention and, ultimately, a cure. His drive and determination led to the creation of the Alzheimer’s Association in 1979.

Mr. Stone is responsible for where we are today in the fight against Alzheimer’s. He took a disease that was cloaked in silence and helped to create a national — and global — conversation. He meant so much to the many who are invested in this cause. We honor his memory and continue his legacy by moving forward to achieve our vision of a world without Alzheimer’s.”

Alzheimer Europe sends its deepest condolences to Mr Stone’s family, friends and colleagues.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 86, representing 26 Member States of the European Union and all political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

Austria: Heinz K. Becker (EPP); Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D).
Bulgaria: Andrey Kovatchev (EPP).
Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).
Cyprus: Eleni Theocharous (EPP).
Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovsky (EPP).
Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D).
Finland: Lisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natra (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP).
France: Nathalie Griesbeck (ALDE); Franoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D).
Germany: Angelika Niebler (EPP); Costas Chrysoyogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Hungary: Ádám Kósa (EPP); Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairéad McGuinness (EPP); Liadh Ní Riada (GUE/NGL).
Italy: Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D).
Lithuania: Vilija Blinkevičiute (S&D).
Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP).
Malta: Therese Comodini Cachia (EPP); Roberta Metsola (EPP).
Netherlands: Esther de Lange (EPP); Lambert van Nistelrooij (EPP).
Poland: Elżbieta Lucakiewska (EPP).
Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Romania: Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP).
Romania: Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D);
Slovakia: Miroslav Mikušišek (EPP); Anna Záborská (EPP).
Slovenia: Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP).
Spain: Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Pablo Zalba Bidegain (EPP).
Sweden: Cecilia Wikström (ALDE).
United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Glenis Willmott (S&D).

EU Projects

8 December: EMIF partners complete second successful year

The EMIF partners closed the second year of the project with a series of conferences, meetings and a public colloquium in Barcelona during 8-12 December.

In the course of the week, some 150 participants from the three topics (Alzheimer’s disease, Metabolics and Platform) presented their results. The public colloquium featured EMIF representatives as well as scientists and researchers from local institutions who presented various aspects of the project and how it can benefit the Catalan region. In addition, the delegates discussed their 2015 activities, including cooperation with other IMI-funded initiatives such as AETIONOMY and the new EPAD project.

Alzheimer Europe (AE) was represented by Board member Jesus Rodrigo. Mr Rodrigo, Executive Director of the Spanish Confederation of Associations of Families of People with Alzheimer’s and other Dementias (CEAFA), gave a presentation on AE activities during the public colloquium.
Porro (Federazione Alzheimer Italia) delivered a presentation on the role of patients and carers’ associations in the Italian context.

The conference was closed by Vito De Filippo (Undersecretary of State to the Ministry of Health) and Jürgen Scheftlein from DG Sanco. The need of further collaboration and the possibility of a follow-up to this conference were addressed by Latvia and Luxembourg, the countries that will take the EU Presidencies for 2015.

1 December: European commission publishes 3rd health report

On 1 December, the European Commission (EC) published the 3rd edition of its “Health at a Glance” report.

The EC introduces the edition as presenting the latest information on health and health systems in 35 European countries, including all European Union Member States, candidate countries (with the exception of Albania due to limited data availability) and European Free Trade Association (EFTA) countries.

The publication is the result of collaboration between the Organisation for Economic Co-operation and Development (OECD) and the EC in the field of health information, with the help of national data correspondents from the 35 countries. It can be downloaded here):


4 December: JPND launches call for research for neurodegenerative diseases

On 4 December, a press release was sent out by the EU Joint Programme - Neurodegenerative Disease Research (JPND), announcing a EUR 30 million call for neurodegenerative disease research topped-up with EUR 10 million from the Horizon 2020 framework programme for research and innovation of the European Union.

This new action, “JPcofUND” - taken together with the European Commission - expects to launch a joint transnational call for proposals in January 2015, aimed at supporting international research collaborations in three JPND priority areas: Longitudinal Cohorts, Animal and Cell Models, Risk and Protective Factors. The initiative will allow more than EUR 30 million, coming from the JPND member countries, to be made available with an additional EUR ten million European Commission top-up.

JPND was established in 2009 to enable participating EU Member States to work together on the challenge of age-related neurodegenerative diseases, in particular Alzheimer’s disease.

A pre-call announcement, with the indicative titles of each topic, was made recently on the JPND website. Further detail on JPcofUND is provided at the link below, and greater detail will be provided on the call launch date in January 2015:

http://www.neurodegenerationresearch.eu/initiatives/jpcofund/
11 December: European Commission wants action on mental health

Mental health is among the first priorities of the public health agenda in Europe and is a priority for the European Commission (EC), says the lead article in the EC’s health newsletter of 11 December.

Over a decade ago, the EC’s Health and Consumers Directorate published a Green Paper - a document published by the EC to stimulate discussion at European level - on developing an EU strategy on mental health. This was followed by the European Pact for Mental Health and Well-being in 2008 and most recently, a Joint Action for Mental Health and Well-being in 2013.

The Joint Action focuses on five areas:
- Mental health at the workplace;
- Mental health in schools;
- Prevention of depression and suicide;
- Developing community-based and socially inclusive mental health care for people with severe mental disorders;
- Integration of mental health in all policies.

National and European working groups have analysed the situation in Europe in each of these five areas with the support of a variety of experts.

Each Work Package has completed a report, with recommendations for action, the first of which (Mental Health at the workplace), was officially presented in Berlin, on 29 and 30 November. The others will be presented soon.

http://www.mentalhealthandwellbeing.eu/

15 December: Michel Goldman bids farewell to IMI

Michel Goldman’s last day as Executive Director of IMI was 15 December. In his farewell message he reflected on IMI’s successes and wrote:

“Before stepping down as Executive Director, I wish to thank all those who made possible the success of the first phase of our public-private partnership. Let’s first acknowledge the key contribution of our founding members, the European Commission and EFPIA, which jointly pioneered a new collaborative model to boost innovation in medicines research and development. Of course, warmest thanks are due to the scientists from public institutions, non-profit and private companies as well as patient groups and regulatory authorities who took advantage of this model to develop unprecedented collaborative efforts and deliver impressive results. Above all, I want to express my deepest gratitude to my collaborators at the IMI Programme Office. Together, we have worked hard to exert our role of honest broker that is critical to the success of multi-stakeholder consortia. I am convinced that they will continue to accomplish their mission with the same remarkable commitment under the leadership of Irene Norstedt, their new acting Executive Director.”

Professor Goldman will now work as a Professor at the Université Libre de Bruxelles, where he will develop new research and teaching activities.

16 December: Irene Norstedt named Acting Executive Director of IMI

The IMI Governing Board has appointed Irene Norstedt as Acting Executive Director of IMI as of 16 December 2014.

Irene Norstedt comes from the European Commission, where she was Head of the Innovative and Personalised Medicine Unit at the European Commission’s Directorate-General for Research and Innovation. She has been at the European Commission since 1996, and was instrumental in the creation of IMI back in 2008. Prior to joining the European Commission, she worked at Swedish life science company Biacore AB and at the Swedish embassy in London.

Meanwhile, the recruitment of a new IMI Executive Director is ongoing; the deadline for applications was in July 2014.

1 January 2015: Latvia takes on the EU Presidency

On 1 January, Latvia took over the mantle of Presidency of the Council of the European Union from Italy. Latvia will preside for the first half of 2015, after which Luxembourg will take its turn for the second part of the year.

At the end of November 2014, Latvia announced its three overarching priorities as:
- **Competitive Europe**: “Europe needs to enhance its entrepreneurial capacity by promoting investment in new and competitive products and services”. The main goal being to generate jobs and economic growth in the EU.
- **Digital Europe**: “Rapidly growing information technologies are providing unprecedented opportunities that have the potential to boost smart, sustainable and inclusive growth for the EU”. The main goal being to develop the foundations of “a truly digital Europe”.
- **Engaged Europe**: “The European Union has the responsibility to assume a full and active role on the global stage. With conflict on EU’s doorstep, the situation in our Neighbourhood is as challenging as ever”. The main goal being to “engage in issues of global importance”.
During a visit to Riga on 4 December 2014, European Parliament President Martin Schulz met with Latvian Prime Minister, Laimdota Straujuma (photographed) in the Latvian capital of Riga.

Mr Schulz has confirmed that Latvia’s priorities during its presidency period are in accordance with EU goals, while Ms Straujuma commented that Latvia and the European Parliament are in full agreement that working together for the good of all EU citizens is paramount. “All of our work must be aimed so that each citizen feels that he or she is needed,” she said.

Concerning EU citizens’ health, the Presidency aims to “highlight the situation of persons with disabilities, as well as the fundamental value of a healthy lifestyle”.

https://eu2015.lv

Members’ News

20 November: Jersey Alzheimer’s Association adopts a new logo

On 20 November, the Jersey Alzheimer’s Association informed us that they have adopted a new logo (pictured).

www.jerseyalzheimers.com

1 December: SDWG members filmed for NHS Education Scotland DVD

The SDWG commented, “Our members are always delighted to take part in any filming work that can be used in educating people on dementia. Archie was very at home in front of the camera and enjoyed his experience. Anne, Henry and David have all taken part in other filming and were also at home in front of the camera.”

The filming, which the members took part in will form part of a DVD in production by NES, which will complement the Scottish national learning resource “Promoting excellence supporting people through a diagnosis of dementia” (which is at the Enhanced Level of Promoting Excellence). The resource and DVD will also be accompanied by a Facilitator’s Guide and will support delivery of learning in teams or on an individual basis.

Patricia Howie, Educational Projects Manager of NES said “the resource will enable health and social service staff to further develop their ability to support people with dementia and their families before, during and after receiving a diagnosis of dementia”.

2 December: The Alzheimer Society of Ireland hosts MEP event

The Alzheimer Society of Ireland hosted a “meet and greet” event for Irish MEPs in the European Parliament on 2 December. The aim of this event was to give MEPs an opportunity to meet with members of The Alzheimer Society of Ireland team, while giving the organisation an opportunity to thank them in person for their support for people with dementia and their carers.

All Irish MEPs have signed the European Dementia Pledge and this event provided a valuable opportunity to revisit the pledge. It was also a good opportunity to update MEPs on the latest regarding dementia care and to discuss how we can continue to make dementia a European Priority.

The event was very successful, with seven MEPs in attendance. The Alzheimer Society of Ireland plans to build on the success of this event by hosting another event in the European Parliament in 2015.

10 December: Alzheimer Bulgaria receives grant for youth project

Alzheimer Bulgaria has received a grant from the NGO Programme in Bulgaria under the European Economic Area Financial Mechanism, for partnering on a project with the “Youth Initiative for Civic Society” association.

The recently-launched project, “Dialogue between Generations for a New Understanding of Dementia” aims to raise awareness and to improve communication between young people and their relatives living with dementia.

Based on a book with the working title “When Memory Goes", Alzheimer Bulgaria would like to explore what happens in a family, when a grandparent or other relative has dementia: What does it mean for the everyday life of young people if they have to look after them? How does it impact their friendships?

Alzheimer Bulgaria will organise meetings in secondary schools, to ask how young people feel when their grandparents go through personality changes and perhaps no longer recognise their grandchildren or forget their names.

Finally, the association will make some proposals on how adults can support and help these young people so that they can get on with their lives, work through any fears and frustrations they may have and become the voices of their grandparents.
12 December: Alzheimer Nederland summarises 2014 - as experienced by people with dementia

On 12 December, Alzheimer Nederland released a video online, called “Zeitgeist 2014: Year in Review”. The video is a spinoff of Google’s annual “Zeitgeist” video, which shows the most searched for events of a particular year.

Alzheimer Nederland took the concept and created a Zeitgeist 2014 video with a twist, in that the events shown are not from 2014 at all. They include:

- The UK Royal Wedding (2011);
- His Holiness Pope Francis’ papal coronation (2013);
- Hurricane Katrina (2005);
- The Challenger space shuttle disaster (1986);
- The deaths of Heath Ledger (2008), Steve Jobs (2011) and Amy Winehouse (2011);
- Spain winning the football world cup (2010).

The closing message reads: “You're now experiencing Alzheimer's disease”.

In fact, the video does not purport to be an accurate representation of what it is like to have Alzheimer’s disease, but is simply intended to raise awareness and stimulate thought and conversation. It seems to be succeeding in its aim, with 344,399 views in just four days (at the time of writing).

https://www.youtube.com/watch?v=waI7_IV_5go

15 December: Alzheimer Scotland brings out three new publications

15 December saw the official launch of three new publications for Allied Health Professionals in Scotland. Published by the Scottish Government and Alzheimer Scotland, these publications highlight the impressive work carried out by AHPs in delivering improvement for people living with dementia and those who care for them, as well as leading change in practice.

Much of this work is being actively supported by Alzheimer Scotland.

The three publications are:

**Agents of Change** – features practice examples provided by some of the AHP Dementia Champions, illustrating how they are implementing new ideas and developing innovations in practice.

**Living Well with Dementia** – features the role AHPs can play, including best practice examples, in supporting people with dementia in the first year after diagnosis, based on Alzheimer Scotland’s 5 Pillar model of Post-Diagnostic support and implemented by the Scottish Government through their Post-Diagnostic Support Guarantee.

**Living Well with Community Support** This publication shows the work AHPs are already involved in at several test sites of Alzheimer Scotland’s 8 Pillar Model of Community Support across Scotland.

You can read the full story on Alzheimer Scotland’s website, which includes links to all three publications, as well as the weekly “Let’s Talk About Dementia” blog:


22 December: Alzheimer’s Society reports on record-breaking total for seasonal UK appeal

On 22 December 2014, the Alzheimer’s Society published an article about their participation in UK television channel, ITV’s “Text Santa” charity appeal:

Last Friday (19 December), ITV’s Text Santa raised the highest total ever at £5,503,065 (Just over EUR 7M), as millions of viewers tuned in to an evening of entertainment.

In four years of fundraising, Text Santa has now raised over £20,500,000 (Just over EUR 26M). The show raises money and awareness for six UK-based charities. This year’s chosen organisations are Alzheimer’s Society, Teenage Cancer Trust, Guide Dogs, WellChild, Marie Curie Cancer Care, and Together for Short Lives.

The Alzheimer’s Society charity video aired on the show featured Paul and Lynne from Cardiff. Lynne was diagnosed with dementia around two years ago. Alzheimer’s Society celebrity spokesperson Carey Mulligan visited the couple’s home to learn about the role Alzheimer’s Society and their Dementia Support Worker, Karen Collins has played in their lives. You can watch the Alzheimer’s Society charity video on the Text Santa website.

Speaking about the money raised, Jeremy Hughes, Chief executive of Alzheimer’s Society said:

“It’s fantastic to hear that we have beaten last year’s fundraising total and we would like to thank ITV viewers for their enormous generosity. By 2015, 850,000 people will be living with dementia in the UK, and the funds raised will be used to support our vital Dementia Support Worker service which is so crucial for people like Paul and Lynne who featured on the show.”

“Text Santa will enable even more people with dementia than we anticipated to receive essential one-to-one advice from our Dementia Support Workers. Funds raised will also go towards a new initiative to support younger people with dementia.”

Some of the highlights from the show included George Clooney appearing in a special sketch of Downton Abbey, performances by Olly Murs and X Factor winner Ben Haenow, and footage from Phillip Schofield’s climb inside the Spire of The Shard.

Last date for donations is 5pm (GMT) on 9 January 2015.

www.itv.com/textsanta/donate
22 December: Finnish Society brings out new publications for children

The Alzheimer Society of Finland has produced new material for children with a parent living with early onset dementia. The new set of material includes a storybook for younger children, a comic book for school-aged children, and a more traditional leaflet for teenagers.

A friendly sea horse (Latin name Hippocampus) features in all the materials as a reminder of the hippocampus in the brain.

25 December: German Alzheimer Society marks 25 years with 25 “advent” articles

To mark the occasion of its 25th anniversary, the German Alzheimer Society (DAzG) published 25 stories written by people living with dementia, relatives of people with dementia, dementia carers and other people involved in the field of dementia. One story was published each day between 1 and 25 December, as a kind of dementia advent calendar.

According to the DazG, the “generated 25 very different articles, showing how diverse the faces of dementia are; that despite dementia, life can have beautiful moments and that that life after diagnosis is far from being over.”

http://www.deutsche-alzheimer.de/ueber-uns/25-geschichten.html

31 December: Alzheimer Portugal continues to push for a national dementia plan

In December, a two-day conference on the National Dementia Plan, organised by the Directorate-General of Health and with the participation of some British experts, took place in Lisbon.

The Directorate-General of Health is the Health Ministry Department that is in charge of creating the National Dementia Plan.

Alzheimer Portugal’s Chairperson was one of the speakers and had the opportunity of explaining that this nationwide Portuguese association has been actively involved in the European Dementia Movement that has as its main objective to urge governments to create national dementia plans or strategies.

The main conclusions of this experts’ meeting were:

- The Plan will necessarily be designed as broad guidelines and so will not allow for many details regarding specificities of the varied geographical areas.
- The idea is to take profit and adapt the already existing structures, promoting better articulation among them and the share of good practices with strong investment in professional and family training.
- The Plan is being prepared in the framework of the Mental Health Program. This means the recognition of the strong impact of dementia on mental health and does not mean ignorance of the neurological origin of many forms of dementia, nor the need to keep in mind the social, economic, ethical and legal impacts.
- Regarding the legal impact, the Social Security Institute drew special attention to the need to change the care legislation, mainly to protect people with no family support (i.e. allowing for professional care).
- The British experience was very inspiring, but it remains very clear that without financing it is not possible to implement a plan.
- Unfortunately, no further steps towards the creation and implementation of a national dementia plan were announced!

31 December: Norwegian Association reacts strongly to reports of human rights breaches in nursing homes

The Norwegian Health Association has reacted strongly to a report that shows improper care for people in nursing homes.

The report from the Norwegian center for human rights reveals that in many nursing homes, actions such as illegal use of force, abuse and neglect, which violate basic human rights, are not uncommon. Many of the people living in nursing homes are people with dementia.

“This is not the first time serious offences like these have been revealed, but this is the first time the investigation has been carried out so thoroughly and on the basis of human rights. Now it is time that the Norwegian government takes action to improve systems to ensure that the basic rights of people living in nursing homes are being adhered to”, says Lisbet Rugtvedt, General Secretary of the Norwegian Health Association.

31 December: Norway’s dementia organisation distributes funds to local initiatives

Over EUR 7.6M has been distributed by the Norwegian Health Association, for local dementia initiatives.

The goal of this distribution has been to promote activities that aim to include people with dementia, as well as to spread information about the condition. The money being distributed was collected in the annual telethon. The different activities span a wide range, including outings, music gatherings and open meetings to inform people about dementia.

“We are using funds from the telethon in different ways, and quite a lot of the money will be allocated to longer-running projects. Some money goes to research and we have already begun recruiting voluntary activity friends for people with dementia. With the local projects we have supported we hope to enable our local groups over the whole country to arrange activities which, hopefully, will improve the life quality of people living with dementia”, says Lisbet Rugtvedt the General Secretary of the Norwegian Health Association.
Policy Watch

2 December: UK Prime Minister and cabinet become Dementia Friends

On 2 December, the UK Cabinet followed Prime Minister Cameron’s lead in becoming “Dementia Friends”.

A training was given to them during the weekly Cabinet meeting, by the Alzheimer’s Society’s CEO, Jeremy Hughes and Eileen Sills, Chief Nurse at Guy’s and St Thomas’ Hospital.

Cabinet members were asked to imagine what it would be like to have dementia and the toll the condition can take on everyday tasks, such as making a cup of tea.

Health Secretary, Jeremy Hunt asked attending Cabinet members to instruct civil servants in their respective departments to undergo the training and become Dementia Friends, a call Mr Cameron endorsed on Twitter after the session: “A brilliant session by @DementiaFriends at Cabinet. I want ministers to ensure staff in their departments join this great scheme.”

Some 600,000 people have taken part in Dementia Friends training, with a national target of one million. The scheme is run by the Alzheimer’s Society in England, Wales and Northern Ireland and by Alzheimer Scotland, in Scotland.

3 December: UK Chancellor announces GBP 15 Million for dementia

UK Chancellor George Osborne’s “Autumn Statement” on 3 December included a pledge of GBP 15 Million (EUR 19 M) towards a new fund for dementia research.

The fund will bring together investors from the public, private and charity sectors to provide investment for innovative research projects. The UK government had previously already committed to spending GBP 66 million on dementia research by next year.

17 December: Irish National Dementia Strategy launched

The Irish National Dementia Strategy was launched in Dublin on 17 December by Taoiseach Enda Kenny, Tánaiste Joan Burton and Minister Kathleen Lynch.

CEO of The Alzheimer Society of Ireland, Gerry Martin welcomed the publication of the report and funding which has been made available for three priority areas: intensive home care supports, GP education and training and dementia awareness. However, Mr Martin described the strategy as just “a first step,” adding that strong leadership was now needed to ensure it delivers for the rising number of people with dementia in Ireland.

Helen Rochford Brennan, Chairperson of the Irish Dementia Working Group and a Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD), has been appointed to a critical role as a member of the National Dementia Strategy implementation group. Helen, who was diagnosed with younger onset dementia in recent years, will continue her sterling work in ensuring the voice of the person with dementia is heard.

You can watch the video about the strategy launch here:
https://www.youtube.com/watch?v=8k-q0BB3Gs


18 December: Alzheimer’s Accountability Act passes into US law

On 18 December, the US Alzheimer’s Association released a statement from its President, Harry Johns, announcing the passing of a new legislative effort led by the Alzheimer’s Association: the Alzheimer’s Accountability Act (AAA). The aim of this new act is to ensure that decisions about funding Alzheimer’s disease (AD) research are guided by the voice of the scientific community.

The US Congress had previously passed the National Alzheimer’s Project Act (NAPA), which led to the creation of a plan, the core objective of which is “to prevent and effectively treat Alzheimer’s by 2025”.

AAA requires National Institutes of Health (NIH) scientists to report to Congress regarding what it will cost to succeed in achieving this goal each year from now until 2025.

USD 25 Million was also added to the budget for AD research, to which Mr Johns said that “while this is certainly not enough, it is 1/6 of the money added to the NIH in this bill and AAA creates the mechanism to raise it higher in future years.” He concluded that, while there remains much to do, the passing of AAA marks “a critical turning point” in AD research history.

Science Watch

18 November: Global consortium hopes to revive promising drugs

A global coalition of charities and funding bodies - The Neurodegeneration Medicines Acceleration Programme (Neuro-MAP) – has pledged up to GBP 30 Million (EUR 38.6 Million) in funding and resources, to try to revive promising drugs for dementia, motor neuron disease and Parkinson’s disease, which had previously stalled in the development stages. Led by medical research charity MRC Technology, Neuro-MAP was launched on 18 November 2014.

The hope is that this new venture will drive forward research on potentially beneficial drugs for neurological diseases, which are currently sitting in pharmaceutical company libraries rather than being developed, then returning them to the companies to test in large-scale clinical trials.
Neuro-MAP will ask pharmaceutical and biotechnology companies to propose projects to the consortium. The Neuro-MAP partner organisations will decide which projects to take on by evaluating patient needs, scientific excellence and commercial potential. Neuro-MAP projects will also support the repurposing of existing drugs and compounds for other conditions, such as testing hypertension drugs for vascular dementia.

Neuro-MAP is composed of the following partners: Alzheimer’s Association (US), Alzheimer’s Research UK, Alzheimer’s Society, ALS Association, Michael J Fox Foundation, MND Association, MRC Technology, Northern Health Science Alliance, and Parkinson’s UK.

18 November: Psoriasis medication could ease the symptoms of AD

The psoriasis medication, acitretin may be effective in alleviating certain symptoms of Alzheimer’s disease (AD), concludes a study published on 18 November in the journal, Neurology. The study was carried out by the Department of Psychiatry and Psychotherapy of the University Medical Centre of Johannes Gutenberg University Mainz (JGU).

It is generally accepted that the activity of enzymes called secretases plays a role in triggering AD. These enzymes cleave proteins on cell membranes, releasing the products of this cleaving process into the extracellular space. In AD, there is increased cleaving of the amyloid precursor protein by beta-secretase, leading to the formation of amyloid-beta peptides, which then aggregate and damage nerve cells.

Acitretin stimulates the activity of the alpha-secretase, ADAM10 (pictured) - a competitor of beta-secretase. It cleaves the amyloid precursor protein in such a way that the synthesis of amyloid beta-peptides is prevented while the growth factor, APPs-alpha is released, protecting the nerve cells.

Taking this as their starting point, the team at JGU decided on a new approach to the treatment of AD. With the cooperation of Professor Stefan Teipel and his team at the German Centre for Neurodegenerative Diseases (DZNE), they administered acitretin (30 mg per day) or placebo in a four week, double-blind study of a group of twenty-one patients clinically diagnosed with mild to moderate AD.

Their results showed elevated levels of APPs-alpha in their spinal fluid, interpreted as a stimulation of the activity of the alpha-secretase ADAM10. This would, in turn, result in the reduced accumulation of AD plaques, they concluded.

Larger-scale and longer-term clinical trials of acitretin would need to be undertaken to ascertain the benefits of the drug for AD patients, the researchers commented.

http://www.neurology.org/content/83/21/1930.short?sid=5c46d7f1-be8d-4ab4-af1e-3c0f0a4f1909

19 November: Roche discontinues phase III AD drug trial

On 19 December, Swiss pharmaceutical company, Roche announced the decision to discontinue its phase III clinical study (WN25203) of gantenerumab in prodromal Alzheimer’s disease (AD), after it failed to prove effective.

Roche commented that the decision was based on results of a pre-planned futility analysis and recommendation by the independent Data Monitoring Committee. The company also said that no new safety signals for gantenerumab were observed in the analysis and the overall safety profile was “similar to that seen in the phase I trial” (NN19866).

Data from the phase III study will be shared with the medical community after review and analysis.

Gantenerumab continues to be studied in another Phase III trial (WN28745) involving patients with later stage disease and Roche has two other experimental Alzheimer’s disease drugs currently in Phase II tests, crenezumab and RG1577.

27 November: Coffee may help protect against Alzheimer’s disease

Drinking coffee may help to protect against Alzheimer’s disease (AD), according to research highlighted in a report published on 27 November, by the Institute for Scientific Information on Coffee (ISIC) - a nonprofit organisation specialising in biomedical research and information dissemination on the potential health benefits of coffee.

According to ISIC’s findings – previously presented by Dr Neville Vassallo, Dr Arfan Ikram and Dr Astrid Nehlig during the Special Symposium, “Nutrition and Cognitive Function” at this year’s Alzheimer Europe (AE) conference in October - the polyphenols and caffeine found in coffee lend it certain protective abilities by inhibiting inflammatory processes linked to neural damage. Caffeine has also been noted in previous studies to help inhibit amyloid plaques and neurofibrillary tangles – both of which are hallmarks of AD.

The team concludes that the most health benefits come from coffee by consuming three to five cups daily.

http://coffeeandhealth.org/topic-overview/coffee-and-alzheimers-disease/

1 December: NHS sets record straight on “wonder drug” for binge-drinking and dementia

On 1 December, the UK’s National Health Service (NHS), released an online response to the British and Irish media’s reports of a “wonder drug” that could cure binge-drinking and dementia.
Stories appeared in late-November and early-December, following a press release from a UK university claiming their scientists had developed a “breakthrough compound reducing harmful side-effects of ‘binge drinking’ and offering potential new ways to treat Alzheimer’s and other neurological diseases”. The press release also stated that the drug, ethane-beta-sultam had been “successfully developed and tested”.

The NHS labelled the media’s reports “premature” and said the university’s press release was “over-excited”, pointing out that the claims were “based on research in rats that has not yet been proven, or even tested, in people”. They conceded that “there may be a way to reduce the effects of excessive alcohol consumption on brain cells. But this is not a “cure” for binge drinking”.

The NHS also pointed out that the drug study only looked at countering the impacts of binge-drinking on the brain, omitting the harmful effects it has on the liver and the rest of the body.

Where the effects of binge-drinking on the brain are concerned, the NHS concluded that the results were indeed promising but that they are only a small step towards achieving a treatment in people. As to claims that ethane-beta-sultam could also be used to treat dementia, it said these were “pure speculation at the moment, as this was not tested.”

The original study was published on 20 February 2014 in the Journal of Alcoholism and Drug Dependence. It was funded by the European Foundation for Alcohol Research and the European Cooperation in Science and Technology (COST) and was carried out by researchers from universities in Italy, Belgium and the UK.

The NHS’ full response can be read here:

The original study can be found here:

1 December: Astra Zeneca and Lilly launch Phase II/III clinical trial

On 1 December, Eli Lilly and Company and AstraZeneca announced they have begun recruitment of patients for a Phase II/III clinical trial for their beta secretes cleaving enzyme (BACE) inhibitor. The drug, AZD3293/LY3314814 is currently under development as a potential therapy for Alzheimer’s disease (AD).

The trial will include more than 1500 patients in 15 countries and aims to evaluate the safety and efficacy of the orally administered drug versus placebo, over the course of two years of treatment.

In Phase I studies it was shown that AZD3293/LY3314814 reduced the amount of amyloid-beta in the cerebro-spinal fluid, which could ultimately decrease the progression of AD.

The study is expected to complete in May 2019, according to the clinicaltrials.gov website.

2 December: US research says diabetes may bring on earlier dementia

In a new analysis of health data, researchers from Johns Hopkins Bloomberg School of Public Health in Maryland, US say they have found direct links between diabetes and cognitive decline.

Their results were published in the journal, Annals of Internal Medicine on 2 December.

The authors studied data from nearly 16,000 participants in four US communities, whose brain health was evaluated three times between 1990 and 2013. The average age upon entry to the study was just short of 60 years and 13 percent of the participants had diabetes.

The team found that, on average, a 60-year-old with diabetes experienced a decline in their brain function that was on par with that of a 65-year-old without diabetes. This apparent speeding up of brain aging by five years in those with diabetes, the researchers conclude, could hasten the onset of dementia in later life.

The findings suggest that people who control their blood sugar or glucose levels early in life may also protect their brain’s health, but the topic needs further study, the researchers conclude.

http://annals.org/article.aspx?articleid=1983393&resultClick=3

2 December: Caution advised as DNA home-testing kit goes on sale in the UK

A home-use DNA testing kit that gives users an insight into their genetic make-up went on sale in the UK on 2 December. The kit, which uses a saliva sample, claims to reveal risk factors for developing various conditions including Alzheimer’s disease, as well as offering over 100 reports on health, trait and ancestry information. The company responsible, however, says its product is not intended as a diagnostic tool.

UK-based Alzheimer’s disease charities have warned that the kit could cause unnecessary alarm and that people should speak to their doctors if they are concerned about developing dementia, rather than relying on a DNA kit for answers.

Professor Frances Flinter, of King’s College London, said the UK has “excellent” genetics services, adding: “Genetic testing without the professional support of experienced staff may be less informative or even misleading.”

The service, which was banned from being advertised by the US Food and Drug Administration in 2013 due to concerns over the accuracy of the data gathered, is costed at GBP 125 [EUR 158] and over 10,000 kits had already been purchased by UK residents at the time of writing.

2 December: Biogen announces Phase III clinical trial for AD drug

Pharmaceutical company, Biogen Idec Inc has announced that it is skipping Phase II and moving its experimental drug for Alzheimer’s disease (AD) straight into a Phase III
clinical trial. The move was announced on 2 December, at the Deutsche Bank BioFEST conference in Boston, US.

The company said its drug, BIIB037 had successfully reduced amyloid plaques and increased cognitive function in asymptomatic patients and those with mild AD symptoms in its Phase Ib trial.

The most significant side effects seen in early testing were signs of possible brain swelling and tiny hemorrhages, which the company described as "largely mild to moderate, and self-resolving." Brain swelling has been a recurrent issue with experimental anti-amyloid AD drugs.

Maria Carrillo, Vice-President of Medical and Scientific Relations at the US Alzheimer’s Association, remained cautious:

"In general, we are encouraged by the notion of positive results, but we need to see the full data before we can say more," she said. "Early clinical trial results need to be replicated in large-scale trials".

It is likely to be 2017 or 2018 before Biogen’s final results are out.

**3 December: Potential drug target identified for frontotemporal dementia**

Boosting the function of the glutamate, N-methyl-D-aspartate (NMDA) may provide benefit to patients with the second most common type of dementia - frontotemporal dementia (FTD), according to research carried out by US scientists. The team, from the University of Alabama at Birmingham (UAB) published their findings in the Journal of Neuroscience on 3 December.

The team’s efforts focused on mutations in certain genes, primarily in the Microtubule Associated Protein Tau gene. They used new mouse models expressing human tau with an FTD-associated mutation, which demonstrated behaviours similar to those seen in humans with FTD, such as compulsive, repetitive actions in grooming. The mice also had impaired synaptic and network function in certain brain network regions.

The team found that mutant tau impairs synapses by reducing the size of the anchoring sites of NMDA. Lead study author, Dr Erik Roberson, Associate Professor in the Department of Neurology explained that "reduction of the anchoring sites left fewer NMDA receptors available at the synapse to receive excitatory signals, thus limiting synaptic firing and network activity."

The team then employed cycloserine, a drug already approved for human use, which is known to assist NMDA receptor function. This boost of NMDA receptor function was able to restore synaptic firing and thereby restore network activity in the mouse models. The restoration of normal network activity reversed the behavioral abnormalities.

The researchers say their findings indicate that boosting NMDA receptor function could potentially treat humans with FTD. Further preclinical validation is required prior to testing their hypothesis in clinical trials.

FTD causes rapid and dramatic changes in behaviour, personality and social skills and often begins quite young, in a person’s mid- to late 50s. People with this type of dementia tend to die within about six to eight years of the initial onset.

http://www.jneurosci.org/content/34/49/16482

**8-9 December: International AD workshop explores diagnosis with biomarkers**

On 8 and 9 December, Alzheimer Europe (AE) Honorary Secretary, Dr Charles Scerri attended an International Workshop in Geneva, Switzerland on "The diagnosis of Alzheimer’s disease with biomarkers: Now despite no cure, or later ‘only if?’”

The aim of this two-day international workshop was to bring together experts in the field of Alzheimer’s disease (AD) biomarker research and discuss recent initiatives and developments in this particular field with the goal of reaching a consensus on biomarker maturity.

Alzheimer Europe was invited to give its views on patients’ preferences and utilities to early and differential diagnosis of neurodegenerative diseases with cognitive impairment. Dr Scerri focused his delivery on the various questions and issues faced by patients and caregivers during the various stages of dementia and the role of Alzheimer Europe in providing information to its member organisations and interested parties through its European Dementia Observatory. The need to view dementia holistically was also mentioned (including the role of psychosocial interventions), together with AE’s latest initiative: the Glasgow Declaration.

Top international scientists in the biomarker and dementia research fields were invited to attend this workshop. These included Bruno Dubois, Giovanni Frisoni (organiser), Clifford R. Jack, Agneta Nordberg, Bengt Winblad, Philip Scheltens, Osman Ratib and Yasui Yukata (discussing biomarker development in oncology). Birgitta Martensson (Alzheimer Suisse – full member of AE) was also invited, together with other representatives of European scientific societies (European Society of Neuroradiology, European Federation of Clinical Chemistry and Laboratory Medicine, Federation of European Societies of Neuropsychology, Swiss Federation of Clinical Neuro Societies and European Association of Nuclear Medicine).

In conclusion, the invited representatives agreed on the need to validate biomarkers in parallel with drug development, the need for more certified memory clinics, run by qualified personnel and the need to focus on the pre-symptomatic stage of dementia.

**11 December: Erectile dysfunction drug could double as dementia treatment**

A commonly prescribed drug used to treat erectile dysfunction in men could become the next treatment for vascular dementia, according to the charities, Alzheimer’s Society (UK) and Alzheimer’s Drug Discovery Foundation (ADDF).
The drug, tadalafil, is to be investigated in new research funded by the two charities in a cross-Atlantic research partnership, it was announced on 11 December.

A team of scientists, led by Dr Atticus Hainsworth at St George’s, University of London, UK will explore whether tadalafil, which works by dilating blood vessels, could help prevent vascular dementia by increasing blood flow to the brain.

Vascular dementia is the second most common form of dementia. The condition is often caused by damage to the small blood vessels of the brain leading to reduced blood flow to brain tissue. This blood vessel damage – known as small vessel disease – is seen in the brains of 50-70 per cent of older people. The researchers hope that tadalafil’s blood-flow boosting properties can prevent the damage that leads to vascular dementia.

15 December: UK report suggests ways to reduce dementia risk

A review of academic studies and data completed by Age UK suggests five steps people can take to maintain brain health and reduce their risk of developing dementia. The resulting report states that approximately 76% of cognitive decline is accounted for by lifestyle and other environmental factors and suggests that there is significant potential to influence these changes.

Age UK drew on the latest international dementia studies, which have indicated that certain lifestyle factors - regular physical exercise, eating a Mediterranean diet, not smoking, not drinking alcohol heavily - decrease the risk of developing dementia. In addition, preventing and treating diabetes, high blood pressure and obesity have been found to reduce the risk.

One large UK study included had found that men aged between 45 and 59, who adhered to at least four out of the five lifestyle recommendations, had a 36% lower risk of developing dementia than those who did not.

Physical exercise three to five times per week for between 30 and 60 minutes was found to be the most beneficial for long-term brain health.


22 December: Non-invasive scans may spot AD early on

An interdisciplinary team of scientists and engineers at Northwestern University, Illinois, US has developed a noninvasive MRI (magnetic resonance imaging) approach to detect Alzheimer’s disease (AD) in a living animal, at the earliest stages - well before typical AD symptoms appear.

The study results - obtained using mouse models and also drawing on human brain tissue both with and without AD - were published on 22 December in the journal, Nature Nanotechnology. Led by neuroscientist, Prof. William L. Klein and materials scientist, Prof. Vinayak P. Dravid, the research team developed an MRI probe that pairs a magnetic nanostructure (MNS) with an antibody, to seek out the amyloid beta brain toxins responsible for onset of the disease.

This ability to detect the molecular toxins may one day enable scientists to spot problems earlier and to better design drugs or therapies to combat and monitor the disease. Also, while not the focus of the study, early evidence suggests the MRI probe may stop memory decline, by binding to the toxins to stop them doing further damage.

http://www.nature.com/nnano/journal/v10/n1/full/nnano.2014.254.html

31 December: Stem cell study may lead to new dementia drug targets

Belgian scientists have completed a study, reprogramming skin cells from three dementia patients into induced pluripotent stem cells (iPSCs) - immature cells that mimic stem cells taken from early-stage embryos. Their findings, which revealed a signalling pathway linked to frontotemporal dementia (FTD), were published in the journal, Stem Cell Reports on 31 December.

Prof. Philip Van Damme, from the Leuven Research Institute for Neuroscience and Disease in Belgium, said: “Our findings suggest that signalling events required for neurodevelopment may also play major roles in neurodegeneration.

Treatment with a drug that suppressed the pathway, known as “Wnt”, restored the ability of neurons affected by the disease to develop normally. “Targeting such pathways may result in the creation of novel therapeutic approaches for frontotemporal dementia”, Prof. Van Damme said.

The researchers found that iPSCs derived from the patients’ cells were unable to generate cortical neurons, the cell type most affected by FTD. Cortical neurons are the cells responsible for most of the brain’s complex higher activity enabling thought, perception and voluntary movement.

Co-author Dr Catherine Verfaillie, from the University of Leuven in Belgium commented that iPSC models could now be used to better understand dementia, and in particular FTD, which accounts for about half of dementia cases before the age of 60.

www.cell.com/stem-cell-reports/abstract/S2213-6711%2814%2900358-0

Dementia in Society

28 November: Darth Vader actor David Prowse reveals he has dementia

Original Darth Vader actor, David Prowse has been diagnosed with dementia. The 79-year-old shared the news of his diagnosis on 28 November, coinciding with the online release of the first

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Mr Prowse, a former bodybuilder turned actor, played the part of Darth Vader in the first three Star Wars movies made, “Star Wars”, “The Return of the Jedi” and “The Empire Strikes Back”. Actor James Earl Jones provided the character’s iconic voice and Olympic swordsman Bob Anderson took over in the fight scenes.

Many original Star Wars actors are returning for the new movie - due for release on 18 December 2015 - including Harrison Ford, Mark Hamill and Carrie Fisher.

16 December: Julianne Moore praised for role as professor with early onset Alzheimer’s disease

In “Still Alice”, due for release in cinemas on 16 January, Hollywood actress Julianne Moore plays Alice Howland, a 50-year-old professor of linguistics with early-onset Alzheimer’s disease (AD). Alice begins to lose her grip on the English language, to forget things and get lost while out running on campus one day, all of which lead to a diagnosis of early-onset Alzheimer’s disease. The story follows her as she tries desperately to cling to her identity, despite losing grip on her prized linguistic skills and wit.

While the film is based on Lisa Genova’s novel of the same name, much of its critically-acclaimed realism was informed by the real-life experiences of writer-director team, Richard Glatzer and Wash Westmoreland. Mr Glatzer and Mr Westmoreland, who married in 2013, have been struggling with Mr Glatzer’s diagnosis of Amyotrophic lateral sclerosis (ALS) since 2011.

Four-time Oscar nominee, Ms Moore has received high praise for her portrayal of Alice Howland and has been strongly tipped to receive the Academy Award for Best Actress in 2015.

Kristen Stewart and Alec Baldwin co-star as her youngest daughter and her husband respectively.

New Publications & Resources

1 December: 3rd Journal of Prevention of Alzheimer’s Disease published

In December, the 3rd issue of the Journal of Prevention of Alzheimer’s Disease (JPAD) was published.

JPAD publishes reviews, original research articles and short reports to help improve knowledge in the field of AD prevention including neurosciences, biomarkers, imaging, epidemiology, public health, physical cognitive exercise, nutrition, risk and protective factors, drug development, trials design and health economic outcomes.

It also publishes the meeting abstracts from Clinical Trial on Alzheimer Disease (CTAD) and will be distributed both in paper and online version worldwide.

You can find the current issue here:
http://www.jpreventionalzheimer.com/current-issue.html

1 December: English charities publish damning dementia care report

Marie Curie Cancer Care and Alzheimer’s Society have collaborated to produce a report on “Living and dying with dementia in England: Barriers to care”.

The report, published on 1 December, says that people with dementia in England often can’t access quality care because the illness is not properly recognised as a terminal diagnosis. Highlighting the issues faced in the late stages of life and the barriers to quality care encountered, the report says: “Many of our responses to terminal illness and ultimately to death and dying have been shaped in response to cancer.” Core services needed to transform to respond to the needs of people with conditions such as dementia, it says.

Jeremy Hughes, chief executive at Alzheimer’s Society, commented: “there are unacceptable failures to prepare and plan for end of life care. Despite much attention on dementia in recent years, many people with dementia are not dying where they had hoped; others face meeting the end of their life in pain or without dignity.”

The Department of Health said: “We are putting an unprecedented focus on ensuring that dementia patients get high quality care tailored to their needs right through their illness - including the end of their lives. NHS England is addressing the issues raised by this report as part of a wide range of initiatives”.

5 December: Swiss brochure on “rights and duties” is published

The Swiss Alzheimer Association published an updated and more complete version of their brochure, “Droits et Devoirs” (rights and duties) on 5 December. It contains two additional sections on independent living with dementia and on judgement and decision-making with dementia.

The publication can be downloaded or ordered for free at:

Job opportunities

11 December: Oxford University seeks two Psychiatry Postdoctoral Research Assistants

Oxford University’s Psychiatry department is looking for two Postdoctoral Research Assistants in Bioinformatics. The positions are full-time, for a fixed term of three years.

The successful candidates will have either a biological/medical or a computational/statistical background. Candidates with a combination of both fields are especially encouraged to apply.

You can find more information about the positions here:
https://www.recruit.ox.ac.uk/pls/hrislivedoc/docs/0011619880.pdf
AE Calendar 2015

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<td>Meeting with Association Luxembourg Alzheimer (Luxembourg, Luxembourg)</td>
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<td>8 January</td>
<td>Exploratory meeting for new joint Action on Dementia (Luxembourg, Luxembourg)</td>
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<td>15 January</td>
<td>GSK HAB meeting (Brentford, UK)</td>
<td>Annette</td>
</tr>
<tr>
<td>21 January</td>
<td>Meeting with representative of University of Wolverhampton (Luxembourg, Luxembourg)</td>
<td>Jean, Dianne</td>
</tr>
<tr>
<td>23 January</td>
<td>Launch meeting of MIND-AD project (Stockholm, Sweden)</td>
<td>Jean</td>
</tr>
<tr>
<td>29 January</td>
<td>Meeting with Sanofi (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
</tbody>
</table>

Future Conferences 2015

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 February</td>
<td>Leading change in dementia diagnosis and support: actions to inform future national strategy, <a href="http://www.kingfund.org.uk">www.kingfund.org.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>16-17 March</td>
<td>First Ministerial Conference on Dementia at the World Health Organization, <a href="http://www.alz.co.uk">www.alz.co.uk</a></td>
<td>Geneva, Switzerland</td>
</tr>
<tr>
<td>18-22 March</td>
<td>AD/PD 2015, The 12th International Conference on Alzheimer’s and Parkinson’s Disease, www2.kenes.com/adpd/pages/home.aspx</td>
<td>Nice, France</td>
</tr>
<tr>
<td>27-28 March</td>
<td>19th annual meeting of the German Society of Neurogenetics (DGNG), <a href="http://www.dgng.de">www.dgng.de</a></td>
<td>Bonn, Germany</td>
</tr>
<tr>
<td>24-17 May</td>
<td>9th Panhellenic Conference on Alzheimer’s Disease and 1st Mediterranean Conference on Neurodegenerative Diseases, <a href="http://9thconference25.med.auth.gr/conference/gr/index.html">http://9thconference25.med.auth.gr/conference/gr/index.html</a></td>
<td>Thessaloniki, Greece</td>
</tr>
<tr>
<td>20-23 June</td>
<td>1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/berlin2015">www.eaneurology.org/berlin2015</a></td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>2-4 September</td>
<td>14th Alzheimer Europe Conference - “Dementia: putting strategies and research into practice”</td>
<td>Ljubljana, Slovenia</td>
</tr>
<tr>
<td>9-12 March 2016</td>
<td>14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ad-springfield.com">www.ad-springfield.com</a></td>
<td>Athens, Greece</td>
</tr>
</tbody>
</table>
25th Alzheimer Europe Conference
Dementia: putting strategies and research into practice
Ljubljana, Slovenia / 2–4 September 2015
Mark the dates!

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.