Editorial

Welcome!

I hope you all enjoyed the summer.

We have been busy as usual in August and September, with final preparations for our Glasgow conference (20-22 October). We have already reached a record number of registrations, but it is still possible to register until 12 October. You can also register for one of Alzheimer Scotland’s free Master classes, which take place the day after the conference, but the closing date for those is 3 October, so please hurry!

We have also been contacting the 84 MEPs who, earlier this year, committed to joining our European Alzheimer’s Alliance (EAA). We are delighted to have already secured three new EAA Vice-chairs. Our campaign to sign even more MEPs up to the alliance continues.

I was recently privileged to attend the Dementia Legacy conference hosted by the Canadian government. The event aimed to explore collaborative opportunities for research and to foster a collective approach to current issues surrounding dementia.

It has been a busy couple of months on the policy front too: In Greece, a national strategy has just been launched; the German Dementia Alliance has launched its agenda too; Ireland should have confirmation on their national strategy any day now and Spominčica has continued to push its strategy agenda forward, meeting with the Slovenian President to get him on board.

There has been plenty of other member activity also, especially on and around World Alzheimer’s Day (WAD) on 21 September. Also in this context, UN Independent Expert, Rosa Kornfeld-Matte called on Member States to do more to protect older people with dementia, while World Dementia Envoy, Dr Dennis Gillings made a video announcement, touching on the “human cost” as well as the financial cost of dementia. This year’s World Alzheimer Report from ADI was released as well, emphasising risk reduction and prevention.

In European news, President Juncker announced his new Commission earlier this month, which has yet to be confirmed by the European Parliament. He also announced a decision to move the pharmaceutical and health technology portfolios from the Directorate for Health and Consumers to the Directorate for Internal Market, which has been met with criticism from the public health community in Europe. We are looking forward to working closely with the Commissioner for Health, Mr Vytenis Andriukaitis and the Commissioner for Research, Mr Carlos Moedas.

Finally, in science news, a study looking into the effects of obesity in middle age and another into the effects of taking benzodiazepine for longer than the recommended maximum time have thrown up possible risk factors to consider. The NFL’s announcement, during a court case, that it believes about 30% of its former players will get dementia may also give players of heavy contact sports pause for thought.

I hope to see you in Glasgow for our annual conference!

Jean Georges
Executive Director
Alzheimer Europe

22 July: Helga Rohra features in Dementia Legacy Event video

Participants at the Global Dementia Legacy Event in London on 19 June were asked which actions they would most like to see taken to increase dementia research. A video of those interviewed, including the chairperson of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD), Helga Rohra, was released online on 22 July.

Many of the interviewees stress the importance of collaboration and cohesion. Indeed, Ms Rohra says that dementia, which she describes as “one of the greater challenges for the whole world” can only be managed if private investors, researchers, people affected and carers work together to identify and to support scientists who can find a cure for the disease.

Her response can be seen at 2.47 in the video:

https://www.youtube.com/watch?v=7ZbpxiIaS8k

8 August: AE continues to comply with EMA financial requirements

On 8 August, the European Medicines Agency (EMA) informed Alzheimer Europe that their financial assessment of the organisation had been finalised and confirmed that Alzheimer Europe continues to comply with the financial requirements as defined within the eligibility criteria.

31 August: Alzheimer Scotland offers master classes at AE conference

Delegates registered at this year’s Alzheimer Europe conference in Glasgow, 20-22 October, are invited to register for one of five master classes being offered by Alzheimer Scotland.

The master classes will take place the day after the conference, are open to all conference delegates and are free of charge. Registration is required, however and should you wish to attend, please register before the closing date of 3 October.

The schedule is 10 am to 3 pm on 23 October.

www.alzscot.org/masterclasses

10 September: Seminar explores and compares care planning and quality of life of older people with dementia in Germany and Sweden

On 10 September 2014, the Nordische Botschaften in Berlin organised a German-Swedish seminar on “Care planning and quality of life of older people with dementia”.

Several interesting topics were addressed such as dementia services and care for migrant populations with dementia, improving quality of life through the Swedish Dementia Centre and Silvia Home and safety alarm systems.

Dianne Gove presented the guidelines on improving continence care of people with dementia living at home developed by Alzheimer Europe in collaboration with SCA.

She raised the issue of incontinence being a predictor for institutionalization and hence the need to provide appropriate support for people with dementia and their carers as a means to promote quality of life and independent living, and the importance of having guidelines dedicated to such support for people with dementia living at home.

Helga Rohra, Chair of the European Working Group of People with Dementia, was a member of the panel discussion on quality of life, where she emphasised the specific needs of younger people with dementia, the importance of social inclusion, dementia-friendly communities and the need to involve people with dementia at all levels of decision making.

25 September: AE makes final arrangements for October conference

Alzheimer Europe (AE) is currently putting the finishing touches to its annual conference in Glasgow from 20 to 22 October.

The final programme of the Alzheimer Europe Conference in Glasgow, Scotland is available online. It includes 169 speakers and 162 poster presentations.

At the time of writing, a record number of 712 delegates were already registered, including 41 people living with dementia. Online registration will end on 12 October 2014 for the conference as well as for the gala dinner, spaces permitting.

Numbers being so high this year, the conference hotel is fully booked. If delegates wish to find a different hotel for their stay in Glasgow, they can contact the Glasgow Marketing Bureau who will be able to assist them.

The conference app, which gives information on the conference programme and speakers, is available for download or update. Delegates can use the web-based app here, download it from the Apple app store for IPhone or IPad or download it from the Google app store for Android phones or tablets.

The official Twitter hashtag for this year’s conference is #24AEC and is already in use.

Register Now!

24th Alzheimer Europe Conference
EU Projects

12 July: PharmaCog partners at the AAIC conference

Various PharmaCog researchers presented project results and posters at the AAIC 2014 conference, which took place during 12-16 July in Copenhagen, Denmark.

Claudio Babiloni presented “On-going frontal alpha rhythms are dominant in passive state and desynchronize in active state in adult gray mouse lemurs” and “Men and mice’ written by PharmaCog: Can EEG markers of Alzheimer’s disease be back-translated to mouse models?”

Dr Babiloni also presented three posters:

- “Frontal cortical sources of auditory oddball event-related potentials are related to cerebrospinal fluid β amyloid in amnestic MCI subjects”
- “Cortical sources of resting state eyes closed EEG rhythms are correlated to cerebrospinal fluid β amyloid in amnestic MCI subjects”
- “Effects of donepezil on EEG-EMG markers in wild type (WT) and triple transgenic (TaupS2APP) mice EEG markers of motor activity in mice in physiological and pathological aging”

Esther Schenker presented the poster “In vivo microdialysis reveals (age-dependent) modification of frontocortical interstitial fluid levels of amyloid b1-40, b1-42, tau and other ‘classical’ neuromodulators in different strains of transgenic mice”.

In November 2014, Dr Schenker will present the poster “Age-dependent changes of beta-amyloid and tau protein in two mouse models of Alzheimer’s disease” at the Neuroscience 2014 conference in Washington, DC.

18 September: AETIONOMY holds General Assembly meeting

The first AETIONOMY General Assembly took place on 18-19 September in Biberach, Germany. The event was hosted by Boehringer Ingelheim and chaired by Martin Hofmann-Apitius, Academic Coordinator for the project.

AETIONOMY aims to generate disease-specific, mechanism-based taxonomies for Alzheimer’s and Parkinson’s diseases, which will hopefully lead to better treatments. Prof Hofmann-Apitius welcomed the delegates and gave a general progress report of the five year project that began in 2014. He was followed by the work package leaders, each of whom gave detailed updates of their ongoing tasks.

Nine months into the project life, AETIONOMY is still in its first phase. Achievements to date include the development of a data model and mapping file, as well as a decision on the biomarkers to be included in the final study. In addition, the External Scientific Advisory Board and the Legal and Ethical Advisory Board have both been established.

The second day consisted of a series of presentations about related research projects that may complement or enhance the efforts of the AETIONOMY partners. The group discussed potential areas of cooperation and also heard about the latest activities of IMI, the Innovative Medicines Initiative.

This work has received support from the EU/EFPIA Innovative Medicines Initiative Joint Undertaking AETIONOMY grant n° 115568.

www.aetionomy.org

European Alzheimer’s Alliance

30 September: European Alzheimer’s Alliance has three new Vice-chairs

The European Alzheimer’s Alliance (EAA) is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) committed to supporting Alzheimer Europe (AE) and its members in making dementia a public health priority in Europe.

Thanks to our European Dementia Pledge campaign, in the run-up to the European Parliamentary elections in May, the EAA has grown in numbers from 71 to 84 MEPs, compared with the last parliamentary term. Our campaign to reach additional MEPs to join the Alliance continues.

During the month of September, we have been contacting all 84 current EAA members to welcome them, as well as asking some to act as Vice-chairs for the Alliance.

At the time of writing, three Vice-chairs were confirmed: Marisa Matias (GUE-NGL, Portugal), Nessa Childers (S&D, Ireland) and Keith Taylor (Greens/EFA, UK). The search for three more continues (one from each of the three other parties: EPP, ECR and ALDE).

http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer’s-Alliance

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Alzheimer Europe Networking

On 2 September (Luxembourg, Luxembourg), Jean met with representatives of the Health Director of the European Commission.

On 10 September (Brussels, Belgium) Annette attended the EFPIA regular Think Tank with patient organisations.

On 10 September (Berlin, Germany) Dianne attended the German-Swedish seminar on “Care planning and quality of life older people with dementia”.

On 11 and 12 September (Ottawa, Canada), Jean participated in the second G7 Legacy Event dedicated to dementia.

On 15 September (Berlin, Germany), Jean participated at the launch meeting of the German “Alzheimer Agenda”.

On 16-18 September (Copenhagen, Denmark) Annette represented Alzheimer’s Disease International at the 64th session of the World Health Organization (WHO) Regional Committee for Europe.

On 18-19 September (Biberach, Germany) Ana and Alex attended the first General Assembly of the AETIONOMY project.

On 22 September (Glasgow, UK) Gwladys met with suppliers for the 24th AEC.

On 21 September (Mexico-City, Mexico) Heike’s welcome video (in Spanish) was featured at a WAD event in the main square, the Zocalo, where 15,000 people gathered to learn about Alzheimer’s disease.

On 22-23 September (Barcelona, Spain), Alex attended an EMIF Communications Task Force meeting.

On 22 September (Amsterdam, Netherlands), Jean participated in a forum organised by Roche on dementia.

On 23 and 24 September (Amsterdam, Netherlands), Dianne and Jean attended the second meeting of the PredictND project.

On 26 September (Brussels, Belgium) Annette attended the European Patients Forum Public Affairs Group meeting.

On 26 September 2014 (Luxembourg), Dianne attended the conference “Programm Demenz Prävention-PDP” organised by the Luxembourg Ministry of Health.

On 29 September (Ljubljana, Slovenia) Gwladys met Štefanija from Spominčica for a site visit to prepare the 25th AEC.

EU Developments

26 August: Ten international working groups funded under JPND call

The EU Joint Programme - Neurodegenerative Disease Research (JPND) has released the results of a “rapid action” call to support ten working groups of scientists in finding ways of enhancing the use of longitudinal cohort studies for neurodegenerative disease (ND) research.

The call was originally launched on 23 April and was facilitated by the UK Medical Research Council. Final funding decisions were based upon scientific evaluation and recommendations to the ten sponsor countries by a JPND Peer Review Panel. They cover a wide ND landscape including, among others, Alzheimer’s disease, Lewy-body dementia and vascular dementia.

Each Working Group is expected to run for a maximum of 6 months, reporting back to JPND by the first quarter of 2015.

http://goo.gl/AlJyp

26 August: EMA releases booklet on EU regulatory system for medicines

On 26 August, the European Medicines Agency (EMA) published an illustrated leaflet explaining how the European regulatory system for medicines operates.

The leaflet describes how medicines are authorised and monitored in the EU and how the European medicines regulatory network – a partnership between the European Commission, the 50 medicines regulatory authorities in the EU and the European Economic Area (EEA) and the EMA – works to try and ensure patients have access to safe and effective medicines.


10 September: Jean-Claude Juncker unveils the new Commission

European Commission President-elect, Jean-Claude Juncker unveiled his new Commission team on 10 September, as well as announcing some changes to its shape. The team still needs to be confirmed by the European Parliament and hearings of Commissioners will be organised to this end.

Having personally interviewed all 28 potential candidates - comprised of the nominated Commissioner from each member country - Mr Juncker named seven Vice-
Presidents, six in addition to already named High Representative of the Union for Foreign Policy and Security Policy, Federica Mogherini of Italy. These posts went to Frans Timmermans of the Netherlands (named First Vice-President), Kristalina Georgieva of Bulgaria, Andrus Ansip of Estonia, Valdis Dombrovskis of Latvia, Alenka Bratusek of Slovenia and Jyrki Katainen of Finland (Commissioner for Jobs, Growth, Investment and Competitiveness).

Vytenis Andriukaitis of Lithuania was named Commissioner for Health & Food Safety; Carlos Moedas of Portugal was named Commissioner for Research, Science and Innovation and Marianne Thyssen of Belgium was names Commissioner for Employment, Social Affairs, Skills and Labour Mobility.

Among the changes to the workings of the Commission is that each Vice-President will lead a project team and will thus have a stronger mandate to oversee a wider policy area. Each will be steering and coordinating the work of a number of Commissioners in compositions that may change according to need and as new projects develop over time.

http://ec.europa.eu/about/juncker-commission/structure/index_en.htm

15-18 September: WHO hosts 64th Regional Committee for Europe meeting

Over 410 participants registered for the World Health Organization (WHO) 64th Regional Committee for Europe meeting, including 53 Members States, UN Agencies and NGOs. It took place from 15 to 18 September, in Copenhagen, Denmark.

This year’s agenda included the first report on the implementation of Health 2020, the outcomes of conferences, a strategy for investing in children, an action plan on food and nutrition in the WHO European Region for 2015–2020, a regional action plan on vaccines for 2015–2020, the WHO reform programme budget, the strategic budget allocation.

A draft framework spelling out WHO Europe engagement with non-state actors, NGOs, private-sector entities, philanthropic foundations and academic institutions in their regional meetings was also discussed. In this area, the International Alliance of Patient Organisations (IAPO), the World Federation of Occupational Therapists (WFOT), the International Confederation of Midwives (ICM), the World Organisation of Family Doctors Europe (WONCA Europe) and Alzheimer’s Disease International (ADI) produced a joint statement indicating their willingness to contribute to WHO Europe’s strategies.

A short ceremony was organised on 16 September for the WHO World No Tobacco Day Awards. These awards are given every year to individuals and/or organisations in recognition of their accomplishments in tobacco control.

WHO Regional Director for Europe, Zsuzsanna Jakab’s mandate coming to an end, the election of a new Regional Director for Europe had to take place. Ms Jakab was re-elected for another five years.

Annette Dumas, EU Public Affairs, Alzheimer Europe, represented ADI at this meeting.

16 September: European Commission adopts EY2012 report

On 16 September, the European Commission adopted a report on the implementation, results and overall assessment of the 2012 European Year for Active Ageing and Solidarity between Generations (EY2012).

According to the report, EY2012 has helped convey a more positive image of population ageing by highlighting the potential of older people and promoting their active participation in society and in the economy. It has mobilised a number of governmental and non-governmental actors. It also states that many Member States and civil society organisations have used the European Year as an opportunity to develop new initiatives or to strengthen their existing ones.

Several tools have been or are being developed for the purpose of maintaining this momentum. In particular:

- the guiding principles on active ageing,
- the active ageing index,
- the covenant on demographic change.

The report is available in all EU languages. The external evaluation is available in English while the executive summary can be read in English, French and German.

http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=2129&further=News+yes

17 September: EC decision to move medicines out of health portfolio sparks concern

On 17 September, 27 actors from the public health community in Europe, including the European Patients’ Forum (EPF) sent an open letter calling on European Commission President-elect, Jean-Claude Juncker to reverse his decision to move the pharmaceutical and health technology portfolios from the Directorate for Health and Consumers to the Directorate for Internal Market.

The signatories express their “astonishment and concern”, regarding Mr Juncker’s decision, stating that “People living in Europe have the right to high quality, safe, affordable and effective treatments. Pharmaceuticals and medical devices are not - and should not - be considered as any other internal market product because they safeguard people’s health.”

They implore President Juncker to reconsider this unexpected decision and point out that the needs of patients can be in conflict with the interests of industry:

“The shift you are proposing sends the wrong signal to European citizens and patients – namely that economic interests come before their health. This is not the sort of signal the EU wants to send.”

The letter labels this move “a major step back” and ends by urging Mr Juncker to “show bold leadership and to put health interests first.”

Members’ News

1 August: Spominčica (Alzheimer Slovenia) has a new logo

Earlier this year, Spominčica (Alzheimer Slovenia) adopted a new logo. The logo now includes the mention “Alzheimer Slovenija” to help make the association more recognisable outside Slovenia.

1 August: France Alzheimer has a new director

France Alzheimer has recently had a change of Managing Director (MD). Mr Benoît Durand has been MD since March 2014, prior to which the role had been occupied by Mr Thierry Jarlet.

1 August: Danish association has a new chairperson

The Danish Alzheimer’s association, Alzheimerforeningen has recently changed its chairperson.

After 6 busy years as chair, Anne Arndal said that while much had been achieved a lot remained to be done and she foresaw an extremely busy few years ahead. Ms Arndal decided that “new and fresh eyes” would be a good thing for the association at this point in time and she announced her decision to step down at the association’s AGM, in May of this year.

Her successor, Birgitte Valund says that she plans “to work with the association on continuing to make a difference in the everyday lives of people affected by dementia and to ensure dementia is kept on the political agenda.”

Ms Arndal will continue to do some work for the association at a regional level.

http://www.alzheimer.dk/en

8 August: Alzheimer’s Society marks 15th anniversary of Research Network with booklet

The Alzheimer’s Society (UK) set up the Research Network in 1999. To mark its 15th anniversary, two of its original members have been looking back at its history and achievements. They interviewed people who have been involved in or worked with the Network over the years, including Alzheimer’s Society staff, members of the research community and research volunteers.

The booklet gives an overview of the Network’s successes and the impact it has had on dementia research, both research funded by Alzheimer’s Society and by other organisations.

Download the booklet here:

25 August: Slovenian president meets with Spominčica and ADI

On 25 August, Spominčica’s Vice President, Štefanija Lukči Zlобec and Alzheimer Disease International (ADI)’s Executive Director, Marc Wortmann met with Slovenian President, Borut Pahor in Ljubljana.

They discussed the need for a national dementia strategy in Slovenia. President Pahor confirmed his support for the development of such a strategy by an expert group and Ms Lukči Zlобec took the opportunity to inform him that a working group was already in existence, but that plans required support from the government.

President Pahor had already accepted patronage of Alzheimer Europe’s conference in Ljubljana in 2015, at the request of Spominčica and this recent meeting is another great step for Spominčica’s work in raising awareness and in promoting the need for a national dementia strategy.

10 September: Alzheimer’s Society publishes two UK dementia reports

On 10 September, the Alzheimer’s Society (UK) published two reports: Dementia 2014 report, “Opportunity for change” and a second edition of “Dementia UK”.

The former is the society’s third annual report looking at the quality of life for people with dementia in England, Wales and Northern Ireland. It aims to provide “a snapshot of how well people are living with their dementia, what support they are receiving, and what barriers they face to living well”. It focusses on what the society thinks needs to happen to effect changes it deems necessary to bring improvement to the lives of people with dementia.

One of the main points this report stresses is that the UK government “must address the artificial divide between health and social care in order to improve quality of life for people with dementia.”

The latter, Dementia UK (second edition), presents new evidence on the prevalence and cost of dementia in the UK. It states that by 2015 there will be 850,000 people with dementia in the UK and that the annual cost of dementia to the UK is GBP 26 billion (EUR 33.3 billion).

Dementia 2014 also pays particular attention to the regional variation in dementia policy across England, Wales and Northern Ireland.

Download Dementia 2014: Opportunity for change
Download Dementia UK: Second edition

15 September: Belgian Alzheimer’s society awards Santkin Prize 2014

On 15 September, the Belgian Alzheimer’s society, Ligue Nationale Alzheimer Liga (LINAL) had the honour of awarding the Santkin Prize 2014. For this special occasion, LINAL organised an academic meeting in the Gothic Room of the Cityhall in Brussels, a historical and magnificent place with tapestries, murals and wooden sculptures. Named after former Health Minister Jacques Santkin, the prize aims to reward, every two years, a researcher or a research team for their work on the
knowledge and the treatment of Alzheimer’s disease and other dementias.

This year, Christine Bastin (University of Liege) was our winner. She is working on the improvement of an early diagnosis, using a non-invasive method combining medical imagery (RMI) and biomarkers. She is currently following patients who only have a mild cognitive disorder for which she tests their cognitive abilities every year. Two years from now, she will analyse, a posteriori, the results in view of the evolution of the patients, to see if they get Alzheimer’s disease or not. Her goal is to highlight evidence of the disease in its earliest stages, or even before its onset.

For the academic meeting, LINAL invited two internationally renowned speakers: Professor Florence Pasquier (University of Lille, France) and Professor Christine Van Broeckhoven (University of Antwerpen, Belgium). They presented their latest research findings respectively about early onset dementia and the involvement of genetics in Alzheimer’s disease and other dementias. Both of them underlined the polymorphism of the disease, which often complicates the development of adapted therapies according to those different forms.

In addition to these renowned persons of the scientific world, LINAL had the honour of counting among others prestigious guests, Marc Wortmann (executive director of Alzheimer’s Disease International), Brigitte Grouwels (the founder of the Mental Health Platform in Belgium), Jacques Santkin’s family and Alain Courtois (the First Alderman of Brussels and Alderman in charge of the seniors).

17 September: Alzheimer Society of Ireland launches Living with Dementia campaign

On 17 September the Alzheimer Society of Ireland (ASI) launched a #LivingWithDementia campaign. The campaign centres on the theme of living well with dementia and talking about dementia with friends and family. The campaign launched in Dublin city centre with an exclusive screening of two new short films to an audience of over 100 guests.

The two short films present the lives of two people living with dementia in different ways. The first film featured Kathy Ryan, who has early onset dementia and lives with her two sons. In the film Kathy talks about learning about her diagnosis and her hopes and fears for the future. The second film features Sean Donal O’Shea who cares for his mother, Debbie, who has advanced early onset dementia. Sean Donal talks about how his mother’s diagnosis changed his life and that of his family.

Both films capture the realities of living with dementia and how dementia affects each person differently. There has been an overwhelming response to the videos online, having been shared on national media platforms, ASI’s YouTube channel, as well as www.alzheimer.ie along with receiving 50,000 views on the ASI’s Facebook page and this number continues to grow.

The ASI has also developed a range of new information resources to support people with dementia who are recently diagnosed. Developed in partnership with the Irish Dementia Working Group, the new resources reflect the lived experience of people with dementia, their words and their experiences. They cover areas such as what to do after a diagnosis, how to live well day-to-day, driving and dementia and include a new help-card to support people when they are out and about in their community. Copies are available on www.alzheimer.ie or by calling the helpline number 1800 341 341.

Policy Watch

1 August: Opinion is divided on international convention on rights of older persons

To address the issues surrounding the human rights of older persons, the UN Open-Ended Working Group on Ageing (OEWG) held a session in New York from 30 July to 1 August, attended by more than 80 Member States.

The main topic on the table was the possibility of a new international convention on the rights of older persons, which - like the UN conventions on the rights of women and people with a disability - would explicitly recognise the rights of older people in international law.

While all speakers referred to an urgent need to protect the rights of older persons, Member States expressed diverging views on how best to approach this. Some, including the European Union, the US, Canada and Australia focused on the need to implement existing human rights standards and mechanisms at national and regional levels. For the time being, they reject the need for a new convention.

Other Member States support a new legally binding international convention on the human rights of older persons and call for taking immediate steps towards such a legally-binding instrument, while still others say more time is needed to reach a consensus.

The 40 or so NGOs who were represented noted that, while non-binding agreements such as the Madrid International Plan of Action on Ageing and the UN Principles for Older Persons provide excellent guidance, in reality they are largely ignored by governments. Most called for the establishment of a new convention, which they said could bridge gaps in the protection of the rights of older people in areas such as elder abuse, dementia, nursing home regulation, protection of the family and the right to an adequate standard of living and health.

Ms. Amina Mohammed, Special Advisor to the Secretary-General on post-2015 development called for “all hands on deck” and encouraged NGOs to keep advocating and to renew their engagement to contribute to a stronger and more effective post-2015 agenda.

14 August: Ireland invests EUR 30 Million in dementia care and research

On 14 August, Irish Minister, Kathleen Lynch announced that private grant-making foundation, Atlantic Philanthropies would be providing EUR 14.7 Million to improve the care and well-being of people living with dementia in Ireland. Ireland’s health service, HSE will provide matching funding of EUR 15 Million. With the Department of Health making a further EUR 1 Million available for dementia research, the overall investment totals just over EUR 30 Million.

The funding will concentrate on three identified priority areas: intensive home care, GP education and training and dementia awareness.

The Alzheimer Society of Ireland welcomed the investment and CEO Gerry Martin said that ring-fenced funding for dementia was long-awaited and much needed.

The timing of this influx of funding is in light of the upcoming dementia strategy in Ireland, which should be launched this September.

31 August: World Dementia Council appoints new members

In the four months since its inaugural meeting on 30 April, the World Dementia Council (WDC) has shed one member (Yves Leterme, former Deputy Secretary General of the Organisation for Economic Co-operation and Development) and has appointed five new members, including three from Alzheimer’s associations.

The WDC began life with 14 members and at the time of writing had 18 members, including World Dementia Envoy, Dr Dennis Gillings.

Among the ranks of the five recently appointed members are Harry Johns, President and CEO of Alzheimer’s Association (USA); Dr Daisy Acosta, Honorary Vice-President of Alzheimer Disease International and cofounder of the Dominican Republic Alzheimer Association; and Meera Pattabiriman, Chairperson at Alzheimer’s & Related Disorders Society of India.

The other two new members are Professor Joël Ménard, Professor of Public Health at the Faculty of Medicine Paris-Descartes and Professor Philippe Amouyel, General Director, Fondation Plan Alzheimer.

The release of the “Understanding of Neurological Conditions in Canada” report, noted the significant impact of dementia on society and made a number of announcements regarding the Canadian Government’s approach, including:

- The release of a report, “Mapping Connections: An Understanding of Neurological Conditions in Canada”.
- The release of the “National Dementia Research and Prevention Plan”.
- The Government of Canada’s intention to work with the Alzheimer Society of Canada (ASC) to bring the

Finance and incentives
Open science
Public health/prevention

Speaking after the meeting, World Dementia Envoy, Dr Dennis Gillings said “having highlighted the problems, we’re now moving forward with real concrete solutions”.

“We must also keep our minds firmly focused on people living with dementia, their families and carers. We are looking into how data can be shared so that best practice in care can be shown around the world, as well as making sure the whole dementia community can share their experiences and priorities for all to see”, he added.

Dr Gillings has also published the second edition of his e-newsletter on 11 September, in which he talks about his role as envoy and the work of the World Dementia Council. Read it here.


11-12 September: Canada hosts second Dementia Legacy event

The second in a series of four Global Dementia Legacy events took place on 11 and 12 September in the Canadian capital, Ottawa. The 200 delegates included experts from the research and industry sectors, health charities, patients, caregivers and government leaders.

The event aimed to:

- Explore collaborative opportunities for research into novel diagnostic, pre-emptive and therapeutic approaches to dementia.
- Provide a better understanding of the impact of the paradigm shift in pharmaceutical research.
- Foster a collective approach to problem-solving, using expert panel discussions to identify practical and creative solutions.

Canadian Health Minister, Rona Ambrose noted the significant impact of dementia on society and made a number of announcements regarding the Canadian Government’s approach, including:

- The release of a report, “Mapping Connections: An Understanding of Neurological Conditions in Canada”.
- The release of the “National Dementia Research and Prevention Plan”.
- The Government of Canada’s intention to work with the Alzheimer Society of Canada (ASC) to bring the
“Dementia Friends” programme to Canada within a year.

Alzheimer Europe was represented at the meeting by Executive Director, Jean Georges.

The next legacy event will be in Japan from 5 to 7 November and the final event in the series will take place in the US on 9 and 10 February 2015.

15 September: German Dementia Alliance launches agenda

“Together for People with Dementia” is the title of the agenda of the Allianz für Menschen mit Demenz (“Alliance for People with Dementia”), started by the German government in partnership with the German Alzheimer Association, Deutsche Alzheimer Gesellschaft (DALZG).

On 15 September, the Alliance launched its agenda in Berlin, with signatures from the Minister of Family Affairs, Senior Citizens, Women and Youth, Manuela Schwesig and the Health Minister, Hermann Gröhe. Upon signing, the Ministers effectively sounded the starting pistol to implement the results of two years of work by the Alliance and have laid the foundation for a national dementia strategy.

Local authorities, health and nursing associations, scientists and civil society have all been engaged in intensive discussions to agree on concrete measures to improve the lives of people with dementia and their families, under the chairmanship of the Federal Ministries and the co-chairmanship of the DALZG.

By 2017, the Ministers aim to have more houses and centers for people with dementia as well as building local support networks. A first progress report is planned for spring 2016.

DALZG and Alzheimer Europe (AE) Chairperson, Heike von Lützau-Hohlein welcomed the signing of the agenda for quick and decisive action. She stressed the importance of the involvement of varied sectors in this Alliance. Heike was particularly insistent that the DALZG will work to ensure that people with dementia are involved in the decisions that affect them and ensure that families are adequately supported. She also hopes for a swift and non-bureaucratic implementation of the agreed objectives even if the agenda contains no binding obligations. “We have no time to lose”, she urged.

AE Executive Director, Jean Georges also participated in the meeting and provided an overview of EU initiatives on dementia. He also called for greater German involvement in these initiatives and for support for the development of a European dementia strategy.

www.allianz-fuer-demenz.de

26 September: Dementia prevention programme for people with a very early diagnosis to be developed in Luxembourg

On 26 September 2014, the Luxembourg Ministry of Health held a conference on the development of a plan for a programme in Luxembourg to improve the quality of life of people with an early diagnosis of Alzheimer’s disease, mixed or vascular dementia (but who are not yet experiencing any or significant symptoms).

This is to be achieved through an individualised prevention programme aimed at delaying the onset of dementia.

The programme will be developed in partnership with the German Institute for the Prevention of Dementia (DIDP) of the University of Saarland.

Dianne Gove attended the workshop and members of the Association Luxembourg Alzheimer were also present.

Science Watch

30 July: History of problem drinking more than doubles risk of dementia, study finds

Research carried out by a team at the University of Exeter Medical School, England, highlights a possible link between a history of harmful patterns of alcohol consumption in middle-aged adults and problems with memory later in life – problems which may lead to an elevated risk of developing dementia. The team’s findings were published in the American Journal of Geriatric Psychiatry on 30 July.

Study author, Dr Iain Lang and his team looked at the association between a history of “alcohol use disorders” (AUDs) - identified using the CAGE questionnaire - and the onset of severe cognitive and memory impairment in 6,542 people born between 1931 and 1941.

Participants were first assessed in 1992 and follow-up assessments took place every other year from 1996 to 2010. Where participants were deemed to have a history of AUDs the incidence of severe memory impairment more than doubled.

Dr Lang commented: “We already know there is an association between dementia risk and levels of current alcohol consumption – that understanding is based on asking older people how much they drink and then observing whether they develop problems. But this is only one part of the puzzle and we know little about the consequences of alcohol consumption earlier in life. What we did here is investigate the relatively unknown association between having a drinking problem at any point in life and experiencing problems with memory later in life.”

He added “this is a public health issue that needs to be addressed...more research is required to investigate the potential harms associated with alcohol consumption throughout life”.

http://www.ajgponline.org/article/S1064-7481(14)00201-7/abstract

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6 August: Lack of vitamin D linked to higher risk of dementia

People with very low levels of vitamin D in the blood may be twice as likely to develop dementia, according to a large British study published in the journal Neurology on 6 August.

According to the research, led by Dr David Llewellyn at the University of Exeter, those with low levels of vitamin D in the blood were 53 per cent more likely to develop any form of dementia and those with severe vitamin D deficiencies were at a 125% greater risk.

The study involved 1,658 participants over the age of 65 who did not have dementia at the beginning of the study. Their progress was followed for an average of six years, at the end of which 171 participants had developed dementia and 102 had Alzheimer's disease.

In addition to an increased risk of developing any form of dementia, participants with low levels of vitamin D were found to be nearly 70 per cent more likely to develop Alzheimer's disease.

Dr Doug Brown, Director of Research and Development at Alzheimer's Society said:

"Shedding light on risk factors for dementia is one of the most important tasks facing today's health researchers. While earlier studies have suggested that a lack of the sunshine vitamin is linked to an increased risk of Alzheimer's disease, this study found that people with very low vitamin D levels were more than twice as likely to develop any kind of dementia...However, we're not quite ready to say that sunlight or vitamin D supplements will reduce your risk of dementia. Large scale clinical trials are needed to determine whether increasing vitamin D levels in those with deficiencies can help prevent dementia from developing."

http://www.neurology.org/content/83/10/930

11 August: Rare condition could lead to new therapeutic target in AD

A patient at the Lipid Clinic of the Cardiovascular Research Institute, University of California, US, has been the subject of a study, the results of which the authors believe support a possible therapeutic target for Alzheimer's disease (AD).

The patient, an American man of 40 has a rare genetic condition called dysbeta lipoproteinemia. His brain is unable to produce apolipoprotein E (apoE), a variant of which (apoE4) is the largest known genetic risk factor for late-onset sporadic AD.

Researchers have previously wondered how dangerous it might be to treat patients with AD by eliminating this protein from the brain completely, so doctors at the clinic saw the man’s rare condition as an opportunity to run consensual tests. They looked to determine the effects of it on neurocognitive and visual function as well as on lipoprotein metabolism, ultimately concluding that “targeted knockdown of apoE in the central nervous system might be a therapeutic modality in neurodegenerative disorders.”

They found that despite a complete absence of apoE, the man “had normal vision, exhibited normal cognitive, neurological, and retinal function, had normal findings on brain magnetic resonance imaging, and had normal cerebrospinal fluid levels of β-amyloid and tau proteins.”

There are caveats to the research. For one thing, the patient is 40 and it is unclear how aging might affect the functioning of his brain, a major consideration given that the onset of AD often occurs later in life.

The researchers also pointed out that since the main potential side effect of reducing apoE would be the effect on cholesterol and triglyceride levels, which would likely lead to cardiovascular disease, therapies would have to target broad areas of the brain without crossing the blood-brain barrier and circulating to the liver.

The study was led by Dr Mary Malloy, director of the Lipid Clinic and was published online on 11 August in the journal, JAMA Neurology.


20 August: Mid-life obesity may triple the risk of dementia

A study, conducted by researchers at Oxford University, England has concluded that obesity in mid-life is linked to a heightened risk of dementia in later life. The observational study, which used anonymised hospital record data from 1999-2011 looked at records where obesity and dementia coincided. Results were published online on 20 August in the Postgraduate Medical Journal.

The age at which a person was found to be obese was seemingly a key factor, with an apparent tripling in the risk of developing dementia for people who fell into the obese weight bracket between the ages of 30 and 39. It also seemed that the increased risk of dementia declined as the later in life obesity occurred.

The researchers suggest that a possible explanation for the particularly high risk found in early to mid-life may lie in the fact that heavier weight is associated with diabetes and cardiovascular risk factors, which are themselves linked to a heightened risk of dementia.

The report concludes that “obesity is associated with a risk of dementia in a way that appears to vary with age. Investigation of the mechanisms mediating this association might give insights into the biology of both conditions.”

The Alzheimer’s Society (UK) commented that since this was an observational study, “no definitive conclusions can be drawn about cause and effect”, but that the findings do seem to support existing published studies which report an increased risk of dementia in people who are obese under the age of 60, but a reduced risk in older obese people. They also point out, however, that the section of the target group falling into the bracket of obesity in their thirties and developing dementia later in
25 August: Mindfulness training may improve quality of life for people with dementia and carers

Mindfulness training eases depression and improves sleep and overall quality of life for people with early-stage dementia as well as for their carers, research conducted at Northwestern University, Illinois, US concludes.

The research team, led by Ken Paller, professor of psychology and fellow of the Cognitive Neurology and Alzheimer’s Disease Center at Northwestern University, published its results in the American Journal of Alzheimer’s Disease and Other Dementias, on 25 August.

Working with 37 participants, including 29 individuals who were part of a “patient-caregiver pair”, they used training techniques such as attending to the present moment nonjudgmentally, which can “help reduce maladaptive emotional responses”.

The training also helps the patient and caregiver accept new ways of communicating, they say.

“One of the major difficulties that individuals with dementia and their family members encounter is that there is a need for new ways of communicating due to the memory loss and other changes in thinking and abilities...The practice of mindfulness places both participants in the present and focuses on positive features of the interaction...It is a good way to address stress.”

“You don’t have to be drawn into wishing things were different.” Professor Paller stressed. “Mindfulness training...takes advantage of people’s abilities rather than focusing on their difficulties.”

The study concludes that mindfulness training can indeed be beneficial for people with early-stage dementia and their caregivers. It also points out that this type of training can be delivered at low cost. 

http://ajp.sagepub.com/content/early/2014/08/24/1533317514545377.abstract

27 August: Marijuana compound may offer treatment for AD

Low levels of delta-9-tetrahydrocannabinol (THC), the active compound in marijuana may offer a treatment for Alzheimer’s disease (AD), suggests a study published on 27 August in the Journal of Alzheimer’s Disease.

Researchers at the Byrd Alzheimer’s Institute, University of South Florida in Tampa, US found that THC both decreases the production of amyloid beta (Aβ) and inhibits its aggregation in cell cultures.

The research team claims that THC inhibits Aβ production as well as aggregation at extremely low doses and that it enhances mitochondrial function as well. Dr Chuanhai Cao, a neuroscientist at the Institute said, “these observations suggest that THC has anti-Alzheimer’s activity”.

For the study, the team incubated THC together with a variant of Aβ protein precursor cells and checked the culture for the presence of Aβ levels over 6-hour, 24-hour and 48-hour time periods.

Concerns about memory impairment are frequently raised in the context of any research associated with potential therapeutic benefits of THC. Dr Cao emphasised, however, that memory impairment is only observed at “abuse” concentrations of THC, which are more than a thousand times higher than the doses used in these experiments.

Study co-author, Neel Nabar recognised the rapidly changing political climate surrounding the debate over medical marijuana:

“We are still far from a consensus...are we advocating that people use illicit drugs to prevent the disease? No. It’s important to keep in mind that just because a drug may be effective doesn’t mean it can be safely used by anyone. However, these findings may lead to the development of related compounds that are safe, legal, and useful in the treatment of Alzheimer’s disease.”

The compound was also tested for synergy with caffeine to see whether the combination of the two led to greater reductions in the Aβ levels of these Aβ protein precursor cells in vitro. The results were negative in this case.

http://www.alz.org/node/388

9 September: Benzodiazepines may increase dementia risk

A French-Canadian research team has completed a case-control study into 8,980 adults over the age of 66, concluding that benzodiazepine use for three months or more is linked to an increased risk (up to 51%) of developing dementia. Their results were published in the British Medical Journal (BMJ) on 9 September.

The study involved 1,796 people, diagnosed with dementia and living in Quebec, Canada between the years 2000 and 2009. These cases were compared with about 7,184 people without dementia, of the same age, living in the same community during the same time period.

The team said that the likelihood of developing dementia among those participants who had previously taken benzodiazepines increased by 51% as compared with those who did not take the drugs.

They warned that while the link is not definitive, “indiscriminate widespread use” of benzodiazepines should stop and that “unwarranted long term use of these drugs should be considered as a public health concern.”

The recommended maximum period for use of benzodiazepines is three months.

http://www.bmj.com/content/349/bmj.g5205

14 September: Brain may compensate for damage caused by AD

A team of researchers at the Helen Wills Neuroscience Institute, University of California, Berkeley, US
have completed a study, concluding that the human brain may be able to compensate for some of the early changes caused by Alzheimer’s disease (AD).

They suggest that people “who spend a lifetime involved in cognitively stimulating activity” may have brains that are “better able to adapt to potential damage”. Their study was published in Nature Neuroscience on 14 September.

71 adult participants with “no signs of mental decline” were asked to complete a series of picture-based memory tests, while scanners were used to track their brain activity.

Brain scans showed that 16 of the older subjects had amyloid deposits in their brains and the scans showed elevated levels of activity as compared with the rest of the group. The scientists say this may be because their brains have an ability to adapt to and compensate for any early damage caused by the protein tangles.

Experts say the target group was too small to draw any firm conclusions and that further research is needed to better understand these processes.

http://www.nature.com/neuro/journal/vaop/ncurrent/full/nn.3806.html

16 September: AstraZeneca and Lilly join forces to develop AD drug

Pharmaceutical companies, AstraZeneca and Eli Lilly and Co (Lilly) announced on 16 September having reached an agreement to jointly develop and commercialise AZD3293, an oral BACE inhibitor currently in development as a potential treatment for Alzheimer’s disease (AD). In Phase I studies, AZD3293 had been shown to significantly and dose-dependently reduce levels of amyloid beta in the cerebro-spinal fluid of trial participants with Alzheimer’s disease as well as in healthy volunteers. AstraZeneca announced its plan to move AZD3293 into registration trials earlier this year. This alliance has been formed with the aim of progressing AZD3293 rapidly into a Phase II/III clinical trial in patients with early Alzheimer’s disease.

Lilly will lead clinical development, working with researchers from AstraZeneca’s Innovative Medicines Unit for neuroscience, while AstraZeneca will be responsible for manufacturing. The companies will take joint responsibility for the commercialisation of AZD3293.

http://www.cambridgenetwork.co.uk/news/alliance-bace-inhibitor-azd3293-alzheimers-disease/

23 September: Brain cells grown in lab could help dementia research

Researchers at Tufts University Medical School, Boston, US have succeeded in creating functional, engineered brains in their lab. They hope their work will help speed up research into head trauma and dementia, by using the “brains” to discover how these conditions might be reversed through the use of drugs.

The resulting study was published in the journal the Proceedings of the National Academy of Sciences on 23 September.

To date, neurons have been grown flat, inside petri dishes rather than in three-dimensional structures. Grown in two dimensions, however, these neurons are unable to replicate the complex structural organisation of brain tissue.

The Boston University researchers discovered that by using a ring-shaped scaffold and a special gel they could encourage rat neurons to form into complex brain tissue. They have now managed to change the scaffold so that it consists of six concentric rings, which mimic the six layers of the human brain cortex.

The 3D tissue created by the scientists contains white and grey matter, has the same chemical and electrical functions as a human brain and can survive for up to two months in the lab.

Jessica Smith, Research Communications Officer, at the Alzheimer’s Society, commented: "The brain is a relative mystery to scientists and clinicians alike. Any tool that can help to uncover the workings of the brain and demonstrate how it reacts to trauma is extremely useful...however, we have yet to see how this could be used for dementia research because this new model uses healthy brain cells - we would need a different approach to understand complex conditions like Alzheimer’s disease.”

http://www.pnas.org/content/111/38/13811.abstract

Dementia in Society

8 August: UK report predicts cost of dementia to businesses will double

On 8 August, Public Health England (PHE) and the Alzheimer’s Society (AS) released a report on the future financial implications of dementia for UK businesses. The report, completed by the Centre for Economics and Business Research (CEBR), states that by 2030 dementia caring obligations will cost UK companies more than EUR 3.8 billion.

As the population ages and the incidence of dementia increases, the report says businesses will be hugely impacted by the growing numbers of workers having to reduce their hours, change their working schedules and even leave their employment altogether, due to the demands of caring.

The report calls on employers to adapt their working methods to support the increasing numbers of people living with dementia and their carers. If, for example, business owners increased their employment rate of dementia carers by 2% over the years to 2030 - for example by offering more flexible terms of employment - the retention of skilled and experienced staff could deliver a saving of EUR 525 million.

To date, more than 100,000 UK employees have become Dementia Friends and 20 of the UK’s largest businesses have committed to being dementia friendly places for staff and customers alike. Many other business owners have also pledged for their staff to become Dementia Friends in the near future, but this report concludes that many more businesses need to make workable changes
and to plan for a future with both staff and customers living with dementia.

21 August: Former Irish Prime Minister dies with Alzheimer’s disease

Former Irish Prime Minister (1992-1994), Albert Reynolds has died at the age of 81. The Fianna Fail politician from County Roscommon played a key role in advancing the peace process in Northern Ireland.

It was revealed last year by Mr Reynolds’s son that he was in the late stages of Alzheimer’s disease and his death was confirmed on 21 August.

8 September: Young musician does 100 gigs in 100 days for Alzheimer’s Society

On 8 September, an aspiring musician completed his 100th gig in 100 days to raise money for Alzheimer's Society. The gig took place at Zigfrid Von Underbelly in Hoxton, London and all proceeds raised from this and the 99 previous gigs went to his chosen charity, Alzheimer’s Society (UK).

The London-born 19 year-old singer-songwriter, Luke Carey, whose main musical influence is internationally renowned artist Ed Sheeran, was inspired by his friends whose grandparents are living with dementia.

His target was to raise GBP 100 (EUR 125) for Alzheimer’s Society, which he exceeded twenty-fold with this unusual challenge. The total accumulated at the time of writing was GBP 2,172.44 (EUR 2,700).

12 September: NFL estimates 30% of ex-players will develop dementia

National Football League (NFL) actuaries predict that 30% of all former players will be diagnosed with some form of dementia during their lifetimes.

An ongoing class action suit filed by former NFL players, alleging that the league hid information about the dangers of concussions incurred playing the sport was the backdrop for the announcement of these statistics by NFL lawyers, on 12 September.

This announcement would qualify 30% of former NFL players to claim payments from a settlement, which had been agreed at USD 765 million in August 2013 — with USD 675 million going to players diagnosed with Alzheimer’s disease, dementia and other related conditions. Judges have since expressed concern that this amount might not cover all retired players’ claims so the league removed the cap and agreed to pay more over time if it becomes necessary.

24 September: Malcolm Young leaves ACDC, reportedly with dementia

Malcolm Young, co-founder of rock ‘n’ roll band, ACDC has been admitted to a care home in Sydney, Australia, which specialises in dementia care. The musician, 61, founded ACDC in November 1973 with his younger brother Angus.

Following a stroke in 2013, Mr Young had taken some time out from the band but it had hoped he might return.

The news of his admission into the Sydney facility was preceded shortly by an announcement that after 41 years with the band, he would sadly not be returning.

New Publications & Resources

22 July: Website aims to connect people to dementia research studies

A new service to connect people to dementia research studies is being piloted in the North Thames area of England.

On Tuesday 22 July, Join Dementia Research became available online to researchers and healthcare services in the North Thames Clinical Research Network.

The service aims to offer patients, carers and the public the chance to register their interest in taking part in dementia research, and the opportunity to be matched with the most suitable research studies for them. The service will then be rolled-out nationally towards the end of this year, after an initial evaluation phase.

One feature of the website is that a carer will also be able to sign up on behalf of someone else, providing they have their consent.

Alzheimer’s Society and Alzheimer’s Research UK are both partners in the project and are supporting delivery of the service to people with dementia, their family members and carers.

5 August: Book on “The Law and Ethics of Dementia” published

“The Law and Ethics of Dementia” edited by Charles Foster, Jonathan Herring and Israel Doron, was published on 5 August. The book brings together contributions from clinicians, lawyers and ethicists on the main perspectives of legal and ethical matters surrounding dementia.

Some of the scientific questions asked are: what is dementia? Who gets it? What are the current and future therapeutic and palliative options? What are the main challenges for medical and nursing care?

Among the ethical questions raised are: is it legitimate to lie to dementia patients if that is a kind thing to do? Who is the person whose memory, preferences and personality have all been transformed by their disease? Should any constraints be placed on the sexual activity of patients?
Are GPS tracking devices an unpardonable interference with the patient’s freedom?

These issues, and many more, are then examined through legal lenses. The book closes with accounts from people living with dementia and carers.

Full details about the book can be found at:


9 August: Dementia South Africa launches bilingual talking book

On 9 August, Dementia SA (South Africa) launched a new talking book, “Making Memories Matter: Dementia is About People”, in English and Xhosa - two of the eleven official languages of the country.

The aim is to help spread the word about dementia in South African communities, with a particular focus on reaching those communities with lower levels of literacy where there is often little or no knowledge of the condition.

The book tells the listener what dementia is and talks about care needs that a person with dementia may have, aiming to reduce currently high levels of neglect and abuse of people with dementia. Dementia SA also hopes to reduce the fear and stigma surrounding dementia.

To hear the book in English:

www.youtube.com/watch?v=xM7BikiGQYE

15 September: University of Tasmania offers free online dementia course

The University of Tasmania, Australia is offering a free online course called “Understanding Dementia”.

The free course ran for the first time in 2013 and was very successful, attracting nearly 25,000 registrants from more than 95 countries.

A new session will begin on 13 October and registration is open to anyone interested in participating:

www.utas.edu.au/wicking/understanding-dementia

17 September: ADI publishes its annual World Alzheimer Report

On 17 September, Alzheimer’s Disease International (ADI) released its annual World Alzheimer Report, this year on the topic of “Dementia and Risk Reduction: An analysis of protective and modifiable factors”.

The 2014 report examines evidence for the existence of modifiable risk factors for dementia, focusing on sets of potential modifiable risk factors in four key domains: developmental, psychological and psychosocial, lifestyle and cardiovascular conditions. It makes recommendations for public health campaigns and disease prevention strategies.

It was researched and authored by Prof. Martin Prince, Prof. Emiliano Albanese, Dr Maelenn Guerchet and Dr Matthew Prina on behalf of the Global Observatory for Ageing and Dementia Care, hosted at the Health Service and Population Research Department, King’s College London.

http://www.alz.co.uk/worldreport2014

22 September: Hello Brain campaign launched to promote brain health

Trinity College Dublin in Ireland played host to the launch event for a new campaign called “Hello Brain” on 22 and 23 September.

Hello Brain is a campaign that promotes brain health through easy-to-understand scientific information.

A website containing entertaining short videos, top tips for brain health and a free app to use on smartphone is hoped to help people to improve their brain health in an enjoyable yet educational manner.

The “Hello Brain Ambassadors” hope the campaign will reach as many people as possible and that their free resources will can be used to promote active and healthy ageing.

World Alzheimer’s Day

19 September: UN expert speaks out on rights of people with dementia

On 19 September, UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte called on Member States to do more to protect older people with dementia from stigma, discrimination, victimisation and neglect.

Speaking two days before World Alzheimer’s Day and in this context, Ms Kornfeld-Matte called for concerted action to ensure that older people with Alzheimer’s disease and other dementias can fully enjoy their human rights in all circumstances.

“The whole of society shares responsibility for the welfare of older persons with dementia and is called upon to find comprehensive solutions”, she said.

Ms Kornfeld-Matte called on states and other stakeholders to raise awareness and to adopt a human rights-based approach to protect the rights and dignity of older people with dementia. She implored all to take appropriate action to ensure that older people with dementia can continue to participate in community life. This includes providing accessible information and support to older people with dementia, both human and technical, to facilitate their continued participation in public life as well as in decisions affecting them.

21 September: AE Chairperson features at opening of Mexican WAD

On 21 September, the Mexican Alzheimer’s Association, Fundacion Alzheimer de Mexico’s World Alzheimer’s Day event took place in the main square in Mexico City, the Zocalo. The event, which attracted 15,000 people,
featured a welcome video made by Alzheimer Europe’s Chairperson, Heike von Lützau-Hohlein.

Heike spoke about the time she lived in Mexico with her husband, where she learned the local language, allowing her to deliver her welcome message in fluent Spanish. She spoke of the importance of focussing on the abilities of people living with dementia rather than on their inability to do certain things. She also stressed the importance of worldwide co-operation in finding a cure and in supporting people with dementia and their loved ones.

21 September: Alzheimerforeningen releases song for WAD

Danish songwriter, Morten Deleuran, whose grandfather died of Alzheimer’s disease has dedicated his new song, “Hillside” to the 90,000 Danes who are currently living with dementia. He asked Danish band, Sas Fenger & Spinning Wheels to record the song and video with him and then donated the resulting track and video to the Danish Alzheimer Association, Alzheimerforeningen.

The lyrics are in English, making it easier for Alzheimerforeningen to share it with people all over the world, in celebration of World Alzheimer’s Day (WAD).

https://www.youtube.com/watch?v=LjN1rsFrxGA

21 September: Alzheimer Austria holds music therapy session for WAD

On the occasion of World Alzheimer’s Day, Antonia Croy and Monika Natlacen from Alzheimer Austria offered a half day workshop with German music therapist Simone Willig for families and professional caregivers. A large number of interested participants learned about music’s effects on body and soul.

The connection with Simone was built during last year’s Alzheimer Europe (AE) conference in Malta, where Simone gave a speech about how music can reach people with dementia and the positive effects it has on everyone.

In Vienna we learned that music is a part of our whole life and an important component in identity development. Music is a lifelong experience and a vital part of a person’s personality, quite independent from the presence of dementia. Music addresses people with dementia as human beings, not as patients. Music is life, is the living expression of life. Listening to music together can build a bridge between a person’s old path of life and his or her new way of perceiving. In this way, music provides a possibility for reorientation, also for family members. Music facilitates an appreciative way of communicating, a dialogue amongst equals, in which the person with dementia can participate and shape his or her own experiences in a significant way. For a person with dementia, the experience of being appreciated and perceived as a person in the musical process, is often motivating and furthers and supports the person’s wellbeing, also in many areas of practical life.

The participants from Vienna with its musical background, did largely benefit from Simone’s long experience and expertise in using music to bring up memories and restoring relationships with people with dementia.

21 September: World Dementia Envoy issues message for WAD

On 21 September, World Dementia Envoy, Dr Dennis Gillings issued a video message for World Alzheimer’s Day (WAD). Dr Gillings spoke of the “human cost of dementia” and the “toll” it has on people with dementia, their families and carers. He stressed, however, that there is also a financial cost:

“The global cost of dementia care is estimated as $604 billion. This figure is expected to rise to $1 trillion by 2030. We simply cannot afford to do nothing.”

Bemoaning the fact that only 3 new drugs have been approved in over 15 years, Dr Gillings called for urgent action on drug research and urged that “while we look for a cure we must do everything we can to lower the risk.” He particularly noted emerging evidence that the population risk of dementia is modifiable with increased physical activity, a reduction in tobacco use and other “risky behaviours long associated with non-communicable diseases” as well as through better treatment for hypertension and high cholesterol.

http://www.youtube.com/watch?v=g0ayrN-Kruz

25 September: Scotland’s Dementia Awards winners announced

Alzheimer Scotland is delighted to announce the winners in the six categories of this year’s Scotland’s Dementia Awards: a partnership between Alzheimer Scotland, NHS Education for Scotland, NHS Health Scotland and Scottish Social Services Council. Over 90 applications were received for this year’s event.

In addition, Dr Donny Lyons (Mental Welfare Commission for Scotland) was recognised with the event’s Lifetime Achievement Award.

The winners were announced at the awards ceremony on 25 September at the Marriott Hotel in Glasgow, in celebration of World Alzheimer’s Day.

Scotland’s Dementia Awards celebrate the work of both professionals and community groups who are committed to helping people with dementia and their families. The awards showcase the creativity, innovation and dedication that make a real difference to the daily lives of people with dementia and their families across Scotland when organisations, groups and teams work together.

www.ScotlandsDementiaAwards.org.uk
## AE Calendar 2014

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<tr>
<td>1-2 October</td>
<td>Croatian Congress on Alzheimer's disease (Brela, Croatia)</td>
<td>Jean</td>
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<tr>
<td>2-3 October</td>
<td>Meeting for project proposal organised by the Tampere University of Applied Sciences (Tampere, Finland)</td>
<td>Ana</td>
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<tr>
<td>3 October</td>
<td>Workshop on ethical challenges of future Alzheimer's disease clinical research (Barcelona, Spain)</td>
<td>Jean</td>
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<tr>
<td>10 October</td>
<td>1st AETIONOMY Legal and Ethical Advisory Board Meeting (Hannover, Germany)</td>
<td>Ana</td>
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<tr>
<td>19 October</td>
<td>Croatian Congress on Alzheimer's disease (Brela, Croatia)</td>
<td>Jean</td>
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<tr>
<td>20-22 October</td>
<td>AE Board meeting, AE Annual General Meeting and 24th Alzheimer Europe Conference &quot;Dignity and autonomy in dementia&quot;, <a href="http://www.alzheimer-europe.org/Conferences">www.alzheimer-europe.org/Conferences</a></td>
<td>AE members, Board and staff</td>
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<td>23 October</td>
<td>Ideas Lab of Dementia Services Development Centre (Stirling, Scotland, UK)</td>
<td>Jean</td>
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<tr>
<td>23 October</td>
<td>Alzheimer Scotland Masterclass 3: Scotland's National Dementia Strategy (Glasgow, Scotland)</td>
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## Future Conferences

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<tr>
<td>20-22 October</td>
<td>24th Alzheimer Europe Conference “Dignity and autonomy in dementia”, <a href="http://www.alzheimer-europe.org/Conferences">www.alzheimer-europe.org/Conferences</a></td>
<td>Glasgow, UK</td>
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<td>23 October</td>
<td>Five free masterclass events, <a href="http://www.alzscot.org/masterclasses">http://www.alzscot.org/masterclasses</a></td>
<td>Glasgow, UK</td>
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<td>7-9 November</td>
<td>17th Asia Pacific Regional Conference of Alzheimer's Disease International, <a href="http://www.apac2014.org/">http://www.apac2014.org/</a></td>
<td>New Delhi, India</td>
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<td>23-26 April 2015</td>
<td>9th Panhellenic Interdisciplinary Conference on Alzheimer's Disease and Related Disorders in combination with the 1st Mediterranean Conference on Neurodegenerative Diseases</td>
<td>Thessaloniki, Greece</td>
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<tr>
<td>20-23 June 2015</td>
<td>3rd 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>
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24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014
Register now!

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.