Welcome!

I’d like to start off by announcing that Alzheimer Europe is looking for a new team member, a Policy Officer, to help support us in our campaigns, develop policy, report on EU and national policy developments and collaborate with our members, among other things. Please see the advert for this position on page 15 of this newsletter or on our website if you are interested in applying. The deadline for applications is 26 June.

To continue the trend, May has been another busy month for us. We joined forces with INTERDEM in the early part of the month, meeting with a representative of the EU Health Commissioner to make our case for greater EU collaboration on dementia. We were delighted to hear of the Commissioner’s continued interest and support to dementia being considered as a European public health priority.

In other AE news, our European Working Group of People with Dementia (EWGPWD) held its first full meeting of the year in Brussels, including a new member from Norway and Early Bird rates have now closed for 25AEC in Slovenia this coming September. The full programme is available on our website and if you are attending, I would urge you to book your hotel as soon as possible for this busy period in Ljubljana. Finally, our Glasgow Declaration campaign is going strong, but we need more support – the Declaration now exists in 31 European languages, so please sign it and share with your network! See our website or use the buttons in this newsletter to sign.

Two of the projects AE is involved in held meetings this month, NILVAD in Greece in mid-May and later in the month, the EPAD project held its AGM and consortium meeting in Scotland. At the latter, two very interesting new studies from the Netherlands were presented, looking at the prevalence of amyloid plaques in adults with and without dementia.

In policy news, a report emerged in France, claiming that only half of the population living with dementia has been diagnosed. The report also noted a huge disparity between geographic regions in the country. In the UK, the Alzheimer’s Society also voiced its concern about the impact of further social care cuts, on people with dementia and their families in the UK.

In more positive news, the Croatian Ministry of Health has lent its support to a number of Alzheimer Croatia’s proposals in a recent meeting, including one stating that the National Dementia Strategy process should be accelerated. Finally, the Norwegian Parliament has made a decision to adopt a law making it mandatory to provide activities for people with dementia in daycare centres, starting from 2020.

As always, there is plenty happening, but plenty more to do, so on that note, I wish you all a very productive June!

Jean Georges
Executive Director
Alzheimer Europe

4 May: Alzheimer Europe and INTERDEM make joint case for greater EU collaboration on dementia

On 4 May, a joint delegation of Alzheimer Europe (Chair Heike von Lützau-Hohlein and Executive Director Jean Georges) and INTERDEM (Prof. Myrra Vernooij-Dassen and Frans Verhey) met with Paula Duarte-Gaspar, a representative of EU Health Commissioner Vytenis Andriukaitis who was unable to attend due to health reasons.

During the meeting, both organisations made a case for greater EU collaboration: Alzheimer Europe presented its Glasgow Declaration which calls for the development of a European dementia strategy and greater coordination of European research activities and INTERDEM presented its important activities in the field of psychosocial interventions and social health.

Paula Duarte-Gaspar highlighted the continued interest and support of the Health Commissioner to dementia being considered as a European public health priority. She stressed that a number of calls of the Glasgow Declaration were already being implemented such as a working group of government experts on dementia or an internal Commission group to better coordinate dementia activities at EU level.

She also pointed out that the Commission paid particular attention to the activities of Alzheimer Europe funded thanks to an operating grant from the EU health programme. A final priority for the Commissioner is the launch of a new Join Action on dementia later in 2015 to attend due to health reasons.

For those who have already registered, please ensure you book your hotel soon as space is filling up quickly for this busy period.

27 May: Early Bird rates for 25th AE annual conference close

At the end of May, the Early Bird rates for our annual conference closed. The detailed conference programme and abstracts for 25AECC, which will take place in Ljubljana, Slovenia from 2 to 4 September, are available on our website: http://alzheimer-europe.org/Conferences/2015-Ljubljana/Detailed-programme-and-abstracts

28 May: Glasgow Declaration campaign continues

This month, the Glasgow Declaration has been translated into German, Turkish and Dutch, thanks to our national member organisations in those countries. The German version is available on our website and the Dutch and Turkish versions will be available very soon. A Finnish version is also available on the Alzheimer Society of Finland, Muistiliitto’s website. This means the Declaration now exists in a total of 11 European languages, including English!

We have also received support from four new organisations this month: INTERDEM, the Slovenian Neurological Society, RePOD (Rotarians easing Problems of dementia) and our very own EWGPWD (European Working Group of People with dementia). We thank them all for their support.

In Slovenia, Human Rights Ombudsman Vlasta Nussdorfer and her deputy, Jernej Rovšek have both signed the Declaration this month, for which we are extremely grateful.

At the time of writing we have signatures from 2,271 individuals, 56 organisations and 57 policy makers (including 51 MEPs).

The Glasgow Declaration is seeking a European Dementia Strategy and national strategies in every country in Europe. Signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

If you have not already signed, please do so today by clicking on the below button. We need your support to make this happen!
EU Projects

13 May: NILVAD partners hold 4th General Assembly

The 4th NILVAD General Assembly took place in Thessaloniki, Greece on 13-14 May 2015. NILVAD’s clinical trial of nilvadipine for mild to moderate Alzheimer’s disease is progressing well, having met its recruitment target of 510 people on 31 March. The trial sites are located in nine European countries and 47 people have already completed the 18-month trial period. Several NILVAD partners are conducting sub-studies on frailty, blood flow and cerebrospinal fluid which are also well populated.

A new sub-study is in development to document the experiences of the trial participants and their carers. This study was conceived by Alzheimer Europe and CHRU Lille and aims to create a picture of a Phase 3 clinical trial from the participants’ point of view. The sub-study is expected to begin during the summer of 2015 with people who have completed the trial in France, Greece, Ireland and the UK. The next NILVAD General Assembly will take place in May 2016.

www.nilvad.eu

19-21 May: AGM and consortium meeting of EPAD held in Edinburgh

The European Prevention of Alzheimer’s Dementia (EPAD) project held its consortium meeting in Edinburgh (UK) on 19 to 21 May. The title of the meeting “Science, Collaboration and Progress” was very appropriate. There were many lively debates between leading researchers, clinicians, ethicists, lawyers and representatives of both pharmaceutical companies and people with dementia (Alzheimer Europe and Alzheimer Scotland).

The key issues were about the scientific, practical, legal and ethical implications related to the setting up of European-wide virtual register of 24,000 patients, of which 1,500 will be invited to participate in a trial to test new treatments to prevent Alzheimer’s dementia.

This initiative is a joint undertaking between the European Union and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

If successful, this project is likely to have a positive impact on the way that future clinical drug trials are organised.

22 May: VPH-DARE@IT project launches new citizen website

On 22 May, the VPHDARE@IT project launched a new citizen website to better inform the general public, as well as patient groups about the project: http://citizen.vph-dare.eu/

Alzheimer Europe Networking

On 29 April (London, UK) Dianne took part in a discussion on ethical issues at the Dementia Festival of Ideas.

On 4 May (Brussels, Belgium), Heike and Jean met with Paula Duarte-Gaspar from the Cabinet of EU Health Commissioner, Vytenis Andriukaitis.

On 6 May (Brussels, Belgium), Annette attended the Interest Group on Carers meeting.


On 13-14 May (Thessaloniki, Greece), Alex attended the 4th General Assembly of the NILVAD project.

On 14 May (Thessaloniki, Greece) Alex gave a presentation at the opening ceremony of the 9th Alzheimer Hellas Conference.

On 14-16 May (Brussels, Belgium) the European Working Group of People with Dementia had its first meeting of the year.

On 19 May (Brussels, Belgium) Annette attended the European Patients’ Forum General Assembly meeting.

On 19-20 May (Frankfurt, Germany) Gwladys attended the IMEX congress.

On 19-21 May (Edinburgh, UK) Jean and Dianne attended the consortium and annual general meeting of the EPAD project.

On 20-21 May (Brussels, Belgium) Annette attended the European Patients’ Forum annual conference and campaign launch on Patient Empowerment.

On 21 May (Paris, France) Ana attended the Alzheimer France symposium, “Politiques publiques et recherche Alzheimer”.

On 26 May (Brussels, Belgium) Annette attended the European Multiple Sclerosis Platform “Call to Action on Access to Employment for People with MS”.

On 29 May (Ascona, Switzerland) Heike attended the Annual Meeting of Association Alzheimer Suisse.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 106, representing 27 Member States of the European Union and six out of seven 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); Koppel Barbara (NI); Rübig Paul (EPP). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni Theocarous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE). **Finland:** Liisa Jaakonmaa (S&D); Anneli Jäätteenmäki (ALDE); Mii Mart Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niedler (EPP); Udo Voigt (NI). **Greece:** Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP). **Hungary:** Ádám Kós (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riain (GUE/NGL). **Italy:** Brando Benifei (S&D); Elena Gennette (S&D); Pier Antonio Panzeri (S&D). **Lithuania:** Rita Bartkiene (S&D); Marius Žemytis (EPP). **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:** Ewelina Lukacijewska (EPP); Marek Plura (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolašík (S&D); Anna Záborska (EPP). **Slovenia:** Franc Bogovčič (S&D); Tanja Fajon (S&D); Alojz Peterle (EPP). **Spain:** Soledad Becedón Ruiz (S&D); Luis de Grandes Pascual (S&D). **Sweden:** Harkin, MEP (Ireland), agreed such examples had to be taken up by a number of stakeholders to continue beyond that date. Marian Harkin (ALDE) mentioned that a transfer of responsibility must be carefully planned and financial resources properly allocated to answer the growing number of people in need of long-term care and the social changes. Annette attended the meeting.

11 May: EP hearing on the European Citizens’ Initiative “Stop Vivisection” takes place


The scientists promoters of the ECI, Gianni Tamino, Claude Reiss and André Menache, explained the scopes of the Initiative and the reasons for the opposition to animal testing in the world of science. The Commission response given by Karl Falkenberg, Director General DG Environment, was clarified some of the issues stated so far. The ECI presents no divergence of views compared to the current legislation. A lot of better and safer testing methods need to be developed. Directive 2010/63/EU already imposes that every other test method be used (Article 4) when possible. After five years of implementation of the current Directive, a full review will be produced and we will then see if other certified alternative measures have made the reduction of animal use possible. Three speakers were then invited to make statements: Ray Greek, president of the American “Americans For Medical Advancement” (AFMA), Françoise

EU Developments

6 May: Meeting of the Interest Group on Carers takes place in Brussels

On 6 May in Brussels, Belgium, the Interest Group on Carers organised a meeting in the European Parliament to discuss the topic of “Family vs. state responsibility for long-term care across the EU - the feasibility of one model?” The aim of the meeting was to allow the participants offer some directions for a way forward, based on their respective activities and research findings.

To set the scene, Heinz Becker, MEP (Austria), talked about his country tax-funded system of care payments to families that is secured by law until 2018 and the fight by many stakeholders to continue beyond that date. Marian Harkin (ALDE), agreed such examples had to be shared between Member States.

Diarmaid O’Sullivan and Paul O’Mahony from The Carers Association delivered a key note address in which they shared between Member States.

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Barré-Sinoussi, 2008 Nobel Laureate for Medicine or Physiology, and Emily Mc Ivor, for the Humane Society International.

The Commission is expected to give an official reply at the beginning of June. Annette attended the meeting on behalf of AE.

19 May: European Patients’ Forum holds Annual General Meeting

On 19 May, the European Patients’ Forum (EPF) organised its Annual General Meeting in Brussels, Belgium. This was an opportunity for the members to hear about EPF’s 2014 achievements (start of its new Strategic Plan, European Parliament election campaign, the development of a strong patient movement with new members, work on Cross Border Healthcare, the IMI-funded EMPATIE project) and present its activities for 2015 (IMI projects, capacity building programme aiming to strengthen the capacity of EPF members, its membership activities, the EPF Youth Group activities). Work on EPF’s “Patient Empowerment” campaign due to be launched the following day at EPF’s annual conference was also presented.

Some Board officers had to be elected in 2015. This year saw the election of Radu Costin Ganescu (Romania) from Coalition of Patients’ Organisations with Chronic Diseases (COPAC) and Pedro Monteliano (Portugal) from the Global Alliance for Mental Illness Advocacy Networks (GAMIAN-Europe). The other officers re-elected were Marco Greco (Italy) from the European Federation of Crohn’s Disease and Ulcerative Colitis Associations (EFCCA), Stanimir Hasardzhiev (Bulgaria) from the National Patients’ Organisation and Robert Johnstone (UK) from National Voices. Annette Dumas represented Alzheimer Europe at the AGM.

20-21 May: EPF holds annual conference and launches Patient Empowerment campaign

On 20-21 May in Brussels, Belgium, the European Patients’ Forum (EPF) organised its annual conference and campaign launch on Patient Empowerment. EPF’s campaign is articulated around 5 Es: Education (information), Expertise (disease self-management and reform design), Equality (with professionals), Experience (collective experience) and Engagement (more effective care and research into new treatments).

Health Commissioner Vytenis Andriukatatis shared his views on patient empowerment in a video speech that was shown at the opening of the conference. Patient empowerment is complex because it needs a mentality change both from medical doctors and patients. Success of the treatment doctors choose relates to patient erudition and trust. This is why partnership is key. The development of information and communication technologies such as e-health and mobile health support patient empowerment and drive patients to engage more actively and manage their chronic diseases. From an economic point of view, patient empowerment is a key aspect for the sustainability of the healthcare systems.

Angela Coulter, Oxford University, presented some research that gave evidence about the value of health literacy, patient empowerment and shared decision making in securing better health and self-management of the disease.

The patient perspective and personal testimonies were given by Robert Johnstone (National Voices), Hilary Doxford (European Working Group of People with Dementia) and Aneela Ahmed (representative of EPF Young Patients). They all stressed the value of empowerment as a mean to tackle the disease and express their own needs and expectations, be it in their relation with the health professional, the work place or their family.

Examples of patient empowerment in real life were given. Camilla Ratchke, Danish Junior Doctors’ Association presented the ‘Hello Healthcare’ initiative and Roza Chelajiska, National Patients Association, Bulgaria, spoke about the ‘Patient University’. The last session of the conference looked at what could be done in the future. David Somelkh, European Health Futures, looked at the policy change needed to empower patients and Maria Gomes Iglesias, European Commission, DG Santé, presented the Commission’s work having an impact on patient empowerment such as the health services performance, the Joint Action on the healthcare workforce. She added the next EU Presidency will identify solutions at EU and national level. The Commission’s next step will be to develop a framework for a sustainable EU collaboration on patient safety and quality of care. This will help Member States go from policies to implementation and all actors need to be involved.

Three parallel workshops were organised to discuss three key aspects of empowerment. The outcomes of the discussions will be used to draft a Patient Empowerment Charter and Multi-Stakeholder Roadmap later on during EPF’s campaign. Annette attended the meeting.

http://www.eu-patient.eu/Events/upcoming-events/conference-on-patient-empowerment/

21 May: European Parliament adopts resolution on the rights of persons with disabilities

On 21 May, the European Parliament adopted a resolution in which it expresses its strong support to the full implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD). It was adopted with an overwhelming majority among the political parties.

The resolution followed a plenary debate of the European Parliament and a public hearing, in which MEPS and representatives from the disability movement and EU institutions discussed the state of play of the implementation of the UN Convention.

The resolution states that the European Parliament should be fully involved in monitoring and implementing the UN Convention. In particular it highlights the UN Convention review process and the constructive dialogue between the EU and the UN CRPD Committee.
Through its resolution, the European Parliament supports the adoption of two key pieces of legislation: the European Accessibility Act and the General Antidiscrimination Directive.

The resolution also calls on the Member States to translate the obligations derived from Article 12 of the UN Convention into national laws and most specifically, the right of all persons with disabilities to vote and to be elected.

26 May: European Multiple Sclerosis Platform launches Call to Action on Access to Employment

EMSP launched its “Call to Action on Access to Employment for People with MS” in the European Parliament. This event follows the launch of the EMSP’s “European Pact for Employment for People with Multiple Sclerosis” in the EP last March calling upon European employers to break down the barriers which people with multiple sclerosis encounter in the workplace and to address the lack of access to employment. The Pact also offers areas for action.

The May event aimed at formally calling upon Members of the European Parliament, as well as individuals, stakeholders and advocacy organisations to support the Pact recommendations. The event was chaired by Adam Kosa, MEP (Hungary) and Co-Chair of the Disability Intergroup in the European Parliament.

Representatives from the European Commission, patients, employers and disabled people agreed a lot existed on paper regarding the employment of people with disabilities but concrete actions still needed to be implemented. The speakers called for more awareness about the disease among employers and employees, the implementation of existing laws, the inclusion of disability in all policies (mobility, access to health, vocational training), access to social benefits. Four priorities for action were identified: the review of the implementation of the UN Convention and the recommendations that will be put forward, the review of the EU2020 strategy and the adoption of the labour mobility package.

The Commission representative announced the Commission would launch an initiative on disability during 2015. Annette Dumas attended the meeting on behalf of AE.

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Members’ News

19 April: Spominčica meets new ADI Chairman

During the recent Alzheimer’s Disease International (ADI) conference in Perth, Australia, Alzheimer Slovenia (Spominčica) President, Štefanija L. Zlobek spoke with ADI’s new Chairman, Glen Rees (pictured). Ms L. Zlobek was delighted to hear that Mr Rees intends to join Alzheimer Europe’s 25th annual conference, 25AEC in Ljubljana in September.

5 May: Dementia Helpline will become available 24/7 in Malta

On 5 May, it was announced that the government in Malta would be working with the Malta Dementia Society to increase the availability of their Dementia Helpline from 3 hours per day to a 24/7 service.

This commitment from the government, announced by the Parliamentary Secretary for Rights of Persons with Disability and Active Ageing, Dr Justyne Caruana follows the recent launch of the national dementia strategy.

6 May: Cyprus Alzheimer’s Association reports on its new sensory room

The Cyprus Alzheimer’s Association’s eastern branch, formed in 2010, has reported that its recently created sensory room for people with dementia and their carers is now in regular use.

The sensory room (pictured) is proving to be a popular tool in helping calm and relax visitors to the support centre, which was created in 2014. The Association adds more equipment to the room as and when money is raised from events they organise.

The room is open to anyone in the area with an illness, who could get some benefit from it.

7 May: Alzheimer Scotland reports on recent election campaigning

The recent UK General Election (7 May) has been exercising the energies of campaigners in Scotland as well as our colleagues elsewhere in the UK.

Alzheimer Scotland used the opportunity of the election to engage with both existing MPs and candidates, to promote support for dementia locally and nationally. We asked candidates to pledge to make the following four commitments:

- To back an ongoing commitment to a human rights based approach to support, care and treatment for people with dementia, their families and carers.
- To champion the globally significant contribution that research in Scotland makes and to ensure equality of access to UK funding opportunities for Scottish institutions.
- To promote awareness and address the stigma of dementia by encouraging more open dialogue and reducing the barriers to seeking help.
- To support the improvement of services for and inclusion of people living with dementia in every constituency in Scotland.
We focussed on issues where the UK Government in London, rather than the Scottish Government in Edinburgh, has responsibility.

Over a third of the hundreds of candidates standing in Scotland supported this pledge, thanks to Alzheimer Scotland supporters tweeting and emailing their local candidates. In these interesting political times, 50 of Scotland’s 59 MPs are new to the job, and Alzheimer Scotland will be working to support them and their more experienced colleagues to in their turn support people living with dementia across Scotland.

14-17 May: Greek Alzheimer Association reports on its 9th conference

The Greek Association of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas), in cooperation with the Panhellenic Institute of Neurodegenerative Diseases, organised with great success the biannual Panhellenic Interdisciplinary Conference of Alzheimer’s Disease and Related Disorders. The event took place from 14 to 17 May at the Grand Hotel Palace in Thessaloniki, Greece.

The 9th Panhellenic Interdisciplinary Conference of Alzheimer’s Disease and Related Disorders took place along with the 1st Mediterranean Conference on Neurodegenerative Diseases, organised with a variety of specialties to present their contributions to patients and caregivers.

The combined conferences achieved their goals of:

- Hosting the most distinguished scientists in the field, who presented and shared results of the latest research, pharmaceutical and non-pharmaceutical clinical trials, as well as the application of new technologies. The Greek press published extensive articles on the scientific results presented.
- Providing an opportunity for health professionals with a variety of specialties to present their contributions to patients and caregivers.

The more than 800 delegates included clinicians (neurologists, psychiatrists, geriatricians), neuroscientists (molecular geneticists, neuropathologists, neurobiologists, neuropsychologists, pharmacists) and representatives from biomedical and pharmaceutical companies, patients, families and caregivers. All left wiser and better able to deal with dementia through this meeting of leading experts.

Alzheimer Hellas would like to express its gratitude to all the speakers, participants, guests from all over Greece and worldwide, who honoured us with their presence, as well as to all conference sponsors and personnel.

The success of the conference is attributed to all the stakeholders who contributed, worked hard and held an amazing event that aimed at informing the professionals and improving the quality of life for people with dementia and their caregivers.

AE Director for Communication, Alex Teligudas gave a presentation at the opening ceremony (pictured, top).

15 May: Alzheimer Scotland announces its biggest ever series of Memory Walks this autumn

On 15 May, Alzheimer Scotland published the following press release announcing its upcoming series of Memory Walks, raising funds for dementia in Scotland:

As the number of people living with dementia in Scotland continues to rise, Alzheimer Scotland is set to deliver its biggest ever Memory Walk series in a bid to rally support for people living with dementia in communities across the country.

There are over 90,000 people living with dementia in Scotland, and tens of thousands of unpaid carers, often partners and family members, supporting them. Alzheimer Scotland will hold over 25 Memory Walks in Scotland this autumn to raise vital funds to deliver support services and raise awareness of the discrimination, isolation and stigmatisation faced every day by people living with dementia. There will be walks from Scalloway in Shetland to Hawick in the Borders – starting late August and finishing in early October.

Anna Devine, Director of Fundraising, Marketing and Communications, said, “Dementia is a huge, growing health crisis and it isn’t going to go away. We must rally our caring and compassionate communities across Scotland to be part of our Memory Walks and embrace the message that dementia is everyone’s business. It costs Alzheimer Scotland millions every year to deliver vital services across Scotland. To sustain that support as the demand for our services increases, we need to raise more funds and more awareness.”

All funds raised will be used to help pay for vital Alzheimer Scotland dementia services across Scotland such as the 24 hour Dementia Helpline, Dementia Advisors, Dementia Nurses and dementia research. Funds will also support important local activities, such as Dementia Cafés, support groups, singing and gardening groups.

Alzheimer Scotland’s Memory Walks are family friendly and accessible to all, and will be the charity’s primary outdoor fundraiser in 2015. Memory Walks are also a significant part of Alzheimer Scotland’s campaign to ensure the voices of those living with and caring for people with dementia are heard. Walks will include memories-themed and family activities and walkers will have the chance to honour loved ones by writing messages on a Memory Wall.

Registration is £10 for adults, £5 for 12-16 year olds and free for under 12s. We’re asking participants to raise £100 in sponsorship. Visit www.MemoryWalksScotland.org to find out more and to register.
15-16 May: Czech Alzheimer Society is involved in 4th ELTECA in Prague

Česká alzheimerovská společnost

On 15 and 16 May, the 4th Exchange of Experience in Long-Term Care (ELTECA) was held in Prague, at the Hilton Old Town hotel. The event was organised by the Czech Society of Gerontology and Geriatrics in collaboration with Czech Alzheimer Society and Centre of Expertise in Longevity and Long Term Care (Charles University in Prague).

The main dementia-related topics discussed were: timely diagnosis and management, dysphagia and psychosocial interventions. Alzheimer Europe’s Vice-Chairperson Ivana Holmerová was the event’s main convener.

Speakers included: Prof. Gill Manthorpe (UK), Olafur Samuelson (Iceland) and Jean-Claude Leners (Luxembourg).

18 May: The Alzheimer’s Society launches “Do Something New” campaign for Dementia Awareness Week

This year’s Dementia Awareness Week in the UK (DAW), from 18 to 23 May, saw the launch of a new campaign by the Alzheimer’s Society (UK).

The Society carried out a survey of the British public, the results of which seem to suggest that many Brits are living unfulfilled lives, with less than a third of people having tried out new activities or hobbies in the last year. Survey respondents cited a lack of confidence, laziness and lack of time as the main things stopping them from being more adventurous.

Over half (59%) also said they are worried that developing dementia would prevent them from enjoying new experiences at all.

For DAW, the Alzheimer’s Society launched a campaign to encourage people to “do something new”, using the Twitter hashtags #DoSomethingNew and #DAW2015.

Jeremy Hughes, Chief Executive at Alzheimer’s Society (pictured) said that while people post selfies on social media every day to tell their friends and followers about exciting things they’re doing, the survey exposes people’s lives as being “more run-of-the-mill and less adventurous than the impression given out on Facebook, Twitter and Instagram.”

Emphasising the importance of taking part in new activities, for everyone the campaign aimed to encourage people with dementia and their loved ones to get involved in new activities, to help build confidence, enhance emotional wellbeing and create positive memories.

“Even the simplest things can help people with dementia feel connected to the world and the people who matter most. While they may not remember the details, the positive emotions remain”, Mr Hughes commented.


19 May: CEFAA reports on its participation in Spanish State Dementia Group meeting

On 19 May, the Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEFAA) participated in a meeting of the State Dementia Group in Spain, promoted by the Instituto de Mayores y Servicios Sociales (IMSERSO). The meeting was held in response to the needs of the Confederation.

Chaired by the Health Minister, this meeting saw the launch of the document “Conclusions and proposals to advance the definition of Alzheimer’s State Policy” - prepared with the support of Lilly.

CEFAA will continue to contribute to the State Group with its knowledge and expertise, leading sub-groups formed to advance specific issues, some of which were raised at this meeting.

It was noted that the Health Minister pledged to approve the Strategy of Neurodegenerative Diseases by the end of year, in which Alzheimer’s disease will feature heavily. This is encouraging news.

CEFAA will also work with the State Reference Centre for Alzheimer’s disease, defining and planning the next steps to take and coordinating the work of the State Dementia Group. This is the first solid step towards a comprehensive approach to Alzheimer’s disease since the National Administration. This approach is demanded by more than 4 million people in Spain, including patients and family carers.

It is a challenge and a responsibility, which CEFAA is willing to take, with knowledge accumulated over 25 years, through the action of its 300 Associations and is an investment for our 25th Anniversary.

21 May: Czech Alzheimer Society co-organises course on the forensic aspects of dementia

The forensic aspects of dementia was the topic of a course delivered by the Department of Long-term care medicine of the Postgraduate School of Medical Education (IPVZ) Prague on 21 May. The course was organised in collaboration with the Czech Alzheimer Society and the Czech Public Defender of Rights.

Course participants were mainly physicians and nurses and discussions were around the medical, psychological and legal aspects of dementia (driving, informed consent, professional responsibility of physicians and dementia, quality of care...).

21 May: Alzheimer France organises a Symposium on national policies and research on dementia

The symposium took place in Paris on 21 May and addressed relevant aspects of medical, economic and psychosocial research on dementia. It also looked at the influence of such
research on public policies, most notably on the three “Plan Alzheimer” that have been developed in France since 2001. Delegates were welcomed by the President of Alzheimer France Ms Desana and by Prof Duyckartes, the director of the bio-bank Neuro-CEB.

The symposium offered to the delegates a better understanding of the complexities and challenges of dementia from a medical point of view and highlighted the impact that new technologies are having on the disease.

The audience was also introduced to the “capabilities” approach. During the round table examples of how this approach could be used in dementia care were discussed. The word capability incorporates aspects of social justice and freedom, opportunities and choice, and being valued by others. The approach is an invitation to look at what the person with dementia can still do rather than to his/her impairments.

During the event it was agreed that whilst many efforts have been made over the last years, better coordinated, interdisciplinary and coherent research is still necessary. This might help to better understand the pathology but also the human dimension of the disease and help people to live well “in spite of, with or outside” of dementia. Research from this perspective was defined as a “democratic innovation”, which is shared by the community of researches and the wider community, which is only possible thanks to the solidarity, generosity and involvement of citizens. Ana Diaz, Alzheimer Europe’s project officer attended the Symposium.

22 May: Federazione Alzheimer Italia delivers free training course for carers in Milan

For the sixth year running, Federazione Alzheimer Italia (FAI), in collaboration with Associazione Alzheimer Milano, organised a free, six-part training course for caregivers in Milan. Attended by 70 family carers, the course aimed to give participants a better understanding of Alzheimer’s disease.

The main objective of the course was to “care for those who care”, easing their isolation and stress, providing professionals who, through their experience, were able to give information and guidance to help manage daily activities.

Specifically, the objectives of the course were:

- to provide medical knowledge about the disease
- to give basic information about rights from a legal standpoint
- to provide guidance, giving practical examples, about simple devices and solutions for everyday life for the management of behavioural problems
- to provide some insight into the language of music, as a possible tool available to the family
- to address psychological problems caregivers may develop
- to indicate how to give proper personal care, the right way to administer medicines and oral hygiene at home.

Communication among family members also continued on the web via social media after the course, while many caregivers in other cities, requested the course handouts and for the course to be replicated by other member associations of the FAI.

FAI believes these requests are the result of a job well done and shows they are truly helping put people in a position to better understand the disease in all its stages supports.


25 May: The Alzheimer Society of Finland publishes report on dementia and working life

The Alzheimer Society of Finland, Muistiliitto has conducted a small scale study into the attitudes and practices of neurologists and occupational health practitioners. It has published a brochure on dementia and working life, as well as publishing the study results online.

Thanks to improvements in knowledge and diagnostic methods, it says, people are being diagnosed with dementia earlier and a diagnosis of dementia does not necessarily mean having to stop work. Muistiliitto stresses that people with early-onset dementia should go through a proper evaluation of their ability to work and their need for rehabilitation, just as people with other diseases do.

However, according to the survey of 27 doctors, completed in summer 2014, a diagnosis of dementia is seen as an obstacle to the continuation of work: 70% of respondents think that the employee wants to continue with their employment, while 60% think that employers are unwilling to continue with the person’s employment. Only 26% estimates that the assessment of rehabilitation is always done, while 15% says it is not normally done. The main obstacles to work are difficulties in modifying job descriptions and a lack of support and rehabilitation, says Muistiliitto. Support should come via a suitable job description, an adjustable work environment and rehabilitation, it says.

Based on the results of the survey, Muistiliitto believes there is a need for change in the attitudes of professionals and employers, as well as need for tailored information, support and materials. A rehabilitation plan should be made for every person with early-onset dementia, it says and it recommends developing good practices and models in working life.

Muistiliitto’s comprehensive brochure on early-onset dementia and working life can be downloaded here:


25 May: Swiss Alzheimer Association reports on its new campaign

Most people know little about dementia and what living with the disease means. Raising public awareness is one of the 18 projects defined in the Swiss National Dementia Strategy 2014-2017. Alzheimer Association
Switzerland is leading the project and has formed a partnership with Pro Senectute Switzerland.

The national campaign, “dementia concerns all of us” consists of posters, print and online ads and a new website, launched on 28 May. For more info contact susanne.bandli@alz.ch or visit:

http://www.memo-info.ch/fr/

27 May: Nancy McAdam reports on the SDWG’s work on travelling with dementia

On 27 May, Nancy McAdam, chair of the Scottish Dementia Working Group (SDWG) Transport sub-group sent us the following report about the group’s recent work on travelling with dementia:

In 2013 we identified transport as an additional work priority and set up The Transport Group, which I chaired. As people with dementia ourselves, we wanted to find safe ways to travel and to be able to share these tips with others across Scotland. We established two priorities:

- Produce a leaflet on tips and strategies for travelling safely
- Use this leaflet to raise awareness amongst transport staff

We produced our leaflet “Travelling with Dementia”, which was extremely well received. We are now on our third version which you can download here:


We also received great feedback from transport agencies and noticed that there was a big demand for more information and training. We decided to produce a training DVD to roll out across Scotland and applied to the Life Changes Trust for money to make this happen. We were delighted to be awarded GBP 7,000 (approx. EUR 9,800) and have now begun this work. We hope the DVD will be available by the summer.

DONATE NOW! Help us make dementia a priority

Policy Watch

29 April: Croatian Ministry of Health supports Alzheimer Croatia’s proposals

Croatia’s Ministry of Health has lent its support to a series of proposals made by Alzheimer Croatia at a meeting held on 29 April in Zagreb, Croatia.

The Ministry adopted several important proposals and agreed on concrete actions aimed at supporting people with dementia and their family caregivers.

Among other things, it was concluded that:

- Dementia medications must be on the ‘free list’ (non-payable health insurance list)
- Society must give better general assistance to families living with Alzheimer’s disease and the status of family caregivers must be defined
- Routine diagnosis of Alzheimer’s disease should include markers which are taken from the cerebrospinal fluid
- Alzheimer’s disease must be seen as a public health priority and actions for its early detection implemented
- Accommodation for people with Alzheimer’s disease must be facilitated in retirement homes, as well as in more specialised centres, which must be established and supplied with palliative psycho-geriatric beds
- Adoption of the National Dementia Strategy must be accelerated

Pictured (left to right): Vesna Škulić and Dr Valerija Stamenić from the Ministry of Health, Dr Marija Kušan Jukić, Tajana Đajić and Prof. Ninoslav Mimica from Alzheimer Croatia.

5 May: One in two French people living with dementia is undiagnosed, study says

According to a study published on 5 May, one half of all people living with dementia in France are currently undiagnosed and are therefore denied proper, personalised support. The study report says that while 500,000 people with Alzheimer’s or a related disease are diagnosed and supported, the disease is estimated to affect a total of more than one million people in France.

The report also notes huge disparity between geographic regions: Areas such as Bouches-du-Rhône and Paris in the North having the highest rates of diagnosis and over 30% of estimated people with dementia actually being supported. However, in rural areas such as the Creuse, the Deux-Sèvres or Gers, this proportion is only 15%.

The study estimates that if all the people estimated to be living with dementia were actually diagnosed, this would increase the current number of home help places 20 fold and would increase the number of day care spaces 10 fold.

The study also revealed that although exercises to slow the progression of the disease in people with moderate or severe dementia residing in nursing homes (relaxation, music therapy, play stimulating motor skills, etc.) are considered "essential", they are only present in one in six facilities.

These findings, among others, were explored in more detail in an article published in a French daily evening newspaper, Le Monde:

17 May: The Alzheimer’s Society is concerned about UK cuts in social care

On 17 May, UK newspaper, The Independent on Sunday published an interview with the Alzheimer’s Society’s Head of Policy, George McNamara about the impact of further social care cuts to people with dementia and their families in the UK.

Speaking just before Dementia Awareness Week in the UK, Mr McNamara expressed concerns that tens of thousands of British people who work and look after older relatives could be forced into unemployment if adult social care is subjected to further cuts by the UK government:

“Workers can’t fit caring responsibilities into a lunch-break. Looking after an elderly parent with dementia takes huge amounts of time, energy and emotional stress. Many carers will have no choice but to give up work unless they get better public services”, he said.

“The government has recognised the need to improve parents’ access to childcare to maintain economic recovery. But side-lining social care for a rapidly growing population of vulnerable older people also poses serious risks to the economy...We want the government to end the crisis in social care and provide a vital lifeline for working families caring for elderly relatives.”

About half a million older and disabled people who would have received social care in 2009 are no longer entitled to it, researchers at the London School of Economics have reported. An estimated 50,000 UK carers were forced to give up their jobs in 2014 because of caring responsibilities, with some 290,000 people having to balance looking after relatives with work commitments, according to the Centre of Economic and Business Research.

25 May: Norway’s daycare centres will have to provide activities for people with dementia from 2020

The Norwegian Parliament has made a decision to adopt a law that will make it mandatory to provide activities for people with dementia in daycare centres in all municipalities. The law will be put in place from 2020.

Lisbet Rugtvedt, Secretary General of the Norwegian Health Association reacted to the news, saying “We have been campaigning for this for many years, and are pleased that all political parties now understand the importance of daycare activities”. Ms Rugtvedt continued, however, saying “we see no reason to wait as long as until 2020 for the law to take effect. And we will continue to campaign for the law to be as good as possible for people with dementia, and also for the law to take effect earlier”.

The Norwegian Health Association will also campaign for increased spending on daycare activities by Norway’s municipalities in the upcoming elections this autumn. “It is important that this area receives attention now, if there is to be services for those who need them in the years to come”, the association stressed.


Science Watch

14 April: Study looks into why AD affects more women than men

According to current statistics, nearly two-thirds of people with Alzheimer’s disease (AD) are women. A study published in the journal Annals of Neurology on 14 April suggests a reason for this disparity between sexes.

Lead author Michael Greicius said he first became curious about the male vs. female risk rate of AD in 2012 after unearthing a scientific paper published in JAMA in 1997. The paper suggested that the gene APOE-ε4, was more commonly expressed in women and was found to be leading to an increased risk of developing Alzheimer’s disease.

Dr Greicius and his team decided to investigate this phenomenon using modern techniques to assess gene expression.

Analysing public data on more than 8,000 people around the age of 60, who had been admitted to Alzheimer’s centres in the United States, the team determined that the risk of developing full-blown Alzheimer’s disease was highest in individuals carrying the APOE-ε4 gene variant.

Interestingly, when the researchers then compared risk rates among female carriers with those among male carriers, they were able to determine that the gene only led to a slight increase in risk among males. On the other hand, women who expressed the variant had nearly double the risk of developing AD compared to women who did not express the gene in that manner.

Brain scans of the gene carriers showed a similar theme, whereas men with the gene commonly showed brain scans no-different from their non-APOE-ε4 expressing counterparts, women with the gene variant showed remarkably different looking brain connections compared to non-carriers.

Dr Greicius and his colleagues say it is still unclear why the variant has such a more severe effect on the brains of women, but simply identifying the variant’s influence is an important step, they say.

1 May: Astronauts could develop dementia en route to Mars

Astronauts could develop dementia if they journey to Mars, says a study conducted at the University of California (UCI), published on 1 May in the American Association for the Advancement of Science (AAAS) journal, Science Advances.

The research team, led by Charles Limoli, Professor of Radiation Oncology in UCI’s School of Medicine, found that exposure to highly energetic charged particles - much like those found in the galactic cosmic rays – can cause significant damage to the central nervous system.
To test the impact, rats were exposed to fully ionized oxygen and titanium to simulate space radiation, at the National Aeronautics and Space Administration (NASA) Space Radiation Laboratory. The researchers found that exposure to these particles resulted in brain inflammation, which disrupted the transmission of signals among neurons. Communication, learning and memory were found to be impaired.

While cognitive deficits in astronauts would take months to manifest, Prof Limoli said, the time required for a mission to Mars is sufficient for such deficits to develop, which he said could affect mission-critical activities, and have "long-term adverse consequences to cognition throughout life."

People working for extended periods on the International Space Station do not face the same level of bombardment with galactic cosmic rays, as they are still within the protective magnetosphere of the Earth, the Van Allen belt.

Prof. Limoli's work is part of NASA's Human Research Program which is looking at the impact of extended periods in space.

http://advances.sciencemag.org/content/1/4/e1400256

4 May: High blood sugar may contribute to AD, new study finds

Research carried out at Washington University School of Medicine, has investigated the link between high levels of the sugar glucose in the blood, a symptom of diabetes, and Alzheimer's disease (AD). The results, which suggest diabetes can have harmful effects on brain function and may exacerbate neurological conditions such as AD, were published in the Journal of Clinical Investigation on 4 May.

While many earlier studies have pointed to diabetes as a possible contributor to Alzheimer's this new study, conducted in mice, shows that elevated glucose in the blood can rapidly increase levels of amyloid beta, a key component of brain plaques in people with AD.

http://www.jci.org/articles/view/79742

5 May: Green tea and exercise slow AD progression in mice, study finds

Researchers at the University of Missouri (MU) in the US have completed a study, which concludes that voluntary exercise and epigallocatechin-3-gallate (EGCG), a green tea extract, slow the progression of Alzheimer’s disease (AD) in mice.

In the first part of the study, a research team led by Todd Schachtmann, Professor of Psychological Sciences in the College of Arts and Science at MU observed mice to determine whether or not they could find a "goal box" in a specialized maze, demonstrating memory and cognition. They also tested the mice on their nest-making ability.

"Mice exhibiting symptoms of the disease had nests that were poorly formed or erratic," said Prof. Schachtmann. "Further, we found that mice with Alzheimer’s symptoms, much like people, can be apathetic about their habitat, or have forgotten how to ‘nest’ appropriately."

Researchers then administered EGCG in the drinking water of the mice and gave them access to running or exercise wheels. After re-administering the maze and nesting tests, they found “remarkable improvements” in the cognitive function and retention in the mice with AD that were given EGCG and were allowed to exercise.

For the second part of the study, a team of biochemists led by Grace Sun, Professor Emerita of Biochemistry in the School of Medicine and the College of Agriculture, Food and Natural Resources at MU analysed mouse brain tissues to determine the effects of EGCG and exercise on A-beta levels in affected regions of the brain.

“Oral administration of the extract, as well as voluntary exercise, improved some of the behavioral manifestations and cognitive impairments of Alzheimer’s,” said Prof. Sun, who also serves as the director of the Alzheimer’s Disease Program at MU. “We also are excited to see a decrease in A-beta levels in the brains of the affected mice as well as improvements in behavior deficits in mice with AD.”

The scientists are now exploring possible future studies of green tea extracts and other botanicals, also known as nutraceuticals.

http://www.j-alz.com/content/green-tea-extract-and-exercise-hinder-progression-alzheimers-disease-mice

5 May: New online journal launched in the US

On 5 May, the Alzheimer’s Association (US) announced the launch of a new open access, online-only journal, Alzheimer’s & Dementia: Diagnosis, Assessment & Disease Monitoring (DADM).

The journal, which will act as a companion publication to the Association’s existing Alzheimer’s & Dementia journal, will allow more researchers to share their findings and knowledge faster than they were previously able to.

Alzheimer’s & Dementia: DADM will contain new research on a range of topics focussed on the early and accurate detection of people with memory complaints and people at risk of various forms of memory disorders.

http://www.dadm.alzdem.com/

5 May: Scottish scientists say new AD drug is performing well in trials

Scientists from Aberdeen University report that a new Alzheimer’s disease (AD) treatment they are working on, known as LMTX, has performed well at clinical trials so far and they believe it could slow halt the progression of the disease by up to 15 years. The research is being led by Professor Claude Wischik of Aberdeen University.

Prof. Wischik summarised the team’s findings so far: “In the phase-two tests, this drug achieved a 90 per cent reduction in the rate of progression on clinical
measurements, and it achieved a similar effect on the rate of loss of brain function, as measured by brain scans. In total we have 1,910 patients enrolled so far; the clinical trials are being conducted in more than 200 clinics around the world in 20 countries."

Henry Simmons, Chief Executive of Alzheimer Scotland welcomed this "exciting development", but stressed that more information on the trial results was needed.

14 May: Medical marijuana may have no effect on dementia symptoms

Low-dose oral tetrahydrocannabinol (THC) may not have no effect on the common behavioural symptoms, which can affect people living with dementia, according to a recent study published in the journal Neurology.

The phase II trial involved 50 people living with dementia, memory or heart rate at this dose. Potential side effects were no more common in those taking it and that they found it had no effects on memory or heart rate at this dose. Potential side effects such as sleepiness and dizziness were no more common in the medical marijuana group than the placebo group, they noted.

"We currently plan to do another study in the same patient group using a higher dose of THC, although the exact dose has not yet been determined," Prof. Olde Rikkert said.

Dr Norman Relkin, Associate Professor of Clinical Neuroscience at Weill Cornell Medical College in New York and spokesperson for the American Federation for Aging Research, however warned that "when (existing) drugs are tested in dementia patients, they just don’t work the same as they do in other contexts."

"The fact that something has a calming effect on a person without dementia does not necessarily mean it's the good, or compassionate, thing to do for a person with dementia," Dr Relkin said. "It's important to try to see things through the eyes of the person with dementia".

19 May: Two Dutch studies analyse prevalence of amyloid plaques in adults with and without dementia

Two studies from the Netherlands have analysed the prevalence of amyloid brain plaque among adults of varying ages - with and without dementia - and its association with cognitive impairment. Both were published on 19 May in the journal JAMA.

In the first study, "Prevalence of Cerebral Amyloid Pathology in Persons Without Dementia", Willemin J. Jansen, M.Sc., Dr Pieter Jelle Visser and their colleagues at Maastricht University used individual participant data meta-analysis to estimate the prevalence of amyloid pathology in study participants with normal cognition, subjective cognitive impairment (SCI), or mild cognitive impairment (MCI).

The researchers found that the prevalence of amyloid pathology increased considerably from age 50 to 90 years and APOE-ε4 gene carriers had 2 to 3 times higher prevalence estimates than non-carriers.

"The observation that key risk factors for AD-type dementia are also risk factors for amyloid positivity in cognitively normal persons provides further evidence for the hypothesis that amyloid positivity in these individuals reflects early AD", the authors write. They also believe their findings suggest an interval of 20 to 30 years between amyloid positivity and the onset of dementia, which "provides a large window of opportunity to start preventive treatments."

The authors note that the exact interval between the onset of amyloid positivity and onset of AD-type dementia needs to be assessed by long-term follow-up studies.

In the second study "Prevalence of Amyloid PET Positivity in Dementia Syndromes", Dr Rik Ossenkoppele of VU University Medical Center Amsterdam and colleagues used individual participant data meta-analysis to estimate the prevalence of amyloid positivity on positron emission tomography (PET) in a wide variety of dementia syndromes.

One of the study’s main findings was that “that the prevalence of amyloid on PET decreased with age in participants diagnosed with AD (greatest in APOE ε4 noncarriers) and increased with age in most non-AD dementias.”

"Data from this study may inform research into the clinical application of amyloid PET and highlight the necessity of biomarker-based participant selection for clinical trials”, they concluded.

Dr Roger N. Rosenberg of the University of Texas Southwestern Medical Center at Dallas, Editor of the journal JAMA Neurology commented on what these two studies have shown in his editorial:

"Jansen et al and Ossenkoppele et al provide succinct meta-analyses of considerable clinical value...Persons without dementia have an increasing prevalence of cerebral amyloid pathology with age, APOE genotype, and cognitive loss as measured by PET imaging or cerebrospinal fluid findings. Similarly, among persons with dementia, the prevalence of amyloid pathology was related to clinical diagnosis, age, and APOE genotype. Together, these data show the immense potential clinical use of amyloid imaging to make the correct diagnosis in early-onset dementia and, more specifically, to establish the diagnosis of AD-type dementia and noncarrier APOE-ε4 genotype among persons older than 70 years.”

http://www.neurology.org/content/early/2015/05/13/WNL.0000000000001675.abstract

http://jama.jamanetwork.com/article.aspx?articleid=2293276&resultClick=3
Dementia in society

29 April: First Dementia Festival of Ideas event takes place in London

To mark its 25th anniversary, the Dementia Services Development Trust is having one year of celebrations in the form of the Dementia Festival of Ideas.

The first event, attended by Dianne Gove from Alzheimer Europe, took place in London on 29 April. The event was a master class consisting of a dinner and breakfast discussion chaired by Professor June Andrews, about the most pressing ethical issues in relation to dementia within society.

Participants were from a range of backgrounds including journalism, communications, technology, medicine, nursing and care. Some of the issues addressed included the ethical issues related to the funding of research and dementia care initiatives and about the choice of images of dementia portrayed in the media.

In the coming months, there will be more discussions leading up to an international conference on pressing issues in dementia and ethics.

14 May: Blues legend BB King dies with vascular dementia

On 14 May, American Hall of Fame blues singer BB King (born Riley B. King on 16 September 1925) has died with multi-infarct dementia, also known as vascular dementia.

The musician’s doctor, Darin Brimhall and Clark County Coroner John Fudenberg told the Associated Press that Mr King had a series of small strokes as a result of the 89-year-old’s chronic type 2 diabetes.

On 27 May, thousands lined the streets of Memphis, Tennessee to pay him tribute. A Dixieland jazz band walked ahead of a black hearse down Beale Street, where the young Mr King was nicknamed the Beale Street Blues Boy - a moniker later shortened to BB.

23 May: Lawrence of Arabia actor Omar Sharif has Alzheimer’s disease

Omar Sharif, best known for his roles in the movies Doctor Zhivago and Lawrence of Arabia, has been diagnosed with Alzheimer’s disease.

The 83-year-old Egyptian-born actor’s only son, Tarek El-Sharif told Spanish newspaper El Mundo of his father’s diagnosis during an interview published on 23 May. Mr Sharif, who won two Golden Globes during his career, now finds it difficult to remember his greatest roles, says Mr El-Sharif:

“He remembers, for example, that it was Doctor Zhivago but he’s forgotten when it was filmed...He can talk about the film but he forgets its name or he calls it something else”.

Mr Sharif, who lives in Cairo, came to international attention in 1962 with his role in Lawrence of Arabia alongside Peter O’Toole. The pair remained friends until Mr O’Toole’s death in 2013. Mr Sharif went on to star in Doctor Zhivago (1965) and Funny Girl (1968) with actress and singer Barbara Streisand.

The news was confirmed by his agent Steve Kenis on 25 May.

New Publications & Resources

30 April: The European Medicines Agency publishes its annual report

On 30 April, the European Medicines Agency (EMA) published its annual report, which focuses on the Agency’s key priorities, including the evaluation of medicines and the support to research and development of new and innovative medicines.


7 May: OECD publishes report of 2014 Lausanne workshop

On 7 May, the Organisation for Economic Co-operation and Development (OECD) published the report of the November 2014 Lausanne Workshop, “Enhancing Translational Research and Clinical Development in Alzheimer’s Disease and other Dementia: The Way Forward”.

You can download the full report here:


11 May: Forget-Me-Knot Game aims to raise awareness of dementia

A new computer game called Forget-Me-Knot has been developed by a student studying Game Design & Production Management at Abertay University in Dundee, Scotland. Forget-Me-Knot is designed to raise awareness of dementia. A video with a simulation of the game, which is currently in the prototype stage and is expected to be released soon, can be seen here:

https://www.youtube.com/watch?v=V-GrreYL-Ng
18 May: UK Department of Health released five videos for dementia Awareness Week

The Department of Health released five new videos on 18 May, highlighting a range of initiatives to support people with dementia in different areas of England. The videos, which were published for Dementia Awareness Week (DAW) 2015, give an insight into the following services:

• Dementia services in Tower Hamlets, London
• Dementia Support Workers in Bath and North East Somerset
• Community Care Model for Dementia at North East London NHS Foundation Trust
• Shires Community Support Team in Derbyshire
• Support for people with early onset dementia at Mersey Care NHS Trust


20 May: New website launched for World Dementia Council

On 20 May, the World Dementia Council (WDC) launched its new website

https://worlddementiacouncil.wordpress.com/

Job Opportunities

29 May: Alzheimer Europe is looking for a Policy Officer

Alzheimer Europe is looking to fill the following position:
Policy Officer (m/f) (Full time).

As the Policy Officer, you will:

• Support the campaign of Alzheimer Europe and its national member organisations in getting dementia recognised as a European priority
• Develop policy statements and contributions to ongoing Commission consultations
• Present the views of Alzheimer Europe to members of European institutions
• Support the activities of the European Alzheimer’s Alliance
• Liaise with other European carers’ and patients’ organisations
• Report on relevant EU and national policy developments and contribute to the organisation’s monthly newsletter and quarterly Dementia in Europe magazine
• Collaborate with the organisation’s national member associations in the development of national reports on dementia policies

You should have the following experience and qualities:

• Completed university education and experience in a similar position (education or background in EU affairs, communication or journalism will be considered as an advantage)
• A good understanding of the workings of the European institutions
• A perfect knowledge of English and good working knowledge of at least two additional European languages
• Excellent writing skills
• Experience of social media
• Good computer knowledge (Internet applications, Word)
• A keen sense of responsibility and initiative
• Willingness to travel to Brussels and Strasbourg for meetings of the European Parliament and other networking opportunities

Please apply by sending your CV, together with a cover letter (both documents in English), by 26 June 2015, to: Alzheimer Europe, 14, rue Dicks, L-1417, L-2611 Luxembourg or via E-mail to info@alzheimer-europe.org.
## AE Calendar 2015

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<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>1 June</td>
<td>Dementia Awareness Week Conference of Alzheimer Scotland (Glasgow, Scotland, UK)</td>
<td>Jean</td>
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<tr>
<td>2 June</td>
<td>Meeting with MEPs and the European Union Geriatric Medicine Society (EUGMS) (Brussels, Belgium)</td>
<td>Dianne, Annette</td>
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<td>3 June</td>
<td>Patients' and Consumers' Working Party of European Medicines Agency meeting (London, UK)</td>
<td>Annette</td>
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<tr>
<td>4 June</td>
<td>Joint Legal and Ethical Workshop of the AETIONOMY project (Hannover, Germany)</td>
<td>Jean</td>
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<td>4-5 June</td>
<td>Symposium “Herausforderungen Demenz” of Health Ministries of German-speaking countries (Bern, Switzerland)</td>
<td>Heike</td>
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<tr>
<td>9 June</td>
<td>European Patients’ Forum Public Affairs Group meeting ( Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>11 June</td>
<td>EFPIA Patients Think Tank (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>11-13 June</td>
<td>7th Kuopio Alzheimer Symposium (Kuopio, Finland)</td>
<td>Jean</td>
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<tr>
<td>12 June</td>
<td>GSK Health Advisory Board meeting (Brentford, UK)</td>
<td>Annette</td>
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<tr>
<td>15-16 June</td>
<td>Meeting on “Addressing the challenge of elder abuse in Europe” organised by the Council of Europe, the European Commission, AGE Platform Europe and ENNHRI (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>15-16 June</td>
<td>Patient Advocacy Engagement Workshop organised by Janssen (Brussels, Belgium)</td>
<td>Kate</td>
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<td>16-17 June</td>
<td>Site inspection for potential venues for AEC2016 (Copenhagen, Denmark)</td>
<td>Gwladys</td>
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<td>23-24 June</td>
<td>2nd General Assembly of the EMIF project (Ochten, Belgium)</td>
<td>Alex</td>
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<tr>
<td>24-25 June</td>
<td>European Commission meeting of governmental experts on dementia (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>29 June-1 July</td>
<td>Lunch debate at the European Parliament, AE Board meeting, Company Roundtable and Public Affairs meeting (Brussels, Belgium)</td>
<td>AE Board and staff members</td>
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## Future Conferences 2015

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<th>Date</th>
<th>Meeting</th>
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<tr>
<td>9 June</td>
<td>Dementia, dignity and compassionate care conference, <a href="http://www.wonk.ac.uk/dementia">http://www.wonk.ac.uk/dementia</a></td>
<td>Birmingham, UK</td>
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<tr>
<td>1-7 June</td>
<td>Dementia Awareness Week - Let’s talk about dementia, <a href="http://daw.dementiascotland.org/">http://daw.dementiascotland.org/</a></td>
<td>Scotland, UK</td>
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<tr>
<td>3-5 June</td>
<td>The Alzheimer’s Show London, <a href="http://alzheimershow.co.uk/">http://alzheimershow.co.uk/</a></td>
<td>London, UK</td>
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<tr>
<td>11-13 June</td>
<td>7th Kuopio Alzheimer Symposium “From mechanisms to prediction and intervention of Alzheimer’s disease”, <a href="http://www.uef.fi/kuopioalzsymposium">http://www.uef.fi/kuopioalzsymposium</a></td>
<td>Kuopio, Finland</td>
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<tr>
<td>17-18 June</td>
<td>Best Practice in Care and Support of Persons with Advanced Dementia, <a href="http://www.uwc.ac.uk/palliareproject/">http://www.uwc.ac.uk/palliareproject/</a></td>
<td>Prague, Czech Republic</td>
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<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>
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<tr>
<td>3-7 July</td>
<td>Summer Course on Ethics in Dementia Care, <a href="https://ghemod.kaivounen.fi/english/research/5000687/50000697/summer-course">https://ghemod.kaivounen.fi/english/research/5000687/50000697/summer-course</a></td>
<td>Leuven, Belgium</td>
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<tr>
<td>26-27 August</td>
<td>Alzheimers disease and other neurodegenerative dementias, <a href="http://www.videnscenterfordemens.dk">www.videnscenterfordemens.dk</a></td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>15-18 October</td>
<td>9th Congress on Vascular Dementia (ICVD 2015), <a href="http://www.cmeecmed.com/evd">http://www.cmeecmed.com/evd</a></td>
<td>Ljubljana, Slovenia</td>
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<tr>
<td>31 October-5 November</td>
<td>XXII World Congress of Neurology, <a href="http://www.wcn-neurology.com">www.wcn-neurology.com</a></td>
<td>Santiago, Chile</td>
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<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>
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</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