



# NEWSLETTER

July 2014

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## Editorial



Welcome!

The heat has been on, this July. In Brussels, I met with the World Dementia Envoy, Dr Dennis Gillings and a delegation of the UK Department of Health to discuss greater international collaboration on dementia. We have also had the great pleasure of welcoming our Board, sponsors and members to Luxembourg for meetings. During these meetings, we reflected on financial and operational matters as well as preparations for our upcoming Glasgow conference. We spoke about practicalities surrounding the G8 priorities, which emerged from the recent dementia legacy meeting in London. AE projects relating to clinical trials and guidelines were also furthered and the aftermath of the European Parliament elections, the campaigns surrounding our EU dementia pledge and the next European Alzheimer's Alliance (EAA) were discussed.

In EU news, Martin Schulz was re-elected as European Parliament President at the beginning of the month. Vice-Presidents and Committee Chairs were also elected as well as a new Commission president in Jean-Claude Juncker. Elsewhere in the EU, Italy took over the rotating role of the EU Presidency. Matteo Renzi, announced his country's priorities, which we are pleased to see include dementia.

On 16 July, Wales set an international human rights example and became the first country in the world to adopt a Declaration of the Rights of Older People. Also in the UK, more than 60 towns and cities in England

have pledged to become dementia-friendly communities, far-exceeding the ambition of 20, set in Prime Minister Cameron's "Challenge on Dementia".

Dementia research was front-page news, mid-month, with stories emerging from the Alzheimer's Association International Conference (AAIC 2014) in Copenhagen. Some of the top stories concerned a new blood test, a variety of drugs in the pipeline as well as therapies for other conditions such as diabetes and arthritis which may be useful AD therapies. The potential for huge reductions in cases with better health and education was also accentuated. On this topic, the WHO/ADI tobacco factsheet came out this month, stating that tobacco is the single biggest risk factor for developing dementia.

Our members have been very active too, with the Alzheimer's Society launching its "Right to Know" campaign in the UK and the Alzheimer Society of Ireland concluding its medical card campaign. For Slovenia's Spominčica however, July has been a month of mourning after the tragic death of its founder, Dr Ales Kogoj, during a climbing trip. Our thoughts are with his family, friends and colleagues.

Finally, as our conference in Glasgow fast approaches, we are delighted to report that registration numbers are looking certain to reach record levels. We were also very honoured to hear that Slovenia's President, Borut Pahor has accepted patronage of next year's conference in Ljubljana and we thank Spominčica for their work in achieving this.

Wishing you all relaxing holidays.

**Jean Georges**  
Executive Director

## Alzheimer Europe

### 1 July: Alzheimer Europe accredited by Department of the European Social Charter



Alzheimer Europe's accreditation to lodge collective complaints regarding infringements of the European Social Charter has been renewed by the Governmental Committee of the European Social Charter and the European Code of Social Security for the period 1 July 2014 to 30 June 2018.

The European Social Charter is a Council of Europe treaty which guarantees social and economic human rights. It was adopted in 1961 and revised in 1996.

[www.coe.int/T/DGHL/Monitoring/SocialCharter/](http://www.coe.int/T/DGHL/Monitoring/SocialCharter/)

### 7 July: AE Board meets in Luxembourg

The Alzheimer Europe Board members held a meeting in Luxembourg on 7-8 July. The Board discussed various financial and operational matters, including preparations for the 24th Alzheimer Europe Conference that will take place in Glasgow on 20-22 October. The next – and last – meeting of the current Board will also be in Glasgow, preceding AE's Annual General Meeting and the Conference.

### 8 July: Alzheimer Europe holds Company Round Table in Luxembourg



On 8 July, Alzheimer Europe held a Company Round Table meeting in Luxembourg. Ten representatives from nine sponsor companies, sixteen representatives from fourteen AE member organisations and five AE staff members attended.

During the afternoon, AE staff members presented updates on the some ongoing projects - Clinical Trial Watch, Policy Watch and 2014 Dementia in Europe Yearbook (national care pathways for people with dementia); An update on the composition of the new European Parliament and the potential impact on AE's work and the G7 legacy event held in June 2014.

Some of the discussions that arose from the presentations were around what the G8 priorities concretely mean for the pharmaceutical industry; the problems surrounding existing databases of clinical trials and AE's plans to create a new dementia-friendly database where up-to-date information will be available to people with dementia and their families; Ana Diaz, AE Project Officer also called for member and company support on the translation of Clinical Guidelines (CGs) in the EU.

Towards the end of the day, Elisabeth Calov from Merz made a brief presentation about a free app they have created to predict individuals' likelihood of getting dementia.

Jean then brought the meeting to a close, speaking about Corporate Affairs and sponsorship opportunities for 2015. He said that AE is looking, not just for funding support, but for partnership on specific events and projects. He asked sponsors to give him feedback on the activities he described and on whether there were others that should be considered.

The next Company Round Table meeting will be in Brussels on 2 December.

### 9 July: Alzheimer Europe holds Public Affairs meeting in Luxembourg



On 9 July, Alzheimer Europe (AE) held a Public Affairs meeting in Luxembourg. Seventeen representatives from sixteen AE member organisations and five AE staff members attended.

During the day, AE colleagues presented updates on the following topics:

- Current status of the AE's ongoing projects - Clinical Trial Watch, Policy Watch and 2014 Dementia in Europe Yearbook (national care pathways for people with dementia).
- Update on the composition of the new European Parliament and the strategy to be followed over the next months in order to reconstitute the European Alzheimer's Alliance.
- The G7 legacy event held in June 2014; the role of AE in this global initiative and the actions to be taken by AE and its members.

In addition, delegates discussed the possibility of launching a new Declaration during the forthcoming AE Conference in Glasgow in October. All delegates showed their support for this initiative.

Kate Ellis, AE Communications Officer talked about AE experiences of using social media in campaigning activities, with a focus on Twitter and presenters from Finland, Ireland and the UK shared their organisations' experiences of national campaigning activities and of lessons learned. The examples provided by these countries showed that social media is a very powerful tool for campaigning but that personal contact is still an essential element of a successful campaign.

To finish the meeting, each AE member represented at the meeting provided an update on their latest campaign work.

The next Public Affairs meeting will be held in Brussels on 3 December.

### 19 July: Alzheimer Europe discusses collaboration with World Dementia Envoy



On 19 July, Jean Georges, the AE Executive Director met with Dr Dennis Gillings, the World Dementia Envoy and a delegation of the UK Department of Health.

During the meeting, the World

Dementia Envoy presented various initiatives undertaken since the G8 Dementia Summit in London in December 2013. In particular, the exchange covered the regulatory framework for the evaluation and authorisation of new medicines. Dr Gillings made a strong case for the introduction of new incentives to speed up and improve the development process of new, much needed treatments for Alzheimer's disease and other forms of dementia.

Jean Georges confirmed the commitment of Alzheimer Europe to support greater international collaboration on dementia and to collaborate with the World Dementia Council in approaching the European Medicines Agency and other European institutions to develop a new and adapted framework for the development of Alzheimer's medicines.

### 21-22 July: AE ethics working group makes progress with ethical dilemmas report

The second meeting of the ethics working group looking at ethical dilemmas faced by people with dementia and their carers was held on 21-22 July 2014 in Brussels. The first draft of the report was discussed and several improvements made. The report is targeted at people with dementia and their informal carers who encounter ethical dilemmas in any setting (e.g. at home, in residential care, at work, in relation to health and social care etc.). It will provide background information about ethics and ethical dilemmas as well as a series of vignettes which will be followed by ethical commentaries.

The information about ethical dilemmas, the vignettes and the ethical commentaries are organised into seven sections, namely: the period of uncertainty (pre-diagnosis), the process of understanding/finding out (diagnosis), the initial period of adaptation (shortly after diagnosis), living with dementia (getting on with routine life and adapting to challenges), caring for/receiving care (when increased levels of support are needed), the possible transition into a care home (when care at home becomes problematic) and care for a dignified end of life.

At the end of the report, there will be a section on tackling ethical dilemmas including an explanation of a care ethics approach, a step-by-step approach to tackling everyday ethical dilemmas and details about several mental traps which might hinder the resolution of ethical

dilemmas. We are now in the process of organising the ethical commentaries and the full report will be printed by the end of 2014 and will also be available on our website.

Dianne Gove, AE's Director for Projects, attended the meeting.

### 31 July: Record numbers for 24<sup>th</sup> AE Conference

Registrations for the 24<sup>th</sup> Alzheimer Europe Conference, which will take place in Glasgow from 20-22 October in collaboration with Alzheimer Scotland, have reached 558, exceeding the previous record for registrations set last year in Malta. Online registrations will remain open until 12 October. The full conference programme is available [online](#).



### 24-25 July: EPAD Consortium meets in London

After submitting an expression of interest under the EPOC-AD call of the Innovative Medicines Initiative, the successful consortium partners met in London for a two-day meeting. Led by Craig Ritchie, Simon Lovestone and José Luis Molinuevo, the academic partners discussed the development of the full project proposal and the consortium agreement with their partners from the European Federation of Pharmaceutical Industries and Associations (EFPIA).

The aim of the EPAD Project is to develop a sustainable, pan-European scientific, analytical and adaptive trial delivery machine to undertake proof-of-concept trials for the secondary prevention of Alzheimer's dementia.

Alzheimer Europe will lead the work package on dissemination and will contribute to the work package on the ethical and societal implications of such a far-reaching project. The association was represented by its Executive Director Jean Georges at the meeting.



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## Alzheimer Europe Networking

On 1 July (Brussels, Belgium) Annette attended the EFPIA/Patients Think Tank.

On 3 July (Brussels, Belgium) Annette met Natalie Turner (AARP) and EU stakeholders.

On 7 and 8 July (Luxembourg, Luxembourg) the AE Board met.

On 8 July (Luxembourg, Luxembourg) AE organised a round table discussion with its corporate sponsors.

On 9 July (Luxembourg, Luxembourg) AE organised a meeting with public affairs representatives of its national member organisations.

On 11 July (Brussels, Belgium) Annette met Camilla Randazzo (Servier) and Magda Chlebus (EFPIA).

On 18 July (Brussels, Belgium), Jean met with Dr Dennis Gillings, the World Dementia Envoy and a delegation of the UK Department of Health.

On 21-22 July 2014 (Brussels, Belgium) Dianne attended the second meeting of Alzheimer Europe's working group on ethical dilemmas faced by people with dementia and carers.

On 22 July 2014 (Brussels, Belgium) Dianne met with Nena Georgantzi from AGE.

On 24 and 25 July (London, United Kingdom), Jean attended a consortium meeting for the IMI funded EPAD project.

## EU Developments

### 1 July: Dementia is a priority for the Italian Presidency of the EU



Matteo Renzi, Prime Minister of Italy since 22 February, took over the EU Presidency on 1 July. In keeping with the calendar of rotations, Italy assumes the Presidency until 31 December.

The six-month Presidency is intended to be an opportunity to focus national governmental, administrative and public attention on the European agenda, and on how best to cultivate a common vision of the goals to be achieved in Europe and of national interests within the European framework.

The priorities, given by the Italian Presidency in its programme published under the title "Europe: a Fresh Start", are largely around growth and employment, freedom and security, citizens' rights and the role of Europe in the world. The Italian Presidency is also very keen to restore citizens' trust in the EU.

Regarding health, the programme lends special importance to the prevention of respiratory diseases and cancer, as well as looking at the situation with regards to HIV since the Dublin Declaration and considering vaccines as an effective tool for public health. Concerning dementia, the programme states that a Presidency Conference will be held on 14 November, focusing on the condition, the treatment of pain and also palliative therapies.

[www.italia2014.eu/en/](http://www.italia2014.eu/en/)

### 1 and 9 July EP President, Vice-Presidents and Committee Chairs elected



After the recent European Parliament elections, meetings were held over the course of just over a week in Brussels, to elect the President and 14 Vice-Presidents of the EP, as well as Chairs and Vice-Chairs of the 20 different Committees and 2 Sub-Committees.

EP President, Martin Schulz (S&D, Germany) was re-elected on 1 July:

[www.europarl.europa.eu/news/en/news-room/content/20140701ST051109/html/Martin-Schulz-re-elected-EP-president](http://www.europarl.europa.eu/news/en/news-room/content/20140701ST051109/html/Martin-Schulz-re-elected-EP-president)

The 14 Vice-Presidents were also elected on 1 July:

[www.europarl.europa.eu/news/en/news-room/content/20140630IPR51011/html/Fourteen-Vice-Presidents-of-the-European-Parliament-elected](http://www.europarl.europa.eu/news/en/news-room/content/20140630IPR51011/html/Fourteen-Vice-Presidents-of-the-European-Parliament-elected)

EP Committee Chairs were elected on 9 July:

[www.europarl.europa.eu/news/en/news-room/content/20140708ST051808/html/EP-committees-find-out-who-will-be-chairing-them](http://www.europarl.europa.eu/news/en/news-room/content/20140708ST051808/html/EP-committees-find-out-who-will-be-chairing-them)

Environment, Public Health and Food Safety Committee Chair is Giovanni La Via (EPP, Italy).

Employment and Social Affairs Committee Chair is Thomas Händel (GUE/NGL, Germany).

Industry, Research and Energy Committee Chair is Jerzy Buzek (EPP, Poland).

Composition of EP Committees:

[www.europarl.europa.eu/news/en/news-room/content/20140630IPR51005/html/Composition-of-parliamentary-committees-set-for-the-new-term](http://www.europarl.europa.eu/news/en/news-room/content/20140630IPR51005/html/Composition-of-parliamentary-committees-set-for-the-new-term)

### 15 July: Jean-Claude Juncker elected as Commission President



With 422 votes in favour, the European Parliament elected Jean-Claude Juncker (EPP) in a secret ballot on 15 July as President of the new European Commission to take office on 1 November 2014 for a five year term. The minimum number of votes required was 376.

For the first time in the history of the EU, the European Parliament elected - and not merely approved - the President of the European Commission following a proposal by the European Council, according to the rules laid down in the Lisbon Treaty (December 2009).

422 members voted in favour, 250 against, 47 abstained. The total number of votes cast was 729, 10 of which were not valid.

Other Commission posts will be filled at a later stage.

## Members' News

### 1 May: The Alzheimer Society of Ireland holds "Tea Day"



The Alzheimer Society of Ireland held their largest annual fundraiser, Alzheimer's Tea Day on 1 May. This year's fundraising drive was particularly special as it marked the 20<sup>th</sup> birthday of Alzheimer's Tea Day. National broadcaster and celebrity Pat Kenny helped to launch the campaign in March and celebrity TV chefs Rachel Allen and Catherine Fulvio supported the campaign by sharing their favourite tea party recipes with the society's Tea Day hosts.

1,500 tea day hosts signed up to support the campaign by hosting a tea party in their home, work place or local community centre and over €400,000 was raised in

support of people living with dementia. All money raised locally stays locally, meaning that funds raised in a community go towards funding supports and services for people living with dementia in that area. (Pictured: Abigail Fitzgerald, Pat Kenny and Alice Sinclair at the official launch)

### 7 May: Alzheimer Croatia celebrates 15 years



On 7 May this year, Alzheimer Croatia (AC) celebrated the 15<sup>th</sup> anniversary of its founding. A special celebratory Alzheimer Café was held in the capital, Zagreb's "Gradska Kavana" in the main square.

Ambitious plans were presented, some of which are already in the pipeline. The "Forget me not" blog was launched, with useful tips and information and weekly advice given by caregivers. AC became active on Facebook, Twitter and LinkedIn and contacts with the media also increased.

Recently, Alzheimer Cafés were also held in Pakrac and AC is currently preparing to spread this concept to other Croatian towns. The idea is to encourage the founding of local organisations which will be active under the umbrella of the national organisation. The first local organisation was founded in Lipik, the second in Dubrovnik and soon there will be others in Osijek, Split and Rijeka.

Raising public awareness about Alzheimer's disease and the activities of AC is encouraging an increasing number of citizens, who up until now have battled the challenges of Alzheimer's disease alone, to come to AC and seek help. The Alzheimer Croatia Caregivers Counselling Centre has doubled the number of hours spent with caregivers, doing individual and group counselling, education and giving support. The number of calls to the helpline have also significantly increased.

AC's new activities have increased the number of members by 52% in the first half of the year. They now have almost 1000 members, mostly from Zagreb.

Under the auspices of Croatia's President, dr. sc. Ivo Josipović, AC is organising Alzheimer's Disease Awareness Month, to be held this coming September in various towns and cities across the country. One of the activities that will be initiated during this event is the widespread education of professional caregivers and General Practitioners regarding the early signs of Alzheimer's disease.

### 23-24 May: Czech Alzheimer Society reports on third annual ELTECA conference



On 23 and 24 May, Prague hosted the international ELTECA conference, an annual event that brings together experts in long-term care from Europe, the US and other countries.

The event aims to promote co-operation and the exchange of information among specialists, physicians, patients and the community and to support the development of long-term care policies and services with special focus on the Central European region.

This year's conference addressed the issue of dementia care in long-term care homes, building on the previous meetings and work of the ELTECA Expert Panel that prepared the principles and recommendations on care of patients with dementia in long-term care settings. The panel included representatives from Alzheimer Europe (AE), EUGMS Special Interest Group on long-term care and AMDA, Interdata, the University of the West of Scotland and GEC NOVA University of Florida. The meetings were hosted and organised (for the third time) by the Faculty of Humanities, Charles University in Prague with the support of Zentiva (Sanofi).

AE Honorary Secretary, Charles Scerri made the opening presentation, emphasising the need to provide quality service for the growing numbers of people in long-term care. AE Vice-Chairperson and Chair of the Czech Alzheimer Society, Iva Holmerová also presented the draft of recommendations on care for people with dementia in long-term care settings.

### 6 June: Scottish Dementia Working Group involved in Alzheimer Scotland's Dementia Awareness Week



Members of the Scottish Dementia Working Group (SDWG) attended the Dementia Awareness Week Conference on 6 June at the Crowne Plaza hotel in Glasgow. The conference

allowed members of the SDWG to experience the location before the Alzheimer Europe (AE) conference in October which is also being held there.

The SDWG was greatly involved in the day's activities. SDWG Chair, Henry Rankin helped launch the Alzheimer Scotland backed Dementia Friends Project. The audience were then treated to a sing along from the Musical Minds Choir who had the auditorium in full voice with the Beatles song "With a little help from my friends".

Two of the working group's sub-groups were involved in a break-out session. The research sub-group launched their booklet "Core Principles for involving people with dementia in research". This publication was produced by members of the sub-group and researchers Nick Jenkins and Sarah Keyes from Edinburgh University, who were also in attendance. Henry read out the Six Core Principles to an engrossed audience and took questions from the 90-strong audience at the end of the session.

To download the publication, please visit: [www.sdwg.org](http://www.sdwg.org)

The IT sub-group panel members were joined for their session by facilitator Rachael Litherland from Dementia Engagement and Empowerment Project (DEEP). Members Archie Latta, Brian Malone and Peter McLaughlin shared their experiences of using "tablet" devices to stay connected with other group members. After a few technical hitches and a big cheer from the audience, Nancy McAdam joined from Inverness on the big screen, using a tablet communication app. Nancy told the group how using a tablet app to attend meetings has kept her more involved in the group and reduced the need to travel to Glasgow as frequently.

After the Q&A session ended, the tablet was passed around the room for the members to chat to Nancy. Both

staff and group members were delighted with the success of the session and spent their lunch break in high spirits.

### 29 June: Monaco's Kate Williams completes Ironman challenge



Kate Williams, Events and Public Relations Officer at AMPA Monaco, successfully completed an Ironman Triathlon challenge consisting of the following events: a 3.9 km swim, a 180 km bicycle ride and a marathon (42.1 km) run, raced in that order and without a break.

Competing under the AMPA colours, Kate raced alongside 2,800 participants and finished the event in 11 hours and 6 minutes with the following results: 5th in her age group, 29th overall woman and 607th overall racer.

Following the race, she said: "I think I can honestly say that it was one of the biggest days of my life, a fantastic experience that I will never forget. I sincerely believe that competing for Alzheimer's disease gave me even more motivation and determination. Thanks to friends and sponsors, I have managed to raise EUR 4,500 for this noble cause."

### 30 June: The Alzheimer Society of Ireland concludes Medical Card campaign



There is much change happening in Ireland in relation to the health care system. Not least the reform of eligibility and access to primary care.

Many people pay for medical care in the community at point of access. Others, who are on a limited income, are entitled to a medical card if they are under a specific means threshold. The medical card entitles a person to free GP visits, free prescription medication, some dental treatment and some personal and social care. In some situations a person may be given a medical card based on 'undue hardship' commonly called a 'discretionary medical card' where ability to pay and medical condition are taken into account even if the person is over the stated means for regular medical card entitlement.

In recent months the system for discretionary cards has come under much scrutiny. As the Irish health system bends under increasing financial pressure, cases came to light where medical cards were revoked even when need was very apparent and the inequity of the system around the country came into stark relief. In response to this an expert group was established within the Health Services Executive (HSE), to identify priority conditions for eligibility to a medical card. This would mean that regardless of means a person would be eligible for a medical card based on their condition. The Alzheimer Society of Ireland (ASI) quickly set their wheels in motion to ensure that dementia would be included on this list.

ASI made a detailed submission to the HSE's expert group outlining the increased need for health and social care when living with dementia, as well as the health benefits of having a medical card for the person and the heavy financial cost of dementia on them and their family. They

gathered relevant case studies which were used in the submission and outlined in national media.

A successful strategy was to use social media to gain public support; creating an image (pictures) to disseminate via Twitter and Facebook, calling on any interested individuals or organisations affected by dementia to make their own submission to the HSE by the deadline of end of June. The social media campaign gained a huge amount of backing, with several thousand 'likes'. It also started a compelling online discussion about the experience and difficulty for people accessing services when they didn't have a medical card.

In addition, the campaign urged staff and volunteers to contact their local political representatives asking them to work to ensure dementia is included on the priority list for eligibility.

ASI will find out if the campaign was successful in September, when the expert group makes their recommendations to the Irish Minister for Health.

### 2 July: Alzheimer's Society launches "Right to Know" campaign in UK



On 2 July, the Alzheimer's Society launched a national campaign called "Right to Know" in the UK, championing the importance of people with dementia having the certainty of a diagnosis as well as the right information and support to come to terms with and manage their condition, post-diagnosis.

According to the society, diagnosis rates in the UK are "unacceptably low", with 52% of people with dementia not having received a formal dementia diagnosis. In England it is estimated that less than half of those living with the condition have a formal diagnosis and in Wales the diagnosis rate is below 40 per cent, although in Scotland more than 70 per cent of people living with the disease have a formal diagnosis.

The society is also concerned about the lack of post-diagnostic support reflected in its recent poll of more than 400 people living with dementia. 90% of respondents said they felt unsupported after their diagnosis and many said the diagnosis itself had been delivered in rushed and insensitive circumstances.

Jeremy Hughes, chief executive of the Alzheimer's Society, said that the Government should guarantee a dementia advisor – a named professional contact – to any patient diagnosed with dementia, to help them come to terms with the news and advise them on the care services they may now need.

A [video](#) called "Nick and June's story" has also been released to bolster support for the campaign.

[www.alzheimers.org.uk/righttoknow](http://www.alzheimers.org.uk/righttoknow)



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## In Memoriam Dr Aleš Kogoj (1962 - 2014)



Aleš Kogoj, M.D., Associate Professor of Psychiatry at the University in Ljubljana, was born in 1962. He studied medicine and later specialised in psychiatry, both in Ljubljana. Since 1986, he had been working at the University Psychiatric Hospital in Ljubljana in the Unit for Gerontopsychiatry of which he became the Head in 2000. He also held the post of Associate Professor of Psychiatry in the Faculty of Medicine at the University in Ljubljana.

Early in his professional career, he became aware of the fact that carers for people with dementia are left more or less on their own and are in desperate need of support. For that reason, in 1997, he founded Spominčica (named after the flower forget-me-not) – the Slovenian association for people with dementia and their carers, following the example of other European countries. Spominčica later became a member of Alzheimer Europe and of Alzheimer Disease International. Until last year, Dr Kogoj was the President of the Association Spominčica, but because of numerous other professional obligations, handed over the management to his colleagues, while he retained the post of Honorary President of the Association.

For his endeavours and successes in the field of dementia in Slovenia he can certainly be called a pioneer in this field. He also published several professional and scientific papers on the topic.

In 1999, a counselling telephone service and helpline for carers was established within the structure of Spominčica and a newsletter with the same title started to be published. Dr Kogoj worked with dementia patients and their carers all over Slovenia and soon established a widespread network of Spominčica members and, later, local Spominčica groups.

For 25 years, he gave lectures about dementia and about patient care. He was an excellent diagnostician and an engaged and patient listener in the process of helping dementia patients themselves as well as their carers. His willingness to listen and to help under any circumstances was outstanding. In recent years, with his support and help, Spominčica succeeded in substantially raising awareness about dementia in Slovenia.

Dr Kogoj was a passionate mountain climber. In early July 2014, he fell to his tragic death during one of his climbing trips in the Alps. He was midway through a distinguished career and life, at only 52 years of age.

All individual members and local groups of Spominčica will try to follow his example and continue with his endeavours in the field of dementia awareness and support.

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### 3 July: Alzheimer's Society study shows training can lessen use of anti-psychotics

 According to research commissioned by the Alzheimer's Society, an innovative training programme for care home staff has cut the use of inappropriate anti-psychotic drugs by a third. The society is delighted with these results as it says that for someone with dementia, antipsychotic drugs can worsen dementia symptoms, double the risk of death, treble the risk of stroke and can leave people unable to walk and talk.

Over 100 care homes were recruited to receive the Focused Intervention Training and Support (FITS) programme with the aim of equipping staff to understand complex behaviours in people with dementia and to deliver person-centred care as an alternative to antipsychotics. When medication was reviewed in this way, residents were more alert, communicative and active, with improvements in mobility, eating, sleeping and in achieving personal goals.

Proven effective in a clinical trial in 2006, the FITS programme was scaled up and completed by staff in 67 care homes across the UK, in what was one of the largest formal evaluations of a training programme ever conducted. The intensive nine-month training and supervision programme was delivered by specialist

coaches and evaluated by the Association for Dementia Studies at the University of Worcester. Training courses focused on person-centred care approaches and alternative ways of managing the behavioural and psychological symptoms of dementia, which can include aggression.

Launched on 3 July at the Alzheimer's Society research conference, the study, led by Professor Dawn Brooker at the University of Worcester, reports that prescriptions of antipsychotic drugs were reduced by 30 per cent in care homes taking part in the programme.

[www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=2081](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2081)

### 23 July: Slovenia's President Borut Pahor to be patron of 25<sup>th</sup> AE conference



Borut Pahor, President of the Republic of Slovenia (2012 – 2017), has accepted honorary patronage of the 25<sup>th</sup> Alzheimer Europe (AE) conference in Ljubljana, which will take place in October 2015.

President Pahor responded to an invitation from the Slovenian dementia association, Spominčica for the patronage and has endorsed the efforts they are making, raising awareness about dementia in Slovenia.

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Spominčiča's activities are helping to raise awareness about dementia in Slovenian society and trying to overcome the stigma surrounding dementia. Six out of eight Slovenian MEPs signed AE's European Dementia Pledge in May as a result of the fervent campaign run by the Slovenian association.

President Pahor is aware of the global problem of dementia. His support and patronage of the Conference will also help Spominčiča to prepare and adapt the national dementia strategy in Slovenia, which will be finalised this year.

### 31 July: Slovak Alzheimer's society prepares for World Alzheimer's Month and 6<sup>th</sup> international conference



The Slovak Alzheimer's society and its partners are currently preparing for several important events, planned throughout September, to increase general awareness about Alzheimer's disease in Slovakia.

On 4 September 2014 an open day will take place in the Centrum MEMORY, which provides help not only in the prevention of Alzheimer's disease but also offers services for patients and their caregivers. During the open day this year, the centre has planned expert lectures, a memory training lecture, brainteasers, a demonstration of occupational therapy, reminiscence therapy and Snoezelen therapy.

Another planned event is a lecture in the Old-town library in Bratislava on 8 September at 3pm, called "Why my mum forgets" given by a psychologist. Visitors will be invited to learn what forgetfulness means, when forgetfulness is linked to a disease and who is at risk of Alzheimer's disease.

Slovakia is also preparing for its 6th international scientific conference "Senior's training and non-pharmacological intervention for Alzheimer's disease", which will take place on 18 and 19 September in Bratislava. The conference is intended for dementia professionals and carers of people with dementia. Lecturers from England, the Netherlands, Estonia, Czech Republic and Slovakia are invited.

## Policy Watch

### 18 June: All-Party Parliamentary Group on Dementia calls for new long-term National Dementia Strategy in UK



The All-Party Parliamentary Group on Dementia (APPG), a UK cross-party group made up of MPs and Peers with an interest in dementia, published a report "Building on the National Dementia Strategy: Change, progress and priorities" on 18 June.

The report, released to coincide with the first legacy G7 event on dementia, explores work done in the UK to improve diagnosis and post-diagnostic support, commissioning of services and ensuring a skilled dementia workforce.

Based on its findings the APPG, together with the Alzheimer's Society, calls for an "urgently needed" long-term national plan for dementia.

[www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1447](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1447)

### 16 July: Wales publishes Declaration of the Rights of Older People



On 16 July, Wales became the first country in the world to adopt a Declaration of the Rights of Older People, having received cross-party support in the National Assembly for Wales.

The Declaration is based on the UN Principles for Older Persons and sets out what older people in Wales have said they value and what rights they feel would support and protect them.

Sue Phelps, Director of the Alzheimer's Society in Wales said:

"People with dementia can be more at risk of discrimination and infringements of their human rights because they may not have the capacity to challenge or report what has occurred...the new Declaration aims to clearly spell out the rights of older people in Wales as already underpinned by law and will therefore be a useful tool for advocates supporting older people by giving them a voice."

[www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=2109](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2109)

## Science Watch

### 8 July: Blood test developed by King's College may predict dementia



A new blood test could predict dementia before symptoms appear, according to research published in "Alzheimer's & Dementia: The Journal of the Alzheimer's Association" on 8

July by a team of researchers at King's College London.

The research used blood samples from over 1,000 people and MRI scans from 473 people. 16 proteins were identified as being strongly associated with brain shrinkage in either MCI or Alzheimer's disease and therefore being possible biomarkers for dementia.

A second series of tests was carried out to establish which of these proteins could predict the progression from MCI to Alzheimer's disease. A combination of ten proteins was found to be capable of predicting whether individuals with MCI would develop Alzheimer's disease within a year, with an accuracy rate of 87%.

The study used samples from 476 people with Alzheimer's disease, 220 people with mild cognitive impairment and a control group of 452 older people without dementia.

Dr James Pickett, Head of Research at the Alzheimer's Society said of the study that, while it was exciting and could potentially revolutionise dementia research, it still remains to be validated in a larger group of people. He warned that "this research does not mean that a blood test for dementia is just around the corner" adding that with accuracy being less than 90% one in ten people

would get an incorrect result. He concluded that higher levels of accuracy and further research in this area were needed.

This is similar to an earlier story published in our March newsletter about a blood test developed at Georgetown University, USA.

[www.alzheimersanddementia.com/article/S1552-5260%2814%2902454-6/abstract](http://www.alzheimersanddementia.com/article/S1552-5260%2814%2902454-6/abstract)

**10 July: US FDA gives TransTech go-ahead on TTP488 Phase III Trial**

On 10 July, TransTech Pharma announced an agreement with the U.S. Food and Drug Administration (FDA) Division of Neurology Products, under the Special Protocol Assessment (SPA) process, on the design of a single Phase III trial of TTP488 for the treatment of patients with mild Alzheimer's disease.

The Phase III trial will be a randomised, double-blind, placebo-controlled, multi-centre study to evaluate the efficacy and safety of TTP488 for treatment use.

Results in TTP488 5mg daily dosage recipients will be compared with those in participants receiving placebo. This will happen over the course of 18 months of treatment. Approximately 800 patients with mild Alzheimer's disease receiving standard of care (i.e. acetylcholinesterase inhibitors) will be enrolled.

The primary efficacy analysis will be based on the changes in ADAS-cog (Alzheimer's disease Assessment Scale – cognitive subscale) and CDR-sb (Clinical Dementia Rating – sum of boxes). TransTech Pharma anticipates beginning enrolment of patients before the end of the year.

**14 July: Targacept's experimental AD drug misses the mark in Phase II**

Biopharmaceutical company, Targacept has been forced to pull the plug on its experimental Alzheimer's disease (AD) treatment, TC-1734 after it announced a Phase 2b study failure on 14 July.

Donepezil is currently the most commonly prescribed Alzheimer's disease treatment. The Targacept study, involving 293 patients, pitted TC-1734 against donepezil, with the primary endpoint of proving superiority. In top-line results, TC-1734 was shown to have missed its main goal.

<http://goo.gl/SpOsfM>

**14 July: One in three cases of AD are preventable says UK study**



Research funded by the National Institute for Health Research in the UK has concluded that one in three cases of Alzheimer's disease (AD) could be prevented by addressing factors that increase the risk of developing the disease. The Cambridge University researchers' findings were published in The Lancet Neurology on 14 July.

Listing diabetes, midlife high blood pressure, midlife obesity, lack of physical activity, depression, smoking, and low educational attainment as being the main risk factors associated with Alzheimer's disease, the researchers

estimate that by reducing the relative risk from each of these by 10% it would reduce the number of AD cases in 2050 by 8.5%. This would prevent 9 million people worldwide from developing the disease.

Their estimate of one in three cases being preventable is lower than the estimate of one in two cases from a 2011 study due to the more recent study having taken into account that some of the risk factors are interlinked, such as physical inactivity being linked with obesity and high blood pressure being linked with diabetes.

[www.thelancet.com/journals/lanneur/article/PIIS1474-4422%2814%2970136-X/fulltext](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422%2814%2970136-X/fulltext)

**15 July: Oxford University says taking vitamin B won't prevent AD**



According to a new review conducted by Oxford University scientists in the UK, taking B vitamins doesn't slow mental decline as we age, nor is it likely to prevent Alzheimer's disease. The researchers assembled data from 11 randomised clinical trials involving 22,000 people, which compared the effect of B vitamins on cognitive function in older people against placebo, to reach this confident, if disappointing conclusion.

High levels in the blood of a compound called homocysteine have been found in people with Alzheimer's disease, and people with higher levels of homocysteine have been shown to be at increased risk of Alzheimer's disease.

Taking folic acid and vitamin B-12 are known to lower levels of homocysteine in the body, so this gave rise to the "homocysteine hypothesis" that taking B vitamins could reduce the risk of Alzheimer's disease.

Participants receiving B vitamins did see a reduction in the levels of homocysteine in their blood by around a quarter. This had no effect on their mental abilities, however, when looking at measures of global cognitive function as compared with those receiving placebo.

The findings were published in the American Journal of Clinical Nutrition on 15 July.

<http://ajcn.nutrition.org/content/early/2014/06/25/ajcn.113.076349.abstract>

**29 July: Phase 2a clinical trial initiated for bryostatin as AD treatment**

US Pharmaceutical company, Neurotrope Bioscience announced on 29 July that it has initiated a Phase 2a randomized, double-blind, placebo-controlled, single dose clinical trial of bryostatin. The study will enrol a total of 15 participants to help evaluate bryostatin for possible treatment of people with Alzheimer's disease (AD).

Bryostatin is a natural product from the marine invertebrate organism, Bugula Neritina and is isolated from organic matter harvested from the ocean. It is known to be a potent modulator of the enzyme protein kinase C epsilon (PKCe) and in preclinical in vivo models, this effect has been shown to play an important role in slowing or reversing AD and in restoring cognition, memory and motor skills.

The primary objective of the clinical trial will be to assess the safety and tolerability of a single dose of bryostatin in the treatment of patients with AD.

The top-line analysis of this study is expected to be reported by the end of March 2015.

## AAIC 2014 watch

### 13 July: AAIC 2014 opens with presentation on dementia prevention



On 13 July Dr Bruno Vellas from Toulouse, France started off this year's Alzheimer's Association International Conference (AAIC 2014) in Copenhagen, Denmark with a big question facing today's dementia researchers: Will we ever be able to prevent dementia? He focused on clinical trials, covering the few completed trials in this area as well as key considerations for the design of future trials.

One of the largest prevention trials conducted to date in dementia was the GuidAge trial which tested ginkgo biloba in more than 2,800 people with memory complaints. The trial found no significant differences between the participants taking ginkgo and those on placebo with regard to developing Alzheimer's disease. Dr Vellas said the trial failed because the recruitment criteria were too broad (over 70, displaying memory complaints) and the effect of the ginkgo biloba was too small.

To be successful, he said, future prevention clinical trials should take one of two strategies: Either they should target a very specific group of people (for example those with both memory complaints and evidence of amyloid plaque buildup in their brain) and test a specific intervention such as a drug that targets the amyloid protein; or the second approach would be to target a broader population, such as those over 60 and to use a less specific intervention, such as targeting a range of lifestyle factors.

Both of these kinds of trials are currently in progress:

The A4 trial in California, US was launched last year and is recruiting 1,000 people aged 65 to 85 and with high levels of amyloid plaque in their brains. People that have high levels of amyloid but no cognitive symptoms will be recruited to the study and will have their memory and cognition measured for three years. The researchers will test whether an amyloid-targeting drug can prevent cognitive decline and dementia, as compared with placebo.

The Multidomain Alzheimer Prevention Trial (MAPT) study is taking the other approach and has enrolled 1,680 people aged 70+ with memory complaints in Toulouse, France. For the first three out of five years, study participants received a broad therapy that included nutritional guidance, omega-3 fatty acid supplements, management of high blood pressure and high cholesterol, physical exercise, cognitive stimulation and social activities. So far the study has shown it is possible to deliver the complex programme with only 22% of participants dropping out over three years. Final trial results will be available early next year and should

indicate whether this intervention has had an effect on memory and the risk of dementia.

### 13 July: Eye scans may detect and even predict Alzheimer's disease



According to clinical trial results presented on 13 July at AAIC 2014, a retinal scan could detect whether or not a person has Alzheimer's disease. It may also be able to predict Alzheimer's disease as early as 15 to 20 years before the appearance of clinical signs.

Researchers presented results from two small studies describing different techniques to detect beta amyloid in the eye. They found that beta amyloid levels in the eye strongly correlate to levels in the brain, amyloid-beta plaques in the brain being a widely accepted indicator of Alzheimer's disease.

Scientists from the Commonwealth Scientific and Industrial Research Organisation (CSIRO) in Australia presented early results based on the first 40 participants in their study of 200 people. Using a proprietary imaging agent based on a chemical in the spice, turmeric – Curcumin fluorescence imaging – the researchers were able to measure levels of amyloid in the retina.

Another study published in February this year in the Journal of Alzheimer's Disease and Other Dementias, used a new imaging technique called Fluorescent Ligand Eye Scanning (FLES) to measure beta amyloid in the eye lenses of 40 participants, 20 of whom had probable Alzheimer's disease and 20 of whom were healthy volunteers.

In both studies, PET scans to measure levels of amyloid in the brains of participants suggested there were significant correlations between levels in the brain and eye, suggesting that either technique has the potential to support Alzheimer's disease diagnosis in the future.

### 13 July: New theories proposed on link between dementia and diabetes

Type 2 diabetes has been shown to significantly and independently increase the risk of Alzheimer's disease but many people with diabetes do not develop dementia. Researchers are trying to better understand the link between the two conditions.

One of the first sessions at AAIC 2014, on 13 July, opened with the following question: Could Alzheimer's disease and diabetes be linked because there is a shared set of genes that predispose people to both conditions? Or does the presence of diabetes affect the brain in a way that causes dementia in some people? The presentations that followed suggest that both questions could be answered in the affirmative.

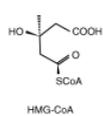
Giulio Maria Pasinetti, prominent in the field of diabetes and Alzheimer's disease research in the US, described a set of studies showing that type 2 diabetes can affect cognition and memory. Prof. Pasinetti identified changes in certain proteins in the brains of people with diabetes, including a regulatory protein called HDAC5 and synaptic proteins that can affect the way brain cells talk to one another. He was able to replicate these protein changes in the brains of mice by feeding them a high sugar diet to induce diabetes. He also showed that the diabetic mice

displayed reductions in long-term potentiation (process in brain cells responsible for forming new memories). Working with brain cells in a Petri dish, he confirmed that an increase in the amount of HDAC5 protein was enough to reduce the synaptic proteins and affect long-term potentiation.

Starting with observations in diabetic post-mortem brain tissue and working back through mouse models and cultured cells, Prof. Pasinetti has discovered a biological mechanism that could play a role in the development of memory problems and possibly dementia in people with type 2 diabetes.

Following Prof. Pasinetti's research presentation, AAIC 2014 attendees also heard from Dr Ke Hao, a geneticist at Mount Sinai, Manhattan, US who presented his research showing that there is an overlapping set of genes linked to both type 2 diabetes and Alzheimer's disease. These common genes are involved in activities such as fat metabolism and the immune response. He hopes that exploring them further will help to uncover biological pathways that are involved in both conditions.

**15 July: Canadian scientists say genetic variant may delay AD onset**



Scientists in Montréal, Canada have completed a large-scale study, which identified naturally occurring genetic variants that they say provide protection against the common form of Alzheimer's disease (AD). Their goal was to identify specific biological processes amenable to pharmaceutical interventions.

Dr Judes Poirier, Douglas Mental Health Institute and McGill University announced his team's findings on 15 July.

"We found that specific genetic variants in a gene called HMG CoA reductase which normally regulates cholesterol production and mobilization in the brain can interfere with, and delay the onset of Alzheimer's disease by nearly four years", said Dr Poirier.

For Diane Roch, the Director General of the Quebec Federation of Alzheimer Societies, the news is a step forward for research and finding a cure to the disease.

"We need to continue supporting research because every little step is progress," Ms Roch said. However, she warned "for the moment it is not going to stop the disease. We're beginning to see a little bit of light but leading a healthy lifestyle can help in controlling and preventing Alzheimer's disease."

[www.sciencedaily.com/releases/2014/07/140715092833.htm](http://www.sciencedaily.com/releases/2014/07/140715092833.htm)

**15 July: Novartis and Banner Alzheimer's Institute announce joint AD prevention study**

On 15 July at the AAIC in Copenhagen, Novartis announced a new study, looking to find out if two investigational anti-amyloid drugs - an active immunotherapy and an oral medication - can prevent or delay the emergence of symptoms of Alzheimer's disease (AD) in people who have a genetic risk of developing the condition in later life.

The pharmaceutical company will work with Banner Alzheimer's Institute on a study involving 1,300 adults aged 60 to 75 who do not have AD but have been identified as carrying genetic mutations associated with the disease.

Novartis has taken a cue from previous research efforts and its two drugs both target amyloid in people who are still cognitively healthy.

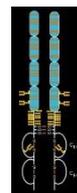
One treatment is a phase II injectable immunotherapy known as CAD106. It is intended to trigger the body's immune system to fight the onset of amyloid plaques.

The other therapy is a phase I BACE inhibitor - a class of drug that has mixed results in treating AD.

Pending regulatory approval, the study is planned to start in 2015 in sites in North America and Europe.

[www.novartis.com/newsroom/media-releases/en/2014/1824651.shtml](http://www.novartis.com/newsroom/media-releases/en/2014/1824651.shtml)

**15 July: Further research conducted into effects of arthritis drug on AD**



Scientists at the University of Southampton have completed a small-scale study into the effects of the arthritis drug, Etanercept on the progression of Alzheimer's disease (AD). The study bears some similarities to earlier ones conducted in 2008 and 2009 into the effects of the same drug and which received a lot of media attention at the time as a possible cure for dementia.

In this new study, participants were given either injections of Etanercept or a placebo of saltwater every week for six months. They were then assessed for memory function, ability to carry out day-to-day tasks and behaviour.

Results showed that those who were given Etanercept did not get any worse during the six month follow up period compared with those on the placebo, who did decline.

Professor Clive Holmes, who led the research and presented the team's results on 15 July in Copenhagen said the results were better than expected.

Although only 41 people took part in the pilot study, researchers are hopeful that larger clinical trials would show the same result.

**16 July: Anti-amyloid drug has mixed study results**

On 16 July, at this year's Alzheimer's Association International Conference (AAIC 2014) held in Copenhagen, Dr Jeffrey Cummings, director of the Cleveland Clinic's Lou Ruvo Center for Brain Health in Las Vegas, US delivered a report on Roche's experimental drug, crenezumab (previously RG7412). The drug, a monoclonal antibody, breaks down amyloid plaque in the human brain to try and combat the effects of Alzheimer's disease (AD). Dr Cummings explained that it had failed to meet its primary endpoints in a phase II trial. However, as was the case with another similar drug, it did show promise in a patient subgroup with mild cognitive impairment (MCI).

Among all patients with mild to moderate Alzheimer's disease enrolled in the ABBY trial, as it was called, those assigned to the study drug showed a 17% reduction in the

rate of cognitive decline over 68 weeks compared with a placebo group.

While this overall difference between crenezumab and placebo did not achieve statistical significance and therefore missed its primary endpoint, Dr Cummings nonetheless pointed out that the subset of patients with MCI (baseline Mini-Mental State Examination – MMSE - score of 22 to 26) did show a 35% slower decline in MMSE score compared with placebo.

Adverse events overall did not appear to differ between groups in the ABBY trial. Five patients died during the trial, with no obvious imbalance between treatment groups. The rate was about what would be expected in an elderly population over a 15 month period. Some potential safety signals were observed, however: One patient in the high-dose group developed sulcal effusions and overall numbers of pneumonia cases (serious and nonserious) increased in the study drug groups.

Roche, which is developing the drug through its Genentech unit, said it would decide whether and how to continue pursuing the drug after fuller analysis of the two trials' results.

The full study report has not yet been published.

## Dementia in Society

### 26 June: Online "MindCrowd" memory test launched to help research



A study of human cognition and how it might relate to Alzheimer's disease and other brain disorders is currently being carried out at the nonprofit Translational Genomics Research Institute (TGen) in the US.

Dubbed "MindCrowd," the study seeks to get 1 million people, aged between 18 and 80, to complete a 10-minute online memory test, launched on 26 June.

After finishing the test, participants receive immediate access to their results and are shown how they compare to the overall average, as well as to different ages, sex, and education levels. At the time of writing, over 32,000 people had already participated. From only 3% of the target group, the data is already revealing unanticipated findings; for example, at every age, women out-perform men in memory tests, but men seem to have the edge when it comes to reflexes and response time.

The test does not predict or diagnose any condition, rather it provides data on one type of memory and how these processes change as people age and have varied life experiences.

The MindCrowd project has two phases: Phase I is the memory testing of 1 million or more study participants. Following an in-depth analysis of the Phase I test results, researchers will then solicit a subset of Phase I participants willing to donate a DNA saliva sample and undergo an additional round of online testing.

You can take the test here:

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

### 15 July: Jens Rohra runs B2Run corporate race in support of his mother



Every year, cities in southern Germany host a charity "B2Run" race, in which companies and organisations can participate for a cause and under a slogan of their choosing. This year, Munich's race took place in the Olympic stadium on 15 July with an impressive 30,000 participants.

Alzheimer Munich's slogan was "Despite Dementia" and one of their runners was Jens Rohra, son of Helga Rohra (chairperson of the European Working Group of People with Dementia).

He said: "Running against dementia – not AWAY from dementia at the B2Run in the Olympic Park in Munich. Therefore I dedicate the run and this medal to my lovely and tough mum, Helga Rohra".

### 28 July: Over 60 English communities to become dementia friendly

The Alzheimer's Society announced on 28 July that 63 towns and cities in England have committed to becoming dementia friendly, thus exceeding, three-fold the ambition set in the Prime Minister's Challenge on Dementia to engage 20 communities in the Dementia Friendly Communities programme by 2015.

A dementia-friendly community is a city, town or village where people with dementia are understood, respected, supported, and confident they can contribute to community life. An economic analysis commissioned by the Alzheimer's Society in September 2013 showed that dementia-friendly communities could save £11,000 (approx. EUR 14,000) per person per year by helping people with dementia to remain independent, stay out of care for longer and have a better quality of life.

Jeremy Hughes, Chief Executive of the Alzheimer's Society said:

"The dedication we have seen from towns working to become dementia friendly is truly inspiring. A diverse range of projects across the country are working to help people with dementia remain independent and active in their local communities. The Alzheimer's Society is keen to motivate more towns and businesses to start on this journey of change. By benchmarking what it really means to become dementia friendly, we can help to empower towns and businesses to support people with dementia and ensure they are welcomed, respected and living well in their communities."

UK Health Secretary Jeremy Hunt said:

"Living well with dementia is made easier by the consideration, respect and support of dementia-friendly communities – which is why I'm delighted so many are getting involved and showing their support."



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Help us make dementia a priority

**31 July: Play about dementia to be an Edinburgh Festival highlight**



The Guardian newspaper in the UK has selected its hot picks for this year's Edinburgh Festival, including a play inspired by Alzheimer's disease, entitled "Six Billion Suns", which will show on the Fringe from 8 to 16 August.

The play has been a huge success in the Czech Republic since its launch in 2013 and was nominated in the category of Best Production of 2013 in Czech Theatre News' opinion poll.

Trying to remain as true to reality as possible, based on stories from people with Alzheimer's disease and their families shared with the cast and crew in the months prior to its launch, the play explores the "black holes" of memory loss for people with dementia. A strange, alternate reality unfurls on stage as five young people immerse themselves in the world of the main character, Augusta, played by 70 year old actress Viera Pavlíková, as her memory begins to dwindle.

Commenting on the play on Czech radio in June, AE's European working group of people with dementia (EWGPWD) Vice-Chairperson, Nina Balackova said that she had been delighted by it and appreciated the work that had gone in by the actors, who spent a lot of time getting into character and talking to people with dementia prior to the play's early performances in the Czech Republic. Nina appreciated the time taken to understand people with dementia and to try and represent them as authentically as possible. She also felt that people with dementia, including herself, may have a different reaction to the play than "healthy" people, saying "I found out that to us the play didn't seem gloomy in any way nor sad (a reaction which was contrary to that of healthy people) – simply, our reality was very accurately expressed. I recognised myself in many situations which amused me."

Nina feels that the play will be very helpful in helping people without dementia to better understand what it is like to live with the condition.

The production is in Czech and English, with projected English subtitles. Produced by Eva Dryjová; Directed by Eva Rysová; Script and Dramaturgy by Ondřej Novotný.

Teaser trailer: [www.youtube.com/watch?v=YtE0UIZ\\_Q-U](http://www.youtube.com/watch?v=YtE0UIZ_Q-U)

**New Publications & Resources**

**5 May: Council of Europe end-of-life care guide launched**



On 5 May 2014 in Strasbourg, the Council of Europe (CoE) Committee on Bioethics (DH-BIO) hosted a symposium which "launched" the new CoE publication "Guide on the decision-making process regarding medical treatment in end-of-life situations". It was held under the auspices of the Austrian Chairmanship of the Committee of Ministers of the Council of Europe.

AE's Vice-Chairperson Iva Holmerová had the honour of participating in the discussions and contributed to the

discussion on the possibilities of using end-of-life guidelines in the various fields of medicine with regard to patients with dementia.

Speakers emphasised the fact that medical advances have led to better control of acute and life-threatening conditions. This success, however, is not always absolute. The progression of some diseases has been slowed down which leads to more chronic courses for the diseases and creates new and complex situations, calling for further debate on the issues of treatment at end of life. In this changing context, the aim of the guide is to facilitate the implementation of the principles enshrined in the Convention on Human Rights and Biomedicine (Oviedo Convention, ECHR No 164, 1997).

**3 July: ILC-UK and Age UK publish report on "Making our Communities Ready for Ageing"**



A report from ILC-UK and Age UK, published on 3 July, takes a futures perspective on how communities need to adapt to an ageing society.

The report argues that policy makers must work to ensure that communities do more than simply cater for people's basic needs. It argues that communities should be places of fun for all. The report highlights the importance of supporting walking and cycling in old age as well as the need to ensure housing is adaptable to an ageing society.

The report incorporates an ideas bank of suggestions to help ensure communities are "Ready for Ageing". It also sets out a ten point action plan for local authorities in the UK.

[www.ilcuk.org.uk/images/uploads/publication-pdfs/Making\\_our\\_communities\\_ready\\_for\\_ageing\\_V3\\_2\).pdf](http://www.ilcuk.org.uk/images/uploads/publication-pdfs/Making_our_communities_ready_for_ageing_V3_2).pdf)

**9 July: WHO publishes tobacco and dementia fact sheet**



The World Health Organisation (WHO), in collaboration with Alzheimer's Disease International (ADI), has developed a factsheet on smoking and dementia. The factsheet, which was released on 9 July, states that smokers have a 45% higher risk of developing dementia than non-smokers,

Evidence reviewed by WHO reveals a strong link between smoking and the risk of dementia, and the more a person smokes, the higher the risk. It is estimated that 14% of Alzheimer's disease cases worldwide are potentially attributable to smoking.

WHO warns that exposure to second-hand smoke (passive smoking) may also increase the risk of dementia.

"Since there is currently no cure for dementia, public health interventions need to focus on prevention by changing modifiable risk factors like smoking," says Dr Shekhar Saxena, Director of the Department for Mental Health and Substance Abuse at WHO. "This research shows that a decrease in smoking now is likely to result in a substantial decrease in the burden of dementia in the years to come."

[www.who.int/tobacco/publications/en/](http://www.who.int/tobacco/publications/en/)

**15 July: Swiss Young onset booklet**



The Association Alzheimer Suisse (AAS) has published a booklet on young onset dementia, which it says affects approximately 2700 people between the ages of 45 and 64 in Switzerland.

The booklet proposes information and advice for people affected by young onset dementia and their loved ones, to help them to live well with dementia. It also presents the organisations which can offer further advice and support.

It can be found on the AAS website for download or an order form can be downloaded at the same location for hard copy versions. It is available in French, German and Italian: [www.alz.ch](http://www.alz.ch)

**17 July: Merz releases free app to estimate dementia risk**

Cardiovascular Risk Factors, Aging, and Incidence of Dementia (CAIDE) risk score allows the estimation of the risk of dementia later in life based on the risk factor profile present in midlife (age 40 to 65).

On 17 July, Merz Pharmaceuticals released a free app, without commercial benefit for the company. It can be used by doctors to calculate an estimated risk score for a patient, in midlife, of developing dementia within the next twenty years and subsequently to show the patient how related changes in their lifestyle could potentially reduce this risk.

There are two versions of the app: physician and personal. Anyone can use the personal version to calculate their own dementia risk and find out how to reduce it as well as tracking this risk over time.

<https://itunes.apple.com/us/app/caide-risk-score-app/id897853817?mt=8>

**Contact Alzheimer Europe:**

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

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**AE Calendar 2014**

Date	Meeting	AE representative
16-17 September	Patient and Consumers' Working Party of the European Medicines Agency (London, United Kingdom)	Jean
18-19 September	AETIONOMY First General Assembly Meeting	Ana & Alex
23-24 September	PredictND Management Board (Amsterdam, Netherlands)	Dianne & Jean

**Future Conferences**

Date	Meeting	Place
5-9 July	9th FENS Forum of Neuroscience, <a href="http://forum.fens.org/2014">http://forum.fens.org/2014</a>	Milan, Italy
12-17 July	AAIC Conference 2014, <a href="http://www.alz.org/aaic">www.alz.org/aaic</a>	Copenhagen, Denmark
18-19 September	6th International conference "Senior's training and nonpharmacological interventions for Alzheimer's disease", <a href="http://www.alzheimer.sk/slovenska-alzheimerova-spolocnost/akcie/konferencia2014.aspx">http://www.alzheimer.sk/slovenska-alzheimerova-spolocnost/akcie/konferencia2014.aspx</a>	Bratislava, Slovakia
18-20 September	4 <sup>th</sup> International CAA Conference - Cerebral Amyloid Angiopathy and related disorders, <a href="http://internationalcaaassociation.org">http://internationalcaaassociation.org</a>	London, UK
25-26 September	Innovation in Ageing Services-Pathways to the Future, <a href="http://uniproject.nl/eahsa/home">http://uniproject.nl/eahsa/home</a>	Amsterdam, Netherlands
30 September	'A Life Worth Living – young onset dementia services and supports', <a href="http://www.youngdementiauk.org/yduk-national-events">http://www.youngdementiauk.org/yduk-national-events</a>	Oxford, UK
20-22 October	24th Alzheimer Europe Conference "Dignity and autonomy in dementia", <a href="http://www.alzheimer-europe.org/Conferences">www.alzheimer-europe.org/Conferences</a>	Glasgow, UK
23-25 October	9th International Conference on Frontotemporal Dementias, <a href="http://ubccpd.ca/course/FTD2014">http://ubccpd.ca/course/FTD2014</a>	Vancouver, Canada
23-25 October	8. Kongress der Deutschen Alzheimer Gesellschaft "Demenz - jeder kann etwas tun", <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a>	Gütersloh, Germany
7-9 November	17th Asia Pacific Regional Conference of Alzheimer's Disease International, <a href="http://www.aprc2014-india.com/">http://www.aprc2014-india.com/</a>	New Delhi, India
24-25 November	EMA workshop on the clinical investigation of medicines for the treatment of Alzheimer's disease, <a href="http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2014/04/event_de_tail_000932.jsp&amp;mid=WC0b01ac058004d5c3">http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2014/04/event_de_tail_000932.jsp&amp;mid=WC0b01ac058004d5c3</a>	London, UK
18-22 March 2015	AD/PD™ 2015, The 12th International Conference on Alzheimer's and Parkinson's Disease, <a href="http://www2.kenes.com/adpd/pages/home.aspx">www2.kenes.com/adpd/pages/home.aspx</a>	Nice, France
23-26 April 2015	9th Panhellenic Interdisciplinary Conference on Alzheimer's Disease and Related Disorders in combination with the 1st Mediterranean Conference on Neurodegenerative Diseases	Thessaloniki, Greece
20-23 June 2015	1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/berlin2015">www.eaneurology.org/berlin2015</a>	Berlin, Germany

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

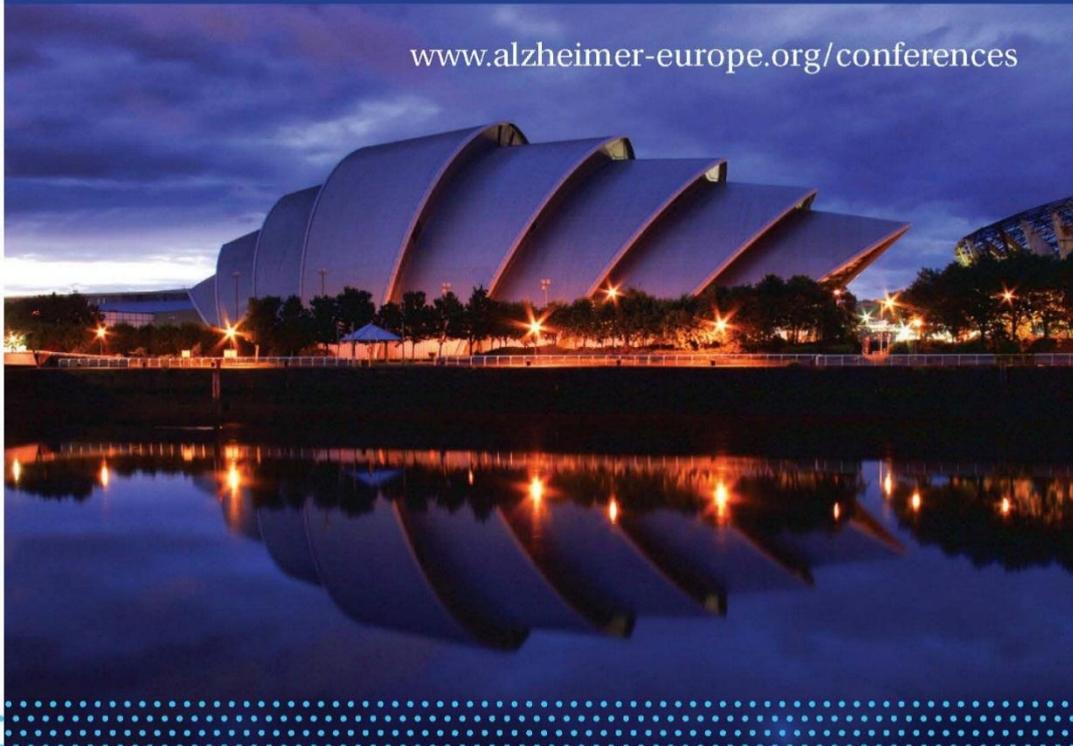
## Dignity and autonomy in dementia

### Glasgow, Scotland, UK

### 20-22 October 2014

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