Welcome to the
ALZHEIMER EUROPE

NEWSLETTER
January 2016

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Editorial
Welcome!
I hope that 2016 has started as well for you as it has for us.

I am delighted to start off our first newsletter of 2016 with the good news that Alzheimer Europe (AE) has been officially announced as one of the founding members of the Covenant on Demographic Change. The Covenant brings together 112 European organisations to build on the outcomes of the AFE-INNOVNET project’s Thematic Network on innovation for age-friendly environments. I would also like to congratulate our Director for Projects, Dianne Gove, who has been elected to the Covenant’s Board of Directors.

2016 has also started very well for two of the EU projects in which AE is involved. The European Prevention of Alzheimer’ Dementia (EPAD) consortium celebrated its first anniversary, released its first newsletter, and selected a new data platform for its cohort study. Meanwhile a new computer programme, PredictAD - developed within the framework of the PredictND project - has been the subject of a study at the VUmc in Amsterdam. The results of this study were the focus of a Dutch radio interview with neuropsychologist Professor Wiesje van der Flier (VUmc and PredictND) in mid-January.

It has been a very good month on the EU policy front as well, with the launch of the new Dutch EU Presidency on 1 January. Dementia has been announced as an official priority for this new presidency, with scientific and social innovation as well as the financial viability of dementia healthcare on the agenda. A two-day dementia conference on 9 and 10 May will look at the evolution of dementia-friendly societies in Europe.

To continue with the theme of EU collaboration, we are delighted to welcome yet another new member to our European Alzheimer’s Alliance (EAA) this month. Spanish MEP Izaskun Bilbao Barandica joined the EAA in mid-January, following her signature on our Glasgow Declaration.

On the national policy front, Wales has just unveiled a new strategy to improve mental health and well-being for all ages. “Together for Mental Health” includes plans to improve services for older people with dementia as one of its key priorities. We have also received good news from Slovenia, where the public consultation on the National Dementia Strategy ended on 9 December. The Slovenian Ministry of Health is now finalising the document, so we look forward to celebrating the launch of the Plan with our friends at Alzheimer Slovenia, any day now! Also this month, a technical committee has met at the Ministry of Health in Rome to try to resolve some issues surrounding the implementation of Italy’s new National Dementia Plan in the country’s various regions. We wish our Italian and Slovenian friends great success in oiling the wheels of their respective governments to speed up the political process.

If we can carry the momentum of these great forward bounds in EU and national policy forward into February and beyond, 2016 promises to be a good year!

Jean Georges
Executive Director
Alzheimer Europe

8 January: Alzheimer Europe continues to comply with EMA’s strict eligibility criteria

On 8 January we received a letter from the European Medicines Agency (EMA) informing us that, following its evaluation, we continue to comply with its strict eligibility criteria and therefore can continue to be involved in its activities.

The list of all the patients’ and consumers’ organisations that are involved in the European Medicines Agency’s activities can be viewed here:


11 January: Dianne Gove’s article on reciprocity and stigma in relation to dementia is published

On 11 January, an article on “General practitioners’ perceptions of the stigma of dementia and the role of reciprocity” was published online in the journal, Dementia. It was written by Dr Dianne Gove, Director for Projects, Alzheimer Europe (AE) in collaboration with Prof. Murna Downs and Prof. Neil Small of the University of Bradford, UK and Prof. Myrra Vernooij-Dassen, Radboud University Medical Centre, The Netherlands.

The article explores whether/how general practitioners (GPs) perceive people with dementia as lacking reciprocity, whether this is linked with “societal opinions about dementia as a stigma” and the possible impact of such perceptions.

Dementia is an international peer-reviewed journal that acts as a forum for social research aiming to improve quality of life and care for people with dementia and their families.

http://dem.sagepub.com/content/early/2016/01/11/1471310115625667.full.pdf?ijkey=vDNDHGlTfVfz&keytype=finite

22 January: AE Honorary Secretary Charles Scerri talks to JPND about neurodegenerative diseases

On 22 January, the EU Joint Programme – Neurodegenerative Disease Research (JPND) published an interview with Alzheimer AE Honorary Secretary, Dr Charles Scerri on its website.

Dr Scerri gave the JPND his thoughts on some of the most pressing issues in research into neurodegenerative diseases, gave some words of advice to young researchers and discussed ways in which research into healthcare and social care can be better supported to build up its capacity, among other things.

Dr Scerri is the co-founder and general secretary of the Malta Dementia Society. He is also a member of the JPND Scientific Advisory Board. In July of 2013, he was appointed as the National Focal Point on Dementia in Malta.


29 January: AE is a founding member of the Covenant on Demographic Change, Dianne Gove is on the Board

On 29 January, Alzheimer Europe officially became a founding member of the EU-funded AFE-INNOVNET European Covenant on Demographic Change. It was also announced that the 68 founding members have elected a Board of Directors, including Alzheimer Europe’s Director for Projects, Dr Dianne Gove.

The Covenant, which was launched on 7 December, brings together 112 organisations to build on the outcomes of the AFE-INNOVNET project’s Thematic Network on innovation for age-friendly environments.

It will become an international non-for-profit organisation established under Belgian law and will work closely with the World Health Organisation (WHO) Global Network of Age-Friendly Cities and Communities.


If you are interested in joining the Covenant on Demographic Change, please visit http://www.agefriendlyeuurope.org

You can read about the launch of the covenant on 7 December 2015 here http://alzheimer-europe.org/News/EU-developments/Monday-07-December-2015-AFE-Innovet-Covenant-on-Demographic-Change-is-launched/

EU projects

11 January: PredictND’s diagnostic tool PredictAD features on Dutch radio

On 11 January, Dutch radio station Amsterdam FM aired a five-minute interview with neuropsychologist Professor Wiesje van der Flier about a new computer programme – PredictAD - developed within the framework of the PredictND project. Prof. van der Flier, VU University Medical Center (VUmc), Amsterdam said a study completed at VUmc shows the programme is a useful tool in recognising Alzheimer’s disease (AD) in people with mild cognitive impairment (MCI).

At the moment, she said, neurologists make diagnoses on the basis of clinical data, possibly using MRI scans and - more invasively - lumbar punctures. The data obtained is difficult to read as it can be contradictory, and a base-line is difficult to establish. Through the additional use of this new computer programme, it appears predictions can be made for each patient as to whether AD underlies the phenomena, or not.

The VUmc study is published in Journal of Alzheimer’s Disease: http://www.j-alz.com/vol50

The full interview is here: http://www.amsterdamfm.nl/alzheimer

Donate now! Help us make dementia a priority
15 January: EPAD celebrates its first anniversary, selects data platform

15 January marked the first anniversary of the official launch of the European Prevention of Alzheimer’s Dementia (EPAD) Initiative, in Paris. To celebrate turning one, EPAD looked back at some of its key achievements of the past 12 months.

19 March: The Innovative Medicines Initiative (IMI) launched its Alzheimer’s Disease Research Platform, with EPAD as one of its cornerstones. The platform aims to facilitate collaboration between projects, helping them to deliver results faster: http://goo.gl/DBTsS5

3 September: EPAD researchers presented the project at the 25th Alzheimer Europe Conference (25AEC) in Ljubljana, Slovenia. Videos of these presentations and of the Q&A session following them are available via http://goo.gl/VQVxKc.

21 September: EPAD chose World Alzheimer’s Day to launch its new website, which is devoted to informing different audiences, including the scientific community, companies, people with dementia, families and carers, Alzheimer associations and the general public about the project: http://ep-ad.org/

6 November: EPAD submitted its Longitudinal Cohort Study (LCS) protocol and Briefing document for Scientific Advice to the European Medicinal Agency (EMA).

Alzheimer Europe networking

On 6 January (Luxembourg, Luxembourg), Jean met with representatives of DG SANTE to discuss the organisation of the meeting of government experts on dementia.

On 12 January (Brussels, Belgium) Vanessa attended the Joint Meeting of the European Parliament Interest Group on Carers and the Interest Group on Mental health Well-being and Brain Disorders.

On 21 January (Brussels, Belgium) Vanessa attended the European Commission Conference, “Better research for better health”.

On 21 January (Brussels, Belgium), Jean attended a meeting to discuss the second stage application of the AMYPAD project.

On 21 January (Brussels, Belgium) Ana participated in the Trilateral AAL information and matchmaking event 2016.

On 22 January (Manchester, UK), Jean attended the “Neighbourhoods and Dementia” study’s Scientific Advisory Group meeting.

On 27 January (Copenhagen, Denmark), Jean and Gwladys met with representatives of Alzheimerforeningen and the Scandic Hotel to discuss organisational issues of the 26th AE Conference (26AEC).

On 27 January (Brussels, Belgium) Ana attended the EP Public Hearing on the Concluding Observations of the UNCRPD.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 126, 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); Kappel 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 Theoharous (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 Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP).
France: Nathalie Griesbeck (ALDE); François Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin (S&D).
Germany: Angelika Niebler (EPP); Udo Voigt (NI).
Greece: Kostas Chrysogonas (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimonios (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg (EPP).
Hungary: Ádám Kósa (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);


This forward momentum has continued into 2016, when EPAD announced on 19 January that it has elected to use AnalytiXagility as its data and analytics platform. AnalytiXagility belongs to Scottish clinical and translational informatics company Aridhia.

The platform combines analytical, collaboration and audit tools to support and accelerate data-driven projects. It will be accessible to all of the consortium partners, and is able to carry out advanced data analytics for any type of data.

The University of Edinburgh is now working with Aridhia to trial the EPAD cohort.

19 January: EPAD features in The Lancet Neurology

On 19 January, the European Prevention of Alzheimer’s Dementia (EPAD) project appeared in the medical journal The Lancet Neurology, in an Event article titled “Lessons learned from Christmas lectures”.

Author Peter Ranscombe recalled the Alzheimer Scotland Christmas lecture on “Prevention: keeping it Real” by Professor Craig Ritchie, in which Prof. Ritchie stated that the EPAD consortium could provide information needed to identify those at risk, and speed up drug development.

“Science is the easy bit,” concluded Prof. Ritchie, pointing out that the public need to lobby policymakers for increased dementia research funding.
European Alzheimer's Alliance

13 January: MEP Bilbao Barandica signs Glasgow Declaration, joins EAA

On 13 January, MEP Izaskun Bilbao Barandica signed the Glasgow Declaration, bringing the total number of policy makers supporting the Declaration to 153, including 84 MEPs. Ms Bilbao Barandica also became a member of the European Alzheimer’s Alliance (EAA) on the same day, bringing the total number of EAA members to 126.

She is a Vice-President of ALDE, the Group of the Alliance of Liberals and Democrats for Europe and sits on the Committee on Transport and Tourism. She is also a substitute on the Committee on Women’s Rights and Gender Equality.

http://www.alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance/Members/Bilbao-Barandica-Izaskun

EU developments

10 December 2015: European Social Charter website is launched

A new website dedicated to the European Social Charter was launched on International Human Rights Day, 10 December 2015.

The European Social Charter is a Council of Europe treaty that guarantees fundamental social and economic rights as a counterpart to the European Convention on Human Rights, which refers to civil and political rights. It guarantees a broad range of everyday human rights related to employment, housing, health, education, social protection and welfare.

http://www.coe.int/en/web/turin-european-social-charter

21 December 2015: EP Motion for Resolution launched on establishment of European strategy for people with Alzheimer’s disease

On 21 December 2015, a Motion for Resolution was launched in the European Parliament (EP), by MEP Mara Bizzotto (ENF, Italy), calling for the establishment of a European strategy to support people with Alzheimer’s disease:

“Motion for a European Parliament resolution on the establishment of a European strategy to support those suffering from Alzheimer’s disease”

The European Parliament,

– having regard to Rule 133 of its Rules of Procedure,

A. whereas, every day, those suffering from dementia and their families encounter great difficulties;

B. having regard to the provisions of the Glasgow Declaration of 20 October 2014, launched by the Alzheimer Europe organisation and adopted by the Alzheimer Italia Federation and by the delegates of another 25 Alzheimer Europe member organisations;

1. Calls on the Commission to develop a European strategy on dementia;

2. Calls on the Commission to set up a European group of experts on dementia in order to share best practice;

3. Calls on the Commission to finance regional, national and European research programmes on dementia.

The motion will be put to the Environment, Public Health and Food Safety Navigation (ENVI) Committee who will decide whether any follow up action will be taken.


1 January: The Netherlands takes over the EU Presidency

For the first half of 2016 the Netherlands will hold the rotating presidency of the European Union. As part of the next “Trio Presidency” the Netherlands is partnered with Slovakia, which will hold the Presidency from July to December 2016 and Malta, which will hold the Presidency from January to June 2017. These three Member States will work together to implement their 18-month work programme.

During its tenure, which will end on 30 June, the Dutch EU Presidency will focus on four priority areas:

- Migration & international security.
Europe as an innovator & job creator.
Sound finances and a robust Eurozone.
Forward-looking climate & energy policy.

For more information about these priorities, visit http://english.eu2016.nl/eu-presidency/input-and-priorities

In terms of priorities in the area of health, the new Presidency will focus on the threat of antimicrobial resistance (AMR), market access rules for medicines, and ingredients of food products. In addition, e-health and patient empowerment will be addressed with a dedicated e-health week in Amsterdam from 8 to 10 June. Furthermore, the Netherlands hopes to inform and encourage a political discussion around access rules for medicines. In this context, the focus will be on innovation for the benefit of patients, early access tools, and addressing the high prices of medicines.

Dementia is also a health priority for the Presidency, with scientific and social innovation, as well as the financial viability of dementia healthcare being a focus. A two-day dementia conference is planned for 9 and 10 May, looking at the evolution of dementia-friendly societies in Europe, and evaluating international cooperation in this area. The conference will also look at sound scientific research, and quality healthcare and support. It is unlikely these discussions will lead to Council Conclusions on dementia.

During the second half of 2015, dementia was at the forefront, with the EPSCO Council adopting the Luxembourg EU Presidency conclusions on a number of health-related items, including those on “Supporting people living with dementia”, which call on all Member States to address dementia as a priority, to develop national strategies or actions plans, and to strengthen the collaboration between European countries.

Written Declaration on Alzheimer’s disease - signatories


The protection of the health of EU citizens remains a key objective. Over the next 18 months the three Presidencies will take forward discussions on ways to improve the health status of the EU population, by fighting non-communicable diseases (NCDs) as well as cooperation between Member States’ health systems.

For more information on the Dutch Presidency visit: http://english.eu2016.nl/
5 January: The EU is to set up a new innovation body

EU Research Commissioner Carlos Moedas (pictured) is moving ahead with his plan to create a European Innovation Council (EIC), which will act as a one stop shop for innovation and bring order to the widely dispersed innovation competitions running under the Horizon 2020 R&D programme.

The aim is to create a cohesive pan-European body for innovation that will parallel what the European Research Council (ERC) has done for science.

Commissioner Moedas launched the debate about setting up the EIC, “modelled on the very successful European Research Council”. The ERC was set up in 2007 and quickly became popular with researchers, in particular due to the relative simplicity of applying for funding, not to mention the generous grants it awards.

Following initial consultations, a European Commission memo has outlined six forms the EIC could take. The ideas put forward range from a light touch approach web portal for innovators, to the formation of a brand new funding institute.

The memo from the Commission, dated 16 December, says it is, “too early to recommend with a high degree of confidence a single EIC model,” promising that the consultation will, “gauge what is politically feasible.”

So far, the EIC initiative has been enthusiastically greeted by universities and companies.

http://www.sciencebusiness.net/news/77370/moedas-advances-plans-for-new-european-innovation-council

12 January: EP Interest Group on Carers and Interest Group on Mental Health, Well-being and Brain Disorders hold joint meeting

"Providing care to people with mental health problems" was the topic of the Joint meeting of the European Parliament (EP) Interest Group on Carers and the Interest Group on Mental Health, Well-being and Brain Disorders, held on 12 January. MEPs Marian Harkin (Ireland) and Sirpa Pietikäinen (Finland) chaired the meeting.

After a welcome from Ms Harkin, Prof. Chantal van Audenhove of the University of Leuven presented the results of CARING4CARERS, which is an international survey by LUCAS - the Centre for Care Research and Consultancy of the University of Leuven. The survey, which was carried out in collaboration with the European Federation of Families of People with Mental Illness (EUFAMI), aimed to assess the experiences of family care givers in caring for a relative with mental illness, from an international perspective, and to highlight the critical role these carers play.

Spyros Zorbas from the Greek organisation KINAPSI spoke about “The carers’ experience” and his family’s experience of caring for his sister who has Schizophrenia. KINAPSI www.kinapsi.gr was founded in 2008, and its mission is to provide support to the siblings of those with mental illness in Greece.

John Dunne from Eurocarers talked about the current situation of carers across Europe and the future of informal care. Increasingly the burden of care has shifted from community health care to family carer which is creating not only financial strain on families but also mental strain.

Jürgen Schefflein, DG SANTE, European Commission (EC) made the closing remarks, saying the EC is aware that carers have very concrete needs. To respond to these needs, a group of government experts from Member States has been set up. He talked about the upcoming EC conference on the Joint Action (JA) on Mental Health and wellbeing to be held on 21 and 22 January, when the final outcomes, recommendations and actions of the JA will be presented.

In summing up, Ms Harkin stressed that family carers want to be recognised as a resource, and a partner, making equal decisions. Even though there are many difficulties faced when caring for a loved one, caring can, and should be a positive experience, she said.

12 January: Patient involvement could improve medicines R&D, industry personnel believes

A new study conducted by the European Patients’ Academy on Therapeutic Innovation (EUPATI) has revealed that pharmaceutical industry personnel believes that greater involvement of patients and the public could improve medicines research and development (R&D). The study, which is one of the first of its kind and is part of the wider EUPATI project, was published on 12 January in the BMJ open.

As a result of this study, the project is discussing the potential for a new direction towards Public and Patient Involvement (PPI) in industry-led medicines R&D and has identified examples of patient-industry partnerships in this area.


14 January: Dutch EU Presidency priorities presented in European Parliament

On 14 January, the Environment, Public Health and Food Safety Navigation (ENVI) Committee held an exchange of views with Sharon Dijksma (Minister for the Environment, NL Council Presidency) and Edith Schippers (Minister of Health, Welfare and Sports, NL Council Presidency) at the European Parliament in Brussels. The two Ministers presented their priorities in the areas of environment, climate, health and food safety.

Fighting antibiotic resistance, ensuring people have access to innovative, yet affordable medicines and working on healthy products are at the top of the list during the Dutch presidency. Next to these three priorities, the Presidency will work on other important areas, including dementia:

“7 million patients in Europe today. 15 million in 2050. We all know someone with dementia. We all have seen or experienced the loss and suffering this disease brings. To patients. To their relatives and friends. Since the French
presidency in 2008, successive presidencies, including Luxembourg, have made dementia a priority. We believe the time is right to combine the numerous activities in every member state into an overarching view: how to tackle all aspects of the challenges dementia poses to us. Not as a binding agreement, but as a guideline combining years of experience on policies, innovation in care, social innovation and research. Hopefully a step forward in enhancing the quality of life of so many people in our ageing societies" said Edith Schippers [Minister of Health, Welfare and Sports, NL Council Presidency].

https://goo.gl/2U9HoH

14 January: EU presidency aims for open access to scientific journals

Over the next few months the Dutch EU presidency will hold a series of discussions on open access. Council Education minister Sander Dekker will push to make more scientific journal papers free to publicly-funded researchers.

At a conference due to take place in April, EU Research Commissioner Carlos Moedas is expected to launch an open science policy platform, with a mandate to investigate how subscription publishers can transition to open access quicker.

Kurt Deketelaere, secretary-general of the League of European Research Universities, spent much of the last year rallying support for open access.

“We will soon hand over almost 10,000 signatures from our open access campaign, and ask for an initiative by Moedas and Dekker to start a round table discussion which must lead – in let’s say 12 months’ time – to a number of breakthroughs in the open access debate,” said Mr Deketelaere.

There will only be one formal Council meeting for research ministers under the Dutch presidency, instead of the usual two. The reason, according to a Council official, is a lack of topics for discussion and few relevant legislative proposals.

http://sciencebusiness.net/news/77386/Dutch-EU-presidency-aims-at-open-access-to-scientific-journals

19 January: Commission publishes non-binding guide to good practice for implementation of Directive on Electromagnetic Fields (EMFs)

The revised EMF Directive (2013/35/EU) adopted in 2013, set minimum safety requirements regarding the exposure of workers to risks arising from electromagnetic fields (EMF).

The European Commission recently published the “Non-binding guide to good practice”, which was developed by Public Health England (PHE) in collaboration with experts from the European Society of Radiology (ESR). This practical guide will assist employers, particularly small to medium sized enterprises (SMEs), in understanding what they will need to do to comply with the Directive. It may also be useful for workers, worker representatives, and regulatory authorities in EU Member States, and consists of two volumes as well as a specific guide for SMEs.

This publication will be available in electronic format in all EU official languages.

http://ec.europa.eu/social/main.jsp?catid=82&langId=en&furtherPubs=yes

19 January: Public consultation on the review of the European Disability Strategy is launched


It has identified eight main actions for action at EU level:

- Accessibility
- Participation
- Equality
- Employment
- Education and training
- Social protection
- Health
- External action

This public consultation asks:

- For opinions on what has been achieved so far in each of these areas.
- For views on the challenges faced by all persons with disabilities.
- How the EU should address these challenges.

The consultation is open until 18 March 2016.

http://ec.europa.eu/social/main.jsp?langId=en&catId=896&newsId=3421&furtherPubs=yes

21 January: Belgium, Switzerland and Luxembourg organise AAL Joint Innovation Matchmaking Event

The event was linked to the Active and Assisted Living (AAL) programme which aims at developing innovative ICT based products and services that can improve the quality of life of older adults. Enterprises, research institutes and end-user organisations from the three countries were invited to participate.

The 2016 call that will be published by the end of February, will support projects on the topic of “living well with dementia”. During the event delegates were provided with information about the national eligibility criteria and various funding rules.

The call has a strong focus on the integration of new or existing ICT solutions to promote the wellbeing of people living with dementia and their communities. Consortiums planning to send an application were encouraged to involve the people who will benefit from the ICT solution (i.e. the “end users”) throughout the life of the project. In some regions of Belgium, Switzerland and Luxembourg, some end-user organisations (e.g. associations) are eligible partners for AAL projects.

The afternoon programme offered delegates the possibility to meet potential partners for R&D cooperation. The event took place on 21 January in Brussels. Ana Diaz, Alzheimer Europe Project Officer participated.

21 January: Health research promoted at Commission scientific panel

“Better research for better health: A holistic approach to challenges & opportunities” was the topic of a public conference held by the European Commission Scientific Panel for Health (SPH) on 21 January. The SPH presented its initial findings, following the end of its first year.

The SPH is a science-led expert group based on the provisions of the Horizon 2020 Specific Programme that has been tasked with helping to achieve better health and wellbeing for all. It has three main roles:

- To analyse and propose solutions to bottlenecks that prevent improvements in health.
- The members of the Panel will identify long term trends influencing health through foresight, and will recommend research and innovation priorities to respond to them.
- The expert group will aid in the translation and implementation of research and innovation results into practice.

This conference was an opportunity for a wide range of stakeholders in health to participate and provide input into this process, as well as to meet with SPH members.

A recorded video of the conference can be viewed here.

27 January: EP organises Public Hearing on UNCRPD committee’s Concluding Observations

In 2010, the European Union (EU) ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The Convention aims to ensure that people with disabilities can enjoy their rights on an equal basis with all other citizens. Since then, the EU is subject to scrutiny by the Committee on the rights of persons with disabilities. In 2014, the EU submitted a report to the UN Committee about the measures taken to implement the Convention, and received, from the UN Committee, a set of comprehensive recommendations on how to better promote, protect and ensure the rights of persons with disabilities in the EU.

The European Parliament (EP) is currently drafting a report that will outline the EP’s approach to the implementation of the Convention, with special regard to the observations specified by the UN Committee. MEP Helga Stevens is leading the work on this report and around 30 other MEPs will be contributing to the report.

The Public Hearing in Brussels, on 27 January, gave people with disabilities and organisations representing them the opportunity to provide input to the draft working report. The event was hosted by MEPs Helga Stevens and Martina Anderson. At the opening of the hearing, Vice-President of the European Disability Forum, Gunta Anca highlighted the CRPD recommendation to review the European Disability Strategy, to adopt the European Accessibility Act and to promote the equal treatment of people with disabilities. She also emphasised the need for a meaningful participation of people with disabilities in decision making around, and implementation of the Convention.

During the hearing four panels were organised and moderated by MEPs working in associated Committees (LIBE - Committee on civil liberties; EMPL – employment and social affairs; PETI – Petitions Committee and DROI - Subcommittee on Human Rights).

Several issues were raised by the audience, among them the need to evaluate in a systematic and independent way the impact that the measures taken might have on the lives of people with disabilities; the need to promote a more positive image of and attitude to people with disabilities; and the need to mainstream disability into all policy areas. The audience also emphasised the need to look at the various access needs of people with different types of disabilities and to make products and services in the community (e.g. banks, transportation, shops, etc.) accessible to all people with disabilities.

Other relevant areas of concern raised by the audience included legal capacity and political participation, involuntary detention and deinstitutionalisation of people with disabilities.

Alzheimer Europe Project Officer, Ana Diaz attended the Public Hearing.

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Members’ news

23 December 2015: Alzheimer Portugal provides training to the Directorate-General of Health

Unfortunately, as yet, no new steps have been made recently, towards a National Dementia Plan in Portugal, wrote Alzheimer Portugal in a report sent to us on 23 December 2015. Nonetheless, the Directorate-General of Health - the Health Ministry department in charge of creating the National Dementia Plan, “recognises Alzheimer Portugal as an important partner and a reference in what concerns best practices on dementia care and training”.

Within this framework, the Directorate asked Alzheimer Portugal to provide specific training on dementia to doctors - particularly General Practitioners (GPs) working as family doctors, nurses, social workers, occupational therapists, psychologists, as well as other health professionals - all working within the National Health System.

Seven training courses took place in different cities throughout the country, reaching 108 trainees. The main topics were: diagnosis and treatment; personal competences; person-centred approach; communication, assertiveness and dementia; relationship issues and psychological consequences; care-provision for people with dementia; wellbeing strategies; and the legal rights of people with reduced capacity for decision making.

The training project aimed to increase knowledge, particularly with regards to the differences between normal ageing and dementia, and to recognise the first...
Alzheimer Europe

Newsletter: January 2016

1 January: Stefanie Becker takes over as director of Alzheimer Switzerland

Alzheimer Switzerland’s Central Committee appointed Stefanie Becker as the Association’s new head, starting from 1 January 2016. Ms Becker has a doctorate in psychology and gerontology. In her previous position she was responsible for the “Institut Alter” within Bern University of Applied Sciences (BFH).

Ms Becker succeeds former director Birgitta Martensson.

1 January: CEFAA has a new president

As of 1 January, the Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEFAA) in Spain has a new President, Ms Chelles Cantabrana Alútiz (pictured).

15 January: A series of podcasts about memory diseases is available from Alzheimer Society of Finland

The Alzheimer Society of Finland (Muistiliitto), together with one of the biggest media companies in the country, has launched a 12-fold series of podcasts about memory diseases. “Unforgettable Memory” (Unohtumaton muisti) is broadcast via Supla, which is a new application for smart devices. Interviewees are experts by experience as well as by occupation.

All the discussions are frank and touching: A young woman talks about how her father - a single parent - who was diagnosed with Alzheimer’s disease when she was just 10; Another woman tells the listener about how her mother got lost, wearing only her slippers and night gown, on a freezing winter’s day and died; Two men talk about how they enjoy life to the full, despite their diagnosis of Alzheimer’s disease; and MEP Sirpa Pietikäinen stands up for human dignity and the right to self-determination.

The podcasts also deal with terminology, as Finland has done ground-breaking work renewing the terms used by people to talk about memory diseases. Finland boldly uses terms that have less stigma attached to them – this is also the plea from people with the disease themselves. No more talk about “dementia”, unless we are talking strictly about the symptoms.

The podcasts were aired in the middle of January and have already been listened to thousands of times. Muistiliitto strongly feels that these kinds of open public discussions and bold statements are needed, to increase awareness about these diseases. All conversations are in Finnish.


19 January: The Czech Alzheimer’s Society participates in conference on “Dementia in the Czech Republic”

On 19 January, the Czech Alzheimer Society participated in the Conference “Dementia in the Czech Republic”, organised by the Association of Providers of Social Services in Prague. The conference was held under the auspices of the Czech Minister of Labour and Social Affairs and the Minister of Health.

Radical demographic changes were highlighted by almost all speakers, especially in the context of the need for a National Dementia Strategy. Iva Holmerová, Martina Mátlová and Lucie Hájková spoke on behalf of the Czech Alzheimer’s Society, arguing that “more than a general declaration, people with dementia and their carers need concrete steps connected to financial resources”.

Czech Ministry of Health representative, Josef Vymazal informed the audience that the “Action Plan for Alzheimer’s Disease” is in its final phase, before it is heard in Parliament.

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19 January: The PanHellenic Federation announces its new Board

Following elections on 19 December 2015 (pictured), the PanHellenic Federation of Alzheimer’s Disease and Relative Disorders is pleased to announce its new Administrative Board:

President - M. Tsalaki
Vice President - M. Tzanakaki-Melissari
Secretary General - C. Ziakas
Treasurer - A. Liapis

25 January: The Alzheimer’s Society (UK) reports on its role ensuring people with dementia are central to new “Vanguard” sites

In January 2015, NHS England introduced “vanguard” sites: Geographic areas where health and social care work together to lead development of new care models - one of the first steps in supporting improvement and integration of health and care services in England.

The Alzheimer’s Society in the UK has been key in ensuring people affected by dementia are central to the vanguard sites and plans.

As part of this, we have developed a new model of care that, when delivered as part of the vanguard offer, will ensure all people affected by dementia in an area receive the care and support they need at the point at which they need it.

This model consists of:

- A single point of contact to help people navigate through care and support services.
- Access to information in a timely way to ensure people with dementia have choice and control over important decisions in their life.
- Increased access to services enabling people to stay active, engaged with their communities and empowered.
- Provision of dementia specific training for staff in health and social care.
- Development of Dementia Friendly Communities.
- Access to on-line advice, information and peer support; and telephone help, advice and support.

Evaluation will take place in the future. We anticipate the following results:

- An established dementia pathway.
- Increased awareness of support services available.
- Increased awareness of support services available.
- Consistent approach and single point of contact for dementia services.
- Dementia trained work force.
- Support in acute care (hospitals).
- Quality dementia care in residential homes.

We anticipate that the findings from delivery of this new model will be beneficial across countries in terms of improved health and care for people affected by dementia.

We are committed to supporting other countries to develop their own Dementia Friends initiatives, and sharing learning with one another. So far Canada, Mauritius, Israel and Nigeria have joined the global Dementia Friends movement, and many more countries are in the pipeline.

For information contact dementiafriends@alzheimers.org.uk or visit www.dementiafriends.org.uk www.alzheimers.org.uk/dementiafriendlycommunities
26 January: The PanHellenic Federation writes about first seminars for its “Train the trainers” programme

The implementation of our pilot programme, “Train the trainers”, with its seminars on “Positive Care in Dementia” started this January, in various cities around Greece. The first seminars took place in Thessaloniki, Athens, Ioannina, Chania (pictured), Rethymno, Xalkida and Larisa.

The response has been great, even in this first month, and there are more applicants than we expected.

This underlines the great need for caregivers and health professionals to focus on practical guidelines about caregiving for people with dementia.

The training is made possible by a grant from Stavros Niarchos Foundation (SNF) to ADI.

Living with dementia

25 December 2015: Helga Rohra writes about a German initiative to combat loneliness at Christmas

Christmas is a time of year for family gatherings, social outings and general merriment for many people, but for some, the festive season is a season of loneliness. Alzheimer Europe Board member and Chairperson of the European Working Group of People With Dementia (EWGPWD), Helga Rohra writes about an initiative she was involved in, during December 2015, to help combat loneliness:

Special events in our lives, like Christmas, bring back memories and are a way of reminding ourselves what was life like without dementia.

Christmas time starts long before Christmas Eve. The way of preparing, decorating the house, of thinking about gifts, and of people who will join to celebrate the feast. People who are lonely, without family and without friends, or have just emigrated to Germany are in a special situation. They shouldn’t be left alone. No matter what religion, what country, what age, whether with or without a disability. Only solidarity and humanity counts. Together with my friends, we organised in Murrhardt, Germany a Christmas event for all lonely hearts. A big thank you to all who contributed to its organisation and success: from the bakery store to the petrol station and pharmacy. Actually, many people were involved and it showed the power of solidarity and the message: “With or without dementia - no one is left alone.”

I am very positive that such actions of being included in humanitarian projects gives us people with dementia a chance to show our still existing abilities, to participate with our minds and our hearts. Welfare organisations all over Europe should use such events to raise awareness about the inclusion of people with dementia. There is a power in working hand in hand, and we feel we are not the victims of our disease, but victors.

On the picture you can see my friend Martina, myself and the dog Cleo being happy about the event.

Policy watch

7 January: Dutch euthanasia rules relaxed, can now apply to people with dementia

On 7 January, euthanasia regulations in the Netherlands were relaxed, to allow doctors to administer lethal injections to patients with dementia, as long as the patient has signed an advance directive specifically requesting this procedure. New government guidance assures doctors they may give such injections to patients who are no longer capable of communicating their wishes, as long as this has been previously specified by the patient in a “living will”, at a time when they had the capacity to make the decision. Previous regulations had insisted that a person could only qualify for euthanasia when they could give their full consent.

The new guidance, issued by Ministries of Health and of Security and Justice, confirms that in dementia cases “a doctor may apply euthanasia even if a patient cannot explain it (a request) in words or gesture. But there has to be a written request for euthanasia that the patient has drawn up earlier”.

The guidance supersedes a 2012 document of the KNMG, the Dutch medical association, which stated that patients must still be able to communicate their desire to die for a request for euthanasia to be valid.

Dr Rutger Jan van der Gaag, chairman of the KNMG, told NOS, the Dutch broadcaster, that the guidance gave clarity, adding that it was vital for doctors to understand the will of their patients.

http://goo.gl/IvhsCH

7 January: Public debate on Slovenian Dementia Strategy completed

The one-month public consultation on the Slovenian Dementia Strategy ended on 9 December. During the public consultation, the Ministry of Health received six reviews, and after completion of the public consultation, another four. The interested public proposed updates of some data, in particular the number and structure of employees in public health institutions. Proposals for a more defined role of stakeholders in the system of dementia patients’ treatment were also received.

The strategy was prepared by a ten-person working group, including representatives of psychiatric and neurological
experts, representatives of family physicians, nursing homes, the Ministry of Labour, Family and Social Affairs, the Ministry of Health, and Alzheimer Slovenia (Spominčica).

The strategy was initiated in 2010 by representatives of Spominčica: Dr Aleš Kogoj, Dr Gorazd Stokin and current President Štefanija L. Zlobec. It was supported by the Health Parliamentary Committee and subsequently the Minister of Health appointed a working group for the preparation of this document.

The Ministry of Health is now finalising the document, which will be “the basis for a high quality and comprehensive addressing of the field of dementia”, said Spominčica. “It will ensure better quality of life for people with dementia, their family and profession”. Many countries represented in the membership of Alzheimer Europe already have strategies in place, and Slovenia says it will soon belong to this group.

The adoption of the strategy will be a forward-leap, towards a dementia-friendly society and contribute to dementia becoming a public health priority in the country, says Spominčica.

16 January: Public Health England launches dementia comparison tool

Public Health England (PHE) has published a new Dementia Profile that allows, for the first time, tailored comparison between local authorities and Clinical Commissioning Groups in England through a single interactive online platform.

The Profile enables sharing of key information between localities, such as number of people with dementia and their age, the number who have received an NHS health check, the number with depression and emergency hospital admissions data.

The idea is to help commissioners better fulfil planning objectives by providing the information necessary to identify variation, investigate the reasons for any differences, and ultimately improve outcomes.

http://fingerips.pho.org.uk/profile/group/mental-health/profile/dementia

18 January: Italian Health Ministry committee discusses implementation of National Dementia Plan

On January 18, a technical committee, including Federazione Alzheimer Italia, met at the Ministry of Health in Rome to discuss the (soon-to-be-official by Ministerial Decree) National Dementia Plan (PND). Discussions surrounded the implementation of the Plan, and committee members also assessed its regional application.

Following its approval in late 2014, the National Dementia Plan (PND) began its long journey to adoption in each of the Italian regions. A year on, some regions have still not adopted the plan. More efforts are needed from local administrators, to ensure a swift resolution of this situation, writes Mario Possenti of Federazione Alzheimer Italia.

During the plan’s first year, the first online map of regional services for people with dementia has been made available. The critical point of this list is that data updates must be reported by individual facilities, says Mr Possenti.

The work of the Health Ministry’s technical committee is not yet finished, however. Two working groups have been formed: One to try to create a consensus document for the Path Diagnostics Therapeutic Care (PDTA) that are not currently homogeneous and in many cases are nonexistent; The other to study the information flows created by the regional health system, which end up at the Ministry of Health, to identify and track patients with a diagnosis of dementia, in order to gather statistics and data for the future implementation of the PND.

The PND text is available in English on the Istituto Superiore di Sanità (ISS) website:


18 January: “Fix Dementia Care” campaign launched in UK after report exposes shocking variation of hospital care for people with dementia

An Alzheimer’s Society (UK) survey, which gathered first-hand testimony of dementia care in hospitals from over 570 people with dementia, has found that 92% find hospital environments “frightening”. The survey report also indicated that “too many people with dementia are falling while in hospital, being discharged at night or being marooned in hospital despite their medical treatment having finished”.

Key findings from the survey include:

- 92% thought hospital environments are frightening for people with dementia.
- Only 2% reported that, in their experience, all hospital staff understood the specific needs of people with dementia.

In response to what it calls “unacceptable national variation in the quality of hospital care across England”, the Alzheimer’s Society has launched a new campaign, called “Fix Dementia Care”. The campaign makes the following recommendations:

- All hospitals to publish an annual statement of dementia care, which includes feedback from patients with dementia, helping to raise standards of care across the country.
- The regulators, Monitor and the Care Quality Commission to include standards of dementia care in their assessments.

“We’re campaigning to end this lottery of care. We want all hospitals to publish an annual ‘dementia statement’ setting out the quality of dementia care they provide. This will arm patients with information about their local hospital and drive improvements throughout the system.”

https://www.alzheimers.org.uk/fixcampaign
18 January: Report from OECD says Governments are failing to respond to needs of ageing population

A recent OECD report says Governments around the world are failing to respond to the needs of an ageing population, and calls on health systems to improve their use of big data.

Ageing has a wide range of impacts on individuals and society as a whole. But the consequences for health care, working life, income and well-being in general are not always what many people imagine. “OECD Insights: Ageing: Debate the Issues” discusses the problems, challenges, and opportunities that ageing brings to citizens and governments in developed and developing countries.

Health systems are still not prepared for an ageing population, and the rapidly growing number of people with dementia is a good illustration of this problem. It is estimated that there are currently 47 million people with dementia worldwide - a figure, which is expected to rise to 76 million by 2030.

Among the OECD countries, France, Italy, Switzerland, Spain, Sweden and Norway have the highest prevalence rates, with 6.3% to 6.5% of the population aged over 60 estimated to be living with dementia.

While the OECD welcomes global efforts to try to find a cure, it warns that “the lives of people living with dementia remain poor in most countries.”

The report calls for governments to better train their doctors and caregivers; to equip them with better tools to assess the needs of people with dementia; facilitate improved care co-ordination – particularly across health and social care services; and encourage a better focus on measuring outcomes for people with dementia.


18 January: New Welsh three-year plan will improve mental health services, dementia services

On 18 January the Welsh Government unveiled a new ten-year strategy to improve mental health and wellbeing, covering all ages.

The Health and Social Services Minister, Mark Drakeford launched the formal consultation on the phase two delivery plan for “Together for Mental Health” which sets out key actions for the Welsh Government, the Welsh NHS and social services over the next three years.

Improving services for children and young people with mental health problems and older people with dementia will be key priorities over the next three years.

A Welsh Government spokesman said: “One of the key priorities is to improve the quality of life and care for people with, or at risk of, dementia and their carers. The Welsh Government will produce a dementia strategic plan by December 2016.”

Other priority areas include:

- Ensuring mental wellbeing is given equal priority with physical wellbeing in the development and delivery of services;
- Providing better outcomes for women, their babies and families with, or at risk of, perinatal mental health problems. Health boards will ensure there is an accessible community perinatal service in each part of Wales by November 2016;
- Ensuring people of all ages experiencing eating disorders are able to access appropriate and timely services; health boards will deliver eating disorder treatment services as close to home as possible, in either inpatient or community settings;
- Improving the quality of life, health and wellbeing of older people in Wales by reducing loneliness and unwanted isolation; the Welsh Government will work with the Ageing Well in Wales network to take forward a programme of work that aims to reduce loneliness and isolation among older people by March 2019;
- A concerted effort to continue to sustainably reduce the stigma and discrimination faced by people with mental health problems.

Professor Drakeford said: “Mental health is one of our main priorities and, as a government, we are investing record levels – more than £600m this year – in our mental health services.

“We want to ensure people of all ages experience improvement to their mental health and wellbeing. But if and when mental illness happens we want to ensure people are treated with dignity and respect.”

http://www.wales.nhs.uk/news/40056

Science watch

21 December 2015: Speeding up brain’s “waste disposal” system could help slow AD

The drug rolipram may work to enhance the brain’s “waste disposal” system and slow the progression of Alzheimer’s disease (AD), says a study published on 21 December 2015, in the journal Nature Medicine. The study is supported by the National Institutes of Health (NIH).

Using mouse models, researchers showed that proteasomes – cellular waste disposal systems – can break down AD, creating a cycle in which increased levels of damaged proteins become toxic, clog proteasomes, and kill neurons.

Results of the study suggest that enhancing proteasome activity with drugs during the early stages of AD may prevent dementia and reduce damage to the brain.

Rolipram was originally developed as an antidepressant in the 1990s but is not used clinically due to its gastrointestinal side effects.

This discovery may have potential as a treatment, but research is still in its very early stages.

http://www.nature.com/nm/journal/v22/n1/full/nm.4011.html
31 December 2015: UK-based clinical trial looks at potential AD vaccine

A new clinical trial is underway in the UK, looking at a potential vaccine that targets tau protein in the brains of people with Alzheimer’s disease (AD).

AD is caused when amyloid and tau proteins clump together in the brain - plaques and tangles respectively - causing damage to neurons.

Scientists at the Research Institute for the Care of Older People (RICE) in the UK are hoping that a new drug will act as a vaccine; targeting tau tangles in the brain to prevent their build-up potentially remove them altogether. The clinical trial will look at whether the drug is safe for people with mild to moderate AD to use. The researchers hope it might slow or halt the progression of the condition.


4 January: Social connections are as important to long-term health as diet and exercise, US study claims

A new study from researchers at the University of North Carolina (UNC) Chapel Hill in the US, suggests that people with good, supportive relationships are healthier: They tend to have lower blood pressure, a smaller waist circumference and body mass index, and lower levels of inflammation than those without these positive social ties. The study was published on 4 January in the journal Proceedings of the National Academy of Sciences.

The effect of relationships on health is so powerful that in young people, social isolation had a negative impact comparable to a lack of exercise.

“We’re able to show for the first time how this link [between social relationships and health] happens, evolves and changes as individuals’ age,” said sociology professor Yang Claire Yang of UNC Chapel Hill and the Lineberger Comprehensive Cancer Center.

Senior study author Professor Kathleen Mullan Harris and her team used data from four large, long-term and nationally representative studies, encompassing a total of about 15,000 participants. They identified associations between the number or quality of relationships and certain health markers, like BMI, waist circumference and inflammation risk.

The study found social isolation was especially harmful in young people aged 12 to 18 and senior citizens. In the teens, social isolation was linked to the same levels of increased inflammation as physical inactivity, and in seniors, social isolation proved even more harmful than diabetes when it came to hypertension levels.

Overall, social isolation had a negative effect on health that was comparable to lack of exercise and even some diseases.

The study didn’t establish definitive causal relationships between social ties and health. However, Professors Yang and Harris are confident that the moral of their study is that making friends and maintaining strong social networks should be a lifelong goal, as well as a public health recommendation.

http://www.pnas.org/content/113/3/578.abstract

5 January: French “Fondation Plan Alzheimer” launches call for projects

Basic research has led to major advances in the understanding of Alzheimer’s disease and related disorders, but the clinical relevance of these findings is still to be demonstrated through translational research, says the Fondation Plan Alzheimer, France. With this in mind, the foundation opens a new project call for 2016. The call is open for a maximum of ten projects worth approximately EUR 150,000, to be selected “on the basis of scientific excellence and feasibility”.

The duration of projects may not exceed 36 months from the date of enrollment of the first individual in the study. Funding can cover all expenses, including salaries, pending a detailed budget and justification for the complete submission of the project.

Interested parties should send a Letter of Intent written in English no later than 8 February.


8 January: Targeting brain inflammation may slow progression of AD

A study published on 8 January in the journal Brain, has found that blocking a receptor in the brain responsible for regulating immune cells could help slow the progression of Alzheimer’s disease (AD). The research was funded by the Dementia Consortium, which is a collaboration between Alzheimer’s Research UK, MRC Technology and pharmaceutical companies, Astex, Eisai, and Lilly.

Researchers at the University of Southampton, led by Dr Diego Gomez-Nicola, used tissue samples from healthy brains and those with AD, both of the same age. They counted the numbers of microglia - a type of immune cell - in the samples and found that these were more numerous in the AD brains. In addition, the activity of the molecules regulating the numbers of microglia correlated with the severity of the disease.

The scientists studied these same immune cells in AD mouse models, to find out whether blocking the receptor responsible for regulating microglia - CSF1R - could improve cognitive skills. Oral doses of an inhibitor that blocks CSF1R were administered to the mouse models, with positive results: The reduced the number of microglia and prevented the loss of communication points between the nerve cells in the brain associated with AD. The treated mice demonstrated fewer memory and behavioural problems compared with the untreated mice.

Results also showed the healthy number of microglia needed for normal immune function in the brain was maintained, which they suggest means the blocking of CSF1R "only reduces excess microglia".

What the study did not find is a correlated reduction of the number of amyloid plaques in the brain, a hallmark of AD.
9 January: US study finds possible link between air pollution and Alzheimer’s disease

The incidence (occurrence of new cases) of dementia, Alzheimer’s disease (AD) and Parkinson’s disease (PD) is higher in the US cities with the highest levels of air pollution with fine particles less than 2.5 microns in volume (PM$_{2.5}$), according to a study published in the journal Environmental Health Perspectives this month.

Marianthi-Anna Kioumourtzoglou and her colleagues at Harvard T.H. Chan School of Public Health reviewed first hospital admissions for eight years between 1999 and 2010, in all people aged 65 and over belonging to the US Medicare system (9.8 million people) and in 50 cities in the north east of the US. The average age was 75.6 years. The average concentration of PM$_{2.5}$ was 12.0 μg / m$^3$ (micrograms per cubic meter of air).

Across the eight years, the researchers found a total of 203,463 of those with first admissions to hospital had AD, 203,463 with dementia, and 119,425 had PD (with AD, PD and dementia as the primary or secondary causes of hospitalisation). For each increase of 1 g / m$^3$, the relative risk of intake increased by 15% for AD, 8% for other dementias and 8% for PD.

The study authors said their results showed “statistically significant, positive associations between long-term PM$_{2.5}$ city-wide exposures and PD, AD, and dementia”.

Their results, they specified, are to be viewed as preliminary, with findings “providing a basis for further exploration in large epidemiologic studies with validated outcomes and more detailed information on potential individual-level confounders.”

Alzheimer Europe reported on a similar study, linking air pollution with dementia and strokes, in April of last year:

http://www.anavex.com/?news=anavex

11 January: Anavex announces positive dose-response data in Phase 2a trial of AD drug

On 11 January, Anavex Life Sciences Corp. - a clinical-stage biopharmaceutical company developing differentiated therapeutics for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD) - reported observing “a positive dose-response relationship” in a Phase 2a trial of its small molecule drug, ANAVEX 2-73 (chemical name: Tetrahydro-N,N-dimethyl-2,2-diphenyl-3-furanmethanamine) for treatment of mild to moderate AD.


Additional information regarding the ongoing Phase 2a clinical trial is available from the U.S. National Institutes of Health (NIH) clinical trials database at

www.clinicaltrials.gov

12 January: US company agrees to pay USD 2 million in deceptive advertising charges for “brain training” programme

Lumos Labs – the company that created the Lumosity “brain training” programme - has agreed to settle US Federal Trade Commission (FTC) charges alleging it deceived consumers with unfounded claims its games can help users perform better at work and in school, and reduce or delay cognitive impairment.

As part of the settlement, the US company will pay USD 2 million in redress and will notify subscribers of the FTC action, as well as providing them with an easy way to cancel their auto-renewal to avoid future billing.

“Lumosity preyed on consumers’ fears about age-related cognitive decline, suggesting their games could stave off memory loss, dementia, and even Alzheimer’s disease,” said Jessica Rich, Director of the FTC’s Bureau of Consumer Protection and Bangor University.

Dr. Gomez-Nicola and his colleagues will now work towards finding a suitable drug that can be tested in humans.

http://www.healthcanal.com/brain

http://brain.oxfordjournals.org/content/early/2016/01/09/brain.awv379

http://www.anavex.com/?news=anavex
Protection. “But Lumosity simply did not have the science to back up its ads.”

According to the FTC’s complaint, the Lumosity programme consists of 40 games purportedly designed to target and train specific areas of the brain. The company advertised that training on these games for 10 to 15 minutes three or four times a week could help users achieve their “full potential in every aspect of life.”


12 January: Dementia drug could help prevent falls in people with Parkinson’s disease, UK study finds

A UK study has found that the incidence of falls in people with Parkinson’s disease (PD) could be reduced by administering the drug rivastigmine, commonly prescribed in the treatment of mild to moderate Alzheimer’s disease (AD).

Results were published in the Lancet Neurology journal on 12 January.

Over an eight-month period, the research team at the University of Bristol, led by Parkinson’s UK research fellow Dr Emily Henderson gave the drug to half of a group of 130 patients with PD, who had fallen in the last year.

They observed that study participants on rivastigmine reduced their chances of falling by 45%. They also found the drug helped to steady their gait.

Dr Henderson said: “With the degeneration of dopamine-producing nerve cells, people with Parkinson’s often have issues with unsteadiness when walking.

“As part of the condition, they also have lower levels of acetylcholine, a chemical which helps us to concentrate - making it extremely difficult to pay attention to walking.

Around 70% of people with PD experience a fall at least once a year, with more than a third (39%) saying they fall repeatedly, the report said. Such falls can often lead to broken bones.

http://www.thelancet.com/journals/laneur/article/PIIS1474-4422%2815%2900389-0/abstract

12 January: Study into early dementia prediction presented at TEDx event in Zurich

On 12 January, a TEDx talk titled “Dementia precaution should become as normal as going to the dentist” was given by Ioannis Tarnanas (pictured), Gerontechnology and Rehabilitation CSO of XtremeVRI AG and Novartis AG fellow 2014-2015 at the University of Bern, Switzerland. He has, been involved with research and development, virtual and augmented reality innovations in Gerontechnology and Rehabilitation.

“Can there be early indicators for Alzheimer’s disease (AD)?” he began.

“For the last 30 years most attempts have focused on the very basic expectation that early indicators or biomarkers of AD follow the same timeline for all individuals. We now know that AD is more complex than originally thought.

However even currently, it is much more common for the assessment of cognition to be based on insensitive screening measures or reports of cognitive problems by patients or their family members. Such blunt screening tools can be very unreliable, which might explain why cognitive decline has traditionally been viewed as occurring later in the disease process.”

The talk re-imagines AD detection, with a sensitive, early-screening marker, which enhances the ability to more accurately identify individuals who are at risk for future progression to AD. It is the story of 11 years of findings that emphasise “the need to improve identification of persons at risk for AD through the use of multiple, diverse assessment tools. This includes sensitive, everyday learning and memory tests capable of reliably identifying cognitive changes at the earliest stages.”

The talk can be viewed at: http://tedxzuurich.com/speaker/ioannis-tarnanas/

It was given at a TEDx event using the TED conference format but independently organized by a local community.

Learn more at: http://ted.com/tedx

The study can be found here: https://www.sciencedirect.com/science/article/pii/S2352872915000846

14 January: Alzheimer’s disease detectable in urine odour at early stages of disease in mice, study says

A research team at the Case Western Reserve University School of Medicine in Cleveland, Ohio, US says that mouse models in the early stages of Alzheimer’s disease (AD) have a unique urine odour, as compared with healthy mice.

The difference in urine odour – which was detectable even before researchers could identify plaque build-up in the mouse models’ brains - could, potentially provide another, earlier disease biomarker, but it is too early to tell whether this could work in humans also.

The study was published in the journal Scientific Reports on 14 January: http://www.nature.com/articles/srep19495

18 January: Cancer drug improves symptoms in AD mouse models

A study published on 18 January in the journal Nature Medicine shows that a cancer drug that activates the body’s immune cells against tumours improves symptoms in Alzheimer’s disease (AD) mouse models.

The drug targets a protein called PD-1, which is found in certain immune cells and is responsible for suppressing their activity. By blocking the function of this protein, known as a “checkpoint”, the immune system can be mobilised to respond to and destroy cancer cells.

The researchers treated the AD mouse models with regular injections of the drug over two months. The mice showed improved learning and memory, and had fewer amyloid plaques in their brains compared to those that did not receive treatment.

The study authors suggest that by stopping PD-1 from suppressing the immune cells, certain elements of the immune system could be used to remove toxic build-ups, such as amyloid plaques.
19 January: Nobilis files patent for its AD drug candidate

On 19 January, Nobilis Therapeutics - a biotechnology company dedicated to clinical development of Noble Gas-based medical interventions - announced it had filed a patent demonstrating inhibition of neuroinflammation using its proprietary product candidate NBTX-001. Experimental in vitro data presented in the patent demonstrates that treatment with NBTX-001 resulted in suppression of inflammatory mediators, as well as blocked maturation of important immunological effector cells termed dendritic cells.

While neuroinflammation is associated with numerous neurodegenerative conditions, Nobilis used an experimental system specifically applicable to Alzheimer’s disease (AD). The experiments demonstrated that, when exposed to AD-associated proteins macrophages produced less inflammatory mediators in the presence of NBTX-001.


20 January: Algae linked to rare neurodegenerative condition similar to AD

Researchers in the US have found evidence suggesting that blue-green algae or cyanobacteria - an organism found in water around the world - can produce a toxin linked to the development of a neurodegenerative disease similar to Alzheimer’s disease (AD).

The mysterious illness, found among populations in the Pacific Island of Guam prompted researchers to attempt to pinpoint a potential environmental cause.

The study – completed by a team of scientists at the Institute for EthnoMedicine in Wyoming - was published in the journal Proceedings of the Royal Society B. It linked the disease in Guam to a neurotoxin called BMMA. As well as algae, the toxin is present in cycad seeds - which Chamorro villagers on the Pacific island use to make flour tortillas.

The team also fed vervet monkeys fruit laced with BMMA, and found that the animals developed neurofibrillary tangles and plaque, linked to neurodegenerative diseases.

BMMA was also discovered in 12 freshwater lakes and reservoirs across the UK and in seafood from isolated areas of the Mediterranean, sparking a media storm, suggesting the toxin may cause AD, Parkinson’s disease and motor neurone disease, via the food chain.

Professor Paul Cox, director of the Institute for Ethnomedicine, however, stressed that he and his team were not asserting that they had caused AD in the monkeys and that the brain plaques present were different to those believed to cause AD.

While the study is certainly interesting, it does not provide evidence that the toxin contributes to AD in other populations.

https://rpb.royalsocietypublishing.org/content/283/1823/20152397

27 January: Increased growth protein in brain linked to slower mental decline, study suggests

A study published on 27 January in the journal Neurology has suggested that older people with higher amounts of a protein, known as BDNF, exhibit a slower decline in their memory than those with a lower amount.

The study involved 535 people with an average age of 81 who were followed until death, for an average of six years. They took yearly tests of their thinking and memory skills, and after death, a neurologist reviewed their records and determined whether they had dementia, memory and thinking problems, or no thinking and memory problems. Autopsies were conducted on their brains after death to measure the amount of protein present.

The rate of cognitive decline was 50% slower for those with the highest 10% concentration of protein (which is found in the brain) compared to those with the lowest 10%. The effect of plaques and tangles in the brain on cognitive decline was reduced for people with high levels of BDNF.

BDNF promotes the growth of new brain cells and is produced in areas of the brain responsible for memory and learning. The study suggests a link between a higher production of this protein and slower mental decline, but it is very early stage research. More research in this area is needed before drawing concrete conclusions.

http://www.neurology.org/content/early/2016/01/27/WNL.0000000000002187.short?sid=5b6c3d55-1ac6-4381-96f3-1626e00d9f69

Dementia in society

1 January: Two thirds of people with dementia feel isolated, study finds

An Alzheimer’s Society (UK) study has found that 64% of people living with dementia feel isolated and that 42%. The new research by Alzheimer’s Society also shows that 42% per cent of people “mistakenly think that once a person with dementia stops recognising loved ones, they don’t benefit a lot from spending time with them”. At the start of January, the Alzheimer’s Society called on people to make a positive New Year’s resolution to spend time with people with dementia and help them take part in activities they enjoy to stay connected.

The survey also found that over half (54%) of people with dementia were no longer taking part in social activities, and almost half (48%) thought what would help people with dementia most to stay connected is seeing family and friends more often, and having someone to help them take part in activities.

15 January: Canadians campaign to dispel myths about dementia

“Life doesn’t end when Alzheimer’s begins” is the message of The Alzheimer Society Canada’s new campaign, “Still Here”, which aims to raise awareness and make positive changes in people’s attitudes towards dementia and towards people living with dementia.

The campaign was launched to kick off “Alzheimer Awareness Month”, which is being observed across Canada this January.

“Words and actions are powerful and can change the story of dementia,” said Alzheimer Society of Canada CEO, Mimi Lowi-Young. “That’s the goal of our campaign, to dispel the myths around what it means to live with dementia and encourage all of us to see the person beyond the condition.”

According to the society, 747,000 Canadians are living with Alzheimer’s disease and other dementias. The figures are expected to increase to 1.4 million in the next 15 years.

http://www.alzheimer.ca/stillhere

18 January: Christopher Eccleston invites us to “share the orange” to raise awareness

An online video featuring British actor Christopher Eccleston has been launched by Alzheimer’s Research UK (ARUK) to address people’s misconceptions about dementia. The video, created by Oscar-winning animation studio Aardman – makers of hit British animation series Wallace and Gromit – uses stop motion techniques to show an orange being stripped away to demonstrate how diseases that cause dementia physically attack the brain.

In the video, Mr Eccleston - whose father Ronnie died following a 14-year battle with the illness - invites viewers to share the video on social media using the hashtag #sharetheorange.

He hopes the film will “fight the misunderstanding and fatalism that surrounds dementia in our society”.

https://www.youtube.com/watch?v=x9MvEZskR6o

New publications and resources

31 December 2015: France Alzheimer publishes “100 idées” – a book of tips for carers

France Alzheimer has published a new book “100 idées pour accompagner une personne malade d’Alzheimer”. The book gives practical advice aimed at people living with dementia and their carers (both family carers and professional carers).

The team of writers included loved ones of people with dementia, a researcher, journalists, a psychologist and a neuropsychologist.

It can be purchased at a cost of EUR 14.50 (tax incl.) in bookshops and online.

http://www.francealzheimer.org/100-id%C3%A9es-pour-accompagner-une-personne-malade-d%E2%80%99alzheimer/137

31 December 2015: Report published on 1st WHO Ministerial Conference on Global Action Against Dementia

A report has been published, following the 2015 “First Ministerial Conference on Global Action Against Dementia” organised by the World Health Organisation (WHO), with support from the UK Department of Health and the Organisation for Economic Co-operation and Development (OECD).

The First WHO Ministerial Conference on Global Action Against Dementia fostered awareness of the public health and economic challenges posed by dementia, a better understanding of the roles and responsibilities of Member States and stakeholders, and led to a “Call for Action” supported by the conference participants.


16 January: Registrations now open for KU Leuven’s 2nd Ethics in Dementia Care summer course

The Centre for Biomedical Ethics and Law of the KU Leuven is organizing the 2nd edition of the “Summer Course on Ethics in Dementia Care”, which will take place in Leuven, Belgium from 6 to 8 July. The objective of the course is to foster exchanges on foundational, clinical-ethical and organisational-ethical approaches to dementia care practices.

During the course, which is in English, national and international experts will give presentations on various ethical topics in the domain of dementia care. There will be time for intensive discussions.

The Summer Course is of interest to participants from diverse professional backgrounds, such as medicine, nursing, psychology, social work, gerontology, health care administration, philosophy and theology, and to PhD students undertaking courses of study in these areas. For detailed information on programme, funding opportunities, registration and payment:


27 January: New German guideline on dementia diagnosis and treatment highlights importance of psychosocial interventions

A new guideline on dementia diagnosis and treatment in Germany was published on 27 January by the German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology (DGPPN) and the German Society for Neurology were (DGN).

There are currently about 1.5 million Germans living with dementia, about two thirds of whom have Alzheimer’s
disease (AD) - the most common cause of dementia. There is currently no cure or disease-modifying therapy for AD.

The new 133 page document, highlights the importance of using psychosocial interventions, alongside existing drugs such as the drug group of acetylcholinesterase inhibitors, to help support patients in their daily activities and to stabilise cognitive function in mild to moderate AD.

"Psychosocial interventions work as well as drugs and are equally central building blocks in the overall treatment of dementia," said Professor Wolfgang Maier, Director of the Clinic for Psychiatry and Psychotherapy at the University Hospital of Bonn and one of the authors of the guideline.

The new guideline is recognised by 23 professional societies and professional associations of doctors, therapists, nurses and patients.

http://goo.gl/78FnnL

29 January: EPAD’s first newsletter is out!

On 29 January, the European Prevention of Alzheimer’s Dementia (EPAD) consortium released its first ever newsletter.

The newsletter can be seen here: http://ep-ad.org/?wysija-page=1&controller=email&action=view&email_id=5&wysija=subscriptions&user_id=125

You can subscribe to receive future newsletters here: http://ep-ad.org/newsletters/

Contact Alzheimer Europe

Alzheimer Europe, 14 rue Dicks, L-1417, Luxembourg; info@alzheimer-europe.org, www.alzheimer-europe.org

Alzheimer Europe Board

Chairperson: Heike von Lützau-Hohlbein (Germany); Vice-Chairperson: Iva Holmerová (Czech Republic); Honorary Secretary: Charles Scerri (Malta); Honorary Treasurer: Maria do Rósario Zincke dos Reis (Portugal); Members: Marie-Odile Desana (France), Sabine Henry (Belgium), James Pearson (UK - Scotland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Helga Rohra (Germany), Štefanija Lukič Zlobec (Slovenia).

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# AE Calendar 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>1-2 February</td>
<td>Meeting of governmental experts on dementia (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>3 February</td>
<td>User Test of a prototype of the EMA’s clinical data publication website (London, UK)</td>
<td>Ana</td>
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<tr>
<td>5 February</td>
<td>Roche Dementia Forum (Frankfurt, Germany)</td>
<td>Jean</td>
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<tr>
<td>15 February</td>
<td>PredictND meeting (Kuopio, Finland)</td>
<td>Dianne</td>
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<tr>
<td>18-20 February</td>
<td>ICCA workshop (Uppsala, Sweden)</td>
<td>Gwladys</td>
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<tr>
<td>24 February</td>
<td>IMI Lunch Debate European Parliament (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>29 February/1 March</td>
<td>AE Board, Board of Alzheimer Europe Foundation and AE Company round table meeting (Luxembourg, Luxembourg)</td>
<td>AE Board, staff and sponsors</td>
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<tr>
<td>2 March</td>
<td>AE Public affairs meeting (Luxembourg, Luxembourg)</td>
<td>AE Board, members and staff</td>
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# Conferences 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>9-12 March</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>
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<tr>
<td>17-20 March</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmed.com/cony">http://www.comtecmed.com/cony</a></td>
<td>Lisbon, Portugal</td>
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<tr>
<td>13-15 April</td>
<td>25th European Stroke Conference, <a href="http://www.eurostroke.convitements.de">www.eurostroke.convitements.de</a></td>
<td>Venice, Italy</td>
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<tr>
<td>9-10 May</td>
<td>Living well with(out) dementia, <a href="http://english.an2016.nl/lates/events/2016/05/10/living-well-without-dementia">http://english.an2016.nl/lates/events/2016/05/10/living-well-without-dementia</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>28-31 May</td>
<td>2nd Congress of the European Academy of neurology, <a href="http://www.eaneurology.org">www.eaneurology.org</a></td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>30 June - 2 July</td>
<td>4th International conference on vascular dementia</td>
<td>Valencia, Spain</td>
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<tr>
<td>24-28 July</td>
<td>AAC Annual Conference, <a href="https://www.alz.org/aac/">https://www.alz.org/aac/</a></td>
<td>Toronto, Canada</td>
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<tr>
<td>6-9 September</td>
<td>2016 IPA International congress, <a href="http://wwwipa-online.org">wwwipa-online.org</a></td>
<td>San Francisco, USA</td>
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<tr>
<td>29 September - 1 October</td>
<td>9th Conference of the German Alzheimer’s Association (DAmbD) on “Dementia. Looking at diversity”, <a href="http://www.demenz.kongress.de">www.demenz.kongress.de</a></td>
<td>Saarbrücken, Germany</td>
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<tr>
<td>31 October - 2 November</td>
<td>26th Alzheimer Europe Conference (ZNAEC) on “Excellence in dementia research and care”</td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>9-13 December</td>
<td>2016 IPA Asian regional meeting, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>Taipei, Taiwan</td>
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26th Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences

The Alzheimer Europe newsletter received funding under an operating grant from the European Union’s Health Programme (2014-2020). The content of this newsletter represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.