Editorial

Welcome!

I trust that 2016 was a successful year for you all and that 2017 has started well. As for the Alzheimer Europe (AE) team, I believe we have every reason to be proud of our achievements over the past 12 months. On the subject of our small but committed team, I am delighted to welcome two new colleagues – Project Officers Chris Bintener and Cindy Birck. I look forward to working with them on our numerous EU projects. Looking back at 2016, I would like to thank the people that supported us in our continuing efforts to make dementia a European priority: our European Working Group of People with Dementia (EWGPWD) - which helps ensure that our activities duly reflect the priorities and views of people with dementia; our Board, national member associations, Expert Advisory Panel, strategic partners, sponsors, the Alzheimer Europe Foundation and the 128 MEPs belonging to the European Alzheimer’s Alliance. Last but by no means least, we owe a debt of gratitude to the EU and its health and research programmes and their support of our activities and projects, without which what we do would simply not be possible.

December began in Brussels for the AE team, with our final series of meetings for the year, including a lunch debate at the European Parliament, on comparing and benchmarking national responses to the dementia challenge. During the lunch debate, we also presented two new publications - a comparative report on decision making and legal capacity and a discussion paper on ethical issues linked to the changing definitions around Alzheimer’s disease (AD). Other meetings in Brussels included our Board meeting and Company Round Table, as well as the 2nd edition of our Alzheimer’s Association Academy.

Later in the month, the EWGPWD held its first meeting since it began a third two-year term of office. This was an opportunity for its six new members, Chairperson and two Vice-Chairpersons to set out their priorities for the coming months. As well as AE’s meetings, I attended a meeting of governmental experts on dementia convened by the Commission, as well as the Slovak EU Presidency dementia conference, both in Bratislava. I also travelled to Barcelona with Kate for the launch meeting of new IMI project MOPEAD (Models of Patient Engagement for Alzheimer’s Disease) and I was in San Diego for the very interesting Clinical Trials on Alzheimer’s Disease (CTAD) Conference. Despite Lilly presenting the disappointing news of its phase III failure, I felt there was a real sense of hope at the conference, in the continued commitment demonstrated by industry and researchers and in some encouraging early stage results from phase I and phase II trials, which will of course need to be confirmed in larger phase III trials.

Finally, we were pleased to see a revised version of the WHO Global Action Plan on dementia, published in late December, following feedback on the Zero Draft. On that positive note for international dementia policy going forward, I wish you all an excellent start to 2017!

Jean Georges
Executive Director
5-6 December: Alzheimer Europe holds Board meeting in Brussels

The members of the Alzheimer Europe Board held a meeting on 31 October in Brussels. This was the first meeting of the 2016-2018 Board and the agenda included various financial and operational matters, such as the 2017 Alzheimer Europe Conference. The next Board meeting will take place in February 2017.

6 December: AE presents European Dementia Monitor results in the European Parliament

On 6 December 2016, Alzheimer Europe held a lunch debate in the European Parliament, hosted by Nessa Childers, MEP (Ireland) and a Vice-Chairperson of the European Alzheimer’s Alliance (EAA). Ms Childers greeted the participants and explained that the debate would focus on comparing and benchmarking national responses to the dementia challenge. She then handed over to Iva Holmerová, the new Chairperson of Alzheimer Europe. Prof Holmerová added her own welcome and introduced the first speaker, AE’s Executive Director Jean Georges.

Mr Georges presented the concept and the results of the European Dementia Monitor, an AE survey of national dementia strategies and policies that compares four key areas:

- Medical and scientific issues, including treatment, research and clinical trials
- Care and social issues, including social support
- Policy and legal issues
- Dementia strategies, including dementia-friendly communities

The report is mainly based on data obtained from AE’s member associations, highlighting the relative strengths and weaknesses of access to care and treatment among European countries. This provides national associations with a means to lobby for change by comparing their country to others. The Monitor also allows policy makers to identify both gaps and best practices, in order to improve care and support of people with dementia and their carers all over Europe. The priority areas are as follows:

- Availability and reimbursement of AD medicines
- Availability and affordability of care services
- Availability of clinical trials
- Involvement in EU dementia research
- Recognition of dementia as a priority
- Recognition of legal issues
- Recognition of human rights
- Carer employment support
- Dementia-friendly communities / inclusiveness

Mr Georges presented comparison charts for each priority area and explained the point system used to derive the rankings. He also showed overall country rankings and added that AE would publish the overall results in early 2017.

The next speaker was Tim Muir, Health and Social Policy Analyst at OECD, the Organisation for Economic Co-operation and Development. He presented “Measuring Dementia - an overview of the facts and figures we have now and those we need to develop in the future”. Mr Muir explained that dementia is a growing priority in many OECD countries, hence the organisation’s interest to measure its current burden and determine future needs. He showed that dementia prevalence will continue to increase, mainly due to an ageing population and added that dementia is globally the second biggest cause of disability for people over the age of 70. Mr Muir also presented figures on the costs of dementia to national health systems and noted that the global overall cost of dementia is estimated at over half a trillion US dollars.

Looking to the future, Mr Muir said that OECD would soon launch a pilot set of indicators, including the use of antipsychotics and the rate of avoidable hospital admissions of people with dementia. The organisation is also evaluating patient-reported measures, which can be especially valuable in the early stages of dementia. Mr Muir concluded that these measures would be a major theme at OECD’s Health Ministerial forum in January 2017.

Impressions from the lunch debate

Speakers (l/r): AE Executive Director Jean Georges, AE Chairperson Iva Holmerová, MEP Nessa Childers and OECD Health and Social Policy Analyst Tim Muir

AE Executive Director Jean Georges presents the European Dementia Monitor

Iva Holmerová speaks at her first lunch debate as AE Chairperson
Prof Holmerová followed with a brief introduction of two new Alzheimer Europe publications. The first is a discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer’s disease and the second is AE’s 2016 Yearbook, entitled “decision making and legal capacity in dementia”. These reports are described in more detail in the article below.

In her concluding remarks, Ms Childers cited the problem of how Member States will be able to fund health programmes. She added that “in public health, dementia competes with other disease areas, so the kind of research we’ve seen today is very important to be able to persuade policy makers to fund dementia efforts.”

The lunch debate was attended by over 60 people, including MEPs Heinz Becker (Austria), Deirdre Clune (Ireland), Sofia Ribeiro (Portugal) and Olga Sehnalová (Czech Rep.), as well as representatives for MEPs Karin Kadenbach (Austria), Stefano Maullu and Patrizia Toia (Italy) and Jana Žitňanská (Slovakia). The audience also included representatives from several pharmaceutical companies and 18 Alzheimer Europe member associations.

6 December: AE supports the rights and dignity of people with dementia with two new publications launched at the European Parliament

On 6 December 2016, Alzheimer Europe (AE) presented two important new publications to Members of the European Parliament (MEPs), representatives from the Organisation for Economic Co-operation and Development (OECD) and a number of European organisations including the European Patients’ Forum (EPF), the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe), as well as representatives from the pharmaceutical industry and the press, at a lunch debate in the European Parliament.

Newly appointed Chairperson Iva Holmerová introduced AE’s comparative report on decision making and legal capacity in dementia, authored by Project Officer Ana Diaz, with the input of all AE member associations as well as experts from Lithuania and Latvia; and a discussion paper on ethical issues linked to the changing definitions and use of terms related to Alzheimer’s disease (AD), authored by a working group of 11 experts from across Europe, chaired by Director for Projects Dianne Gove.

About the comparative report

Decision making and legal capacity are not new topics for AE, which started looking at these issues almost two decades ago in 1997, with its Lawnet project on legislation relating to the rights of people with dementia from the then 15 Member States of the European Union. The Lawnet project was presented in AE’s 2010 Dementia in Europe Yearbook, while the 2009 report focused on national laws in Europe, with regard to healthcare decision making by people with dementia. The 2016Dementia in Europe Yearbook, “Decision making and legal capacity in dementia” provides an update on information collected in both these earlier reports.

All AE members as well as experts from Lithuania and Latvia were invited to participate, with a total of 31 countries contributing. In addition, some members of the European Working Group of People with Dementia (EWGPWD) participated, providing personal accounts of their experiences related to the main topics discussed.

The first part of the report provides information on how legislation regulates the issue of legal capacity in questions such as: contractual capacity, testamentary capacity, criminal responsibility, civil responsibility/ liability, marriage and political rights (i.e. the right to vote). The second section of the report looks at issues related to consent to treatment and research, and refers to the legal
framework in each country and provisions for consent for people lacking the capacity to consent. The final section introduces the topic of systems of substitute decision making and reviews the existing legislation across Europe applying to court-appointed decision makers (i.e. guardians) and powers of attorney.

Some of the new legal approaches move away from public protection as the main priority, towards an approach that safeguards and promotes the rights and dignity of the person, but also highlights the need to balance care and protection, against empowerment and rights. In line with this, and following the requirements of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), some of the most recent legislation has moved away from proxy to supported decision-making approaches.

In publishing this report, AE hopes to support Alzheimer’s associations and other campaigners wishing to promote a human rights-based approach to dementia, as well as policy makers interested in reforming their legal systems to better promote the rights of people living with dementia.

This report is part of AE’s 2016 work plan and has received funding from the European Union.

AE Executive Director Jean Georges said:

“I am delighted to see how many positive legislative changes we have been able to identify. Whilst previously we had quite a number of legal frameworks that described capacity as an “all or nothing” affair, this is very much the exception today.

“Overall, the new mechanisms in place appear to be more flexible and potentially better suited to the evolving needs of people with dementia and their families due to the progressive nature of the disease.

“Everyone should have the right to decide how he/she wants to lead his/her life and a diagnosis of dementia should not change that. Whilst the wellbeing of the person should always be safeguarded, the emphasis should be on empowering rather than on simply protecting the individual.”

For further information about the comparative report please contact Dr Ana Diaz, Project Officer: ana.diaz@alzheimer-europe.org

About the discussion paper

Recent and ongoing developments in the field of research into the causes and development of AD have led to new ways of understanding this condition. Researchers now suggest AD should be considered as a continuum, ranging from an “at risk” state through to a dementia state, emphasising AD as a possible cause rather than a form of dementia.

AE welcomes continued work towards a better understanding of AD, resulting in the possibility of preventive measures, effective treatments and good quality care. At the same time, it recognises the need to try to ensure these definitions have a positive impact on people who already have or may later have AD and ensure they are adequately supported, fully respected and fairly treated.

With this in mind, the Ethics Working Group reflected on a range of ethical issues linked to the new AD model, for the “Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer’s disease”.

The working group was comprised of experts in the fields of ethics, the experience of dementia, ageing, psychiatry, psychology, dementia research and policy. AE would like to thank the members of the group - Dianne Gove (Chair), Jean Georges, Hilary Doxford, Karine Fauria, Julian Hughes, Tina Leonard, Anneli Sarvimäki, Mark Schweda, Sarah Smith, Hinesh Topiwala and Guy Widdershoven - for their valuable contributions.

Some of the stand-out conclusions reached were:

- New definitions may give rise to a change in societal views on AD and either to a decrease or on the contrary, to an extension of the stigma currently associated with AD dementia. This requires further investigation and calls for alternative, more positive perspectives and interpretations of AD, for reflection and action by individuals and societies to ensure that people with AD are empowered, valued and have the same opportunities as others.

- As the new definitions may lead to shifts in research and care, policy makers have an important role to play in helping ensure that the focus on biomedical research into the early stages of AD does not jeopardise social science research aimed at improving the quality of life of people with AD dementia. Policies are needed to promote an equal distribution of research funding and care provision between various socio-economic groups, at national and European level.

- The previous definition of AD was linked to some degree of uncertainty, but the new definitions also give rise to possible uncertainties and misunderstandings in both the clinical and the research context. The importance of pre-diagnostic counselling and post-diagnostic support must be recognised and every effort made to train researchers and healthcare professionals and to ensure informed consent is a reality for research participants as well as informed decision-making for patients.

AE is confident that recent research, leading to the new terminology surrounding AD, as discussed in this paper, will improve understanding of the stages preceding the development of dementia and hopefully one day provide better treatment to prevent, halt or delay the apparition of symptoms. It hopes to compliment these positive developments with this discussion paper, by helping ensure that the ethical and societal implications of these developments are fully addressed.

AE Chair Iva Holmerová said:

“As Chair of Alzheimer Europe and as a geriatrician and researcher, I think it is important that we reflect on the possible ethical implications of the changing definitions of AD. As a caring, responsible society, it is important that we are all aware of these implications at the level of the individual, communities and wider society. In this way, we can try to ensure that people affected by AD can continue to enjoy the same rights and opportunities as everyone else.”
On 6 and 7 December 2016, Alzheimer Europe (AE) hosted its second annual Alzheimer's Association Academy. Participants included 23 representatives from AE member organisations; 8 representatives from various European and national institutions and organisations including the European Parliament, the European Medicines Agency (EMA) and the European Patients’ Forum (EPF); 6 companies representatives; 6 AE staff members and a representative of the European Working Group of People with Dementia (EWPWP). There were 13 expert speakers on the packed agenda, and topics were defined based on a survey of participants at the 2015 Academy and AE members.

The first day began with a session on “The workings of the European institutions”, moderated by AE Policy Officer, Vanessa Challinor. This session included presentations by Aino Fant from the office of MEP Sirpa Pietikainen (Finland) and Camille Bullot from the EPF. Ms Fant described the roles of the European Commission, the European Parliament and the Council of Ministers in the legislative process of the European Union (EU), while Ms Bullot provided delegates with some ideas about how to influence the EU decision-making process, using her organisation as an example.

The second session of the day was on “Lobbying for change at national level” and was moderated by AE Director for Communications Alex Teligadas. This session included presentations by Tina Leonard from the Alzheimer Society of Ireland and George McNamara of the Alzheimer’s Society, UK. Ms Leonard spoke about using election campaigns to raise awareness about dementia and influence policy, using examples from her organisation’s #voteorremember campaign during the February 2016 elections in Ireland, to give delegates ideas about how they might set up similar campaigns in their own countries. Mr McNamara’s presentation on “Working with your allies in national parliaments” gave provided examples from his organisation’s experiences with the UK’s All Party Parliamentary Group on Dementia.

Day two of the Academy began with a session on “Understanding the clinical trial process”, moderated by Charles Scerri, General Secretary of the Malta Dementia Society and Vice-Chairperson of AE. This session included presentations by Joanna Robaczewska of EUPATI Poland and Florence Butlen from the European Medicines Agency (EMA). Ms Robaczewska gave participants some insights into the development process for new medicines, while Dr Butlen shared details of how the EMA assesses and approves new medicines. Both speakers helped give delegates a deeper understanding of the complex processes behind bringing new medicines and therapies to market.

The second morning session, moderated by AE Chairperson Iva Holmerová from the Czech Alzheimer’s Society, was devoted to the subject of “Researching new medicines for Alzheimer’s disease” and included presentations by Carla Abdelnour from Fundación ACE, Spain and Marc Stauf from Leibniz Universität Hannover, Germany, as well a second presentation by Dr Butlen. Dr Abdelnour spoke about assessments, examinations and scales used in clinical trials, while Dr Stauf gave participants some insight into the ethical approval process and some of the difficulties encountered in the recruitment of research participants. Dr Butlen enlightened delegates about the EMA’s guidance for the investigation of medicines for the treatment of dementia.

In the afternoon, a session on “Understanding research results” was moderated by AE Project Officer Ana Diaz. Presenters were James Howlett from the University of Cambridge, UK, Ebru Karakoc from Lundbeck, Denmark and Preciosa Coloma from Roche, Switzerland. Dr Howlett’s presentation aimed to give delegates an understanding of key statistical concepts in research and looked at different ways to present research results, while Dr Karakoc shared her knowledge on the subject of understanding AD trials results. Dr Coloma closed this session with her presentation “Research results in AD trials: what do they mean for patients and caregivers?” - in collaboration with the ROADMAP project, in which AE is a partner.

The final session of the Academy was moderated by AE Honorary Secretary James Pearson from Alzheimer Scotland. It was dedicated to “Pricing and reimbursement and health technology assessment of new AD medicines” and included presentations from Robin Thompson of Biogen, Switzerland and Sietse Sikkes of the VU University Medical Center in Amsterdam, Netherlands. Dr Thompson covered pricing, reimbursement and Health Technology Assessment (HTA) challenges, while Dr Sikkes closed the day with her presentation on “Value for money in AD treatment”.

The two-day Academy was a highly interactive event, with lots of time for questions after presentations and plenty of lively and thought-provoking discussion. Given the success of its first two Academies, AE plans to organise a third in December 2017.
6 December: Alzheimer Europe updates sponsors on its activities

At a meeting on 6 December in Brussels, Jean Georges, the AE Executive Director updated the organisation’s sponsors on its 2016 activities with a particular focus on those projects for which the organisation had received funding from its commercial sponsors (European Dementia Monitor, Alzheimer’s Association Academy and Clincal Trials Watch). It was also an opportunity to highlight Alzheimer Europe’s planned activities and sponsorship opportunities for 2017.

This was the third and last meeting in 2016 bringing together Alzheimer Europe and its sponsors to discuss issues of common interest. It was attended by representatives from Axovant Science, Biogen, GE Healthcare, Lilly, Nestlé, Otsuka Pharmaceuticals and SCA.

12-14 December: EWGPWD holds its first meeting with the new group

On 12-14 December 2016, the EWGPWD held its first meeting with the newly elected members of the group. The meeting was chaired by Helen Rochford-Brennan with the assistance of Vice Chairs Alv Orheim and Chris Roberts. During the meeting, the group took part in a consultation in the framework of the DEM-2, Joint Action on Dementia project. The focus of the discussion was on the definition of dementia-friendly communities, factors which contribute towards involvement in the community, and positive and negative experiences of being involved in community activities. One of the key issues raised by the EWGPWD was the relevance of education and training for people in the community and for people with dementia themselves (e.g. to know their rights and to speak up for themselves).

The group also provided feedback on research materials which will be used for two projects, namely the Acticare project and the Smart4MD project. Acticare is about finding out why people with dementia and carers do not use available services and support. Smart4MD involves developing a computerised platform for people with mild dementia, their carers and healthcare professionals. This was followed by a discussion about the definition of palliative care in the context of the PACE project, which aims to compare the effectiveness of palliative care training in care homes for people with and without dementia at the end of life. The group felt that it was important to emphasise that palliative care is not just about the end of life and was keen contribute towards the PACE user-led forum which Alzheimer Europe will be organising in October during the annual conference in Berlin.

Members of the EWGPWD were very enthusiastic about the projects which Alzheimer Europe is either leading or involved in during the course of 2017, and several volunteered to take an active role in this upcoming work. The next meeting will be in March 2017.

20 December: Alzheimer Europe continues to comply with EMA’s strict eligibility criteria

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

On 20 December 2016, the European Medicines Agency (EMA) confirmed that Alzheimer Europe continues 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 EMA activities can be viewed here:


2 January: Alzheimer Europe welcomes two new colleagues

As of 2 January, Alzheimer Europe is pleased to welcome two new colleagues to its Luxembourg office:

Christophe Bintener, Project Officer

Christophe will contribute to the development and maintenance of a database for diagnosis and treatment guidelines in Europe and collaborate in the MOPEAD and ROADMAP projects.

He obtained a Master in Gerontology in 2016 at the University of Vechta. Between 2011 and 2016 he worked as a research assistant in different scientific projects focusing on psychological Gerontology.

He can be reached at christophe.bintener@alzheimer-europe.org

Cindy Birck, Project Officer

Cindy will collaborate in different research projects supported by Alzheimer Europe including EPAD and AMYPAD. She will also help in the dissemination of EU funded research projects. In addition, Cindy will develop and update the Alzheimer Europe database on clinical trials in Europe.

After completing a master’s degree in cellular and molecular biology in France, Cindy started her PhD at the University of Luxembourg. Her thesis was focused on the major cell of the central nervous system called “astrocyte”.

On 28 November 2016, Cindy was successfully awarded the title of Doctor in Biology for her PhD thesis entitled “Astrocyte phenotype during differentiation: implication of the NFkB pathway”.

She can be reached at cindy.birck@alzheimer-europe.org
EU projects

1-2 December: AETIONOMY project holds steering committee meeting and General Assembly

The AETIONOMY project aims to generate disease-specific, mechanism-based taxonomies for Parkinson’s (PD) and Alzheimer’s diseases (AD), which will hopefully lead to better treatments. A project Steering Committee meeting took place in Paris on 1 December 2016 and the meeting was followed by the annual General Assembly (GA) on 1 and 2 December.

In addition to progress updates and inter-work package meetings, there was an excellent key note lecture on 2 December, delivered by Prof. Jose Obeso from the University of Pamplona, Spain on “What makes humans uniquely vulnerable to neurodegeneration? Insights from Parkinson’s disease”.

Alzheimer Europe was represented at the AETIONOMY meetings by Executive Director, Jean Georges and Director for Projects, Dianne Gove.

7 December: MinD symposium takes place in London

10 months into the project, the MinD consortium convened its first annual symposium at Europe House, London. The symposium, which was open to the public, had the purpose of bringing together researchers, healthcare professionals and designers engaged in improving the lives of those living with dementia and to facilitate discussion about current approaches and developments.

The symposium began with the keynote lecture of Professor Cathy Treadaway, who reported on her research and experiences of working with people with dementia through the LAUGH project as well as previous research. Prof Treadaway highlighted the need for considering the human aspects of care through focus on sensory aspects, the need for connection and personalised approaches, showing examples of the work conducted. The discussion also highlighted the difficulty of qualitative or ‘soft’ evaluation measures: while these are appropriate for this kind of work, they are not always accepted in the medical world, nor by funders.

The keynote was followed by three short presentations about the MinD project by Dr Isabelle Tournier from Luxembourg University, Professor Vjera Holthoff from Alexianer St Hedwig Krankenhaus Berlin, and Professor Kristina Niedderer, Co-ordinator of the MinD project,

University of Wolverhampton. Dr Tournier introduced the concept of mindfulness with its two major schools of thought, and how it has been applied in the context of dementia care so far, as well as the idea of using it in the context of the MinD project. Prof Holthoff presented a summary of the data collection with people with dementia and their carers, conducted as part of the first phase of MinD and contextualised the work to show the importance of involving people with dementia in primary research on decision making/empowerment related to subjective wellbeing, and not only to making an Action Plan for Dementia Care or Advance Care Planning. The third presentation by Prof Niederer explained the possibilities of implementing mindfulness through design, including the analytical frameworks developed so far, which will be used to mine the data from Phase 1 for the design development.

The afternoon of the symposium was given over to discussion of a number of issues surrounding the state of dementia care, as well as the use, role and potential of design within dementia care.

The symposium concluded with a panel discussion around a further two themes concerned with the issue of “independence and social integration” and our perceptions of interaction with persons. The three panel speakers were Prof Katy Treadaway, Prof Vjera Holthoff, and Prof Tom Dening, Nottinghamshire Healthcare NHS Foundation Trust. The discussion highlighted various aspects such as deficit-oriented language and goal-orientated care and came back to the issue of qualitative evaluation measures, which will be pursued jointly by the MinD and the LAUGH team in the future.

http://designingfordementia.eu/

12 December: AETIONOMY project welcomes new partner from France

The AETIONOMY project is pleased to welcome a new project partner - Aix-Marseille Université (AMU) in France.

AETIONOMY is a five-year project that began in February 2014. It aims to identify subgroups of dementia and Parkinson’s disease - based on the underlying genetic or molecular causes of the variants - in order to allow tailored therapies. The project involves the collection of clinical data, imaging and genetic data, aiming to create a new way to combine all of these together to look for patterns, which could identify sub-groups of patients with similar causes of their disease.

www.aetionomy.eu

13 December: EPAD gets a mention in the Financial Times

On 13 December 2016, the Financial Times (FT) published a letter to the Editor, from a member of the Executive Committee of the European Prevention of Alzheimer’s dementia (EPAD) project. The letter, written by Dr Jose Luis Molinuevo, BarcelonaBeta Brain Research Center was titled “Early intervention is key to tackling Alzheimer’s”.

Newsletter: December 2016
Making reference to the FT editorial “The case for prioritising Alzheimer’s research” of 26 November 2016 - which talks of the growing consensus in the scientific community that the genesis of Alzheimer’s disease (AD) precedes the onset of dementia by over 20 years and the therefore urgent need to increase focus on research into an effective treatment - Dr Molinuevo highlights the importance of focusing on research into prevention also. Researchers are increasingly focusing their efforts on prevention and early intervention before symptoms appear, as a more effective way to tackle the disease, he points out.

The letter lists some examples of prevention research programmes in Europe, research initiatives funded by governments in the US and Europe, public private partnerships, international clinical trials aimed at preventing Alzheimer’s dementia, as well as the creation of registries linked to these trials. Aside from the US registries, Dr Molinuevo talks describes the EPAD project and its goal of creating a Europe-wide register of 24,000 people.

https://www.ft.com/content/b319996e-c09b-11e6-9bca-269a6856354

14-15 December: MOPEAD project will identify and test models of efficient earlier identification of people with mild AD dementia

On 14 and 15 December 2016, the kick-off meeting for MOPEAD (Models of Patient Engagement for Alzheimer’s Disease) was hosted by project co-lead Fundació ACE in Barcelona, Spain.

The MOPEAD project, funded by the Innovative Medicines Initiative (IMI), aims to identify and test models of efficient earlier identification of people with mild Alzheimer’s dementia and prodromal Alzheimer’s disease (AD). The project also hopes to raise awareness of AD, memory complaints and cognitive decline risks.

There are four main proposals on how to go about this:

- An online service
- An “open house” to get a diagnosis
- Through GPs
- Through diabetologists (specialists in diabetes).

The aim is not to find the best solution as such, but rather to evaluate each and identify good practices, which may vary from country to country. The hope is to get a good idea of what works best in each country and to promote the sharing of experience by involving partners from Slovenia, Sweden, the Netherlands, Germany and Spain.

The kick-off meeting, attended by a total of 39 representatives from 14 project partners, including Alzheimer Europe Executive Director Jean Georges and Communications Officer Kate Boor Ellis, was an excellent opportunity to gain a deeper understanding of the project’s five distinct Work Packages (WPs), each of which was presented in detail. This was an excellent platform for discussions about some of the practicalities going forward.

Alzheimer Europe (AE) will be involved in the project’s dissemination activities and ethics discussions. On the evening of 14 December, Jean and Kate also attended a WPS Dissemination meeting of the MOPEAD project.

To keep up to date with the MOPEAD project, please follow @MopeadEU on Twitter, or visit http://www.mopead.eu/.

1 January: PACE article published in the International Journal of Nursing Studies

An article by PACE project researchers has been published in the January 2017 edition of the International Journal of Nursing Studies.

The article, “Preconditions for successful advance care planning in nursing homes: A systematic review” provides an important contribution to the evidence base regarding preconditions for optimal implementation of advance care planning in nursing homes.

The findings support efforts to improve advance care planning by giving particular attention to health-care professionals and the facility, and highlight that a whole-system approach must be followed.

By specifying these preconditions, PACE expects to be able to make well-founded choices from different components for the advance care planning intervention that is to be developed in the subsequent steps of the project.

https://dx.doi.org/10.1016/j.ijnurstu.2016.12.003

Alzheimer Europe networking 2016

On 1 and 2 December (Paris, France), Jean and Dianne attended the Steering Committee and General Assembly of the AETIONOMY project.

On 5 and 6 December (Brussels, Belgium), the Alzheimer Europe Board met.

On 6 December (Brussels, Belgium), Alzheimer Europe organised a lunch debate entitled “Benchmarking national responses to the dementia challenge” in the European Parliament.

On 6 December (Brussels, Belgium), Alzheimer Europe organised a company round table meeting with the organisation’s corporate sponsors.

On 6 December (Stockholm, Sweden) Dianne participated in the dissemination and validation workshop - Community care for people with dementia organised by the Swedish Ministry of Health and Social Affairs.
On 6 and 7 December (Brussels, Belgium), Alzheimer Europe organised its second Alzheimer’s Association Academy.

On 8 December, Dianne took part in a telephone conference for the work package on ethics of the ROADMAP project.

From 12 to 14 December (Brussels, Belgium), Dianne and Ana attended the EWGPWD meeting.

From 9 to 11 December (San Diego, US), Jean attended the Clinical Trials on Alzheimer’s Disease (CTAD) conference.

On 9 December (San Diego, US), Jean met with representatives of AbbVie and Biogen to discuss the companies’ research programmes and opportunities for collaboration in 2017.

On 10 December (San Diego, US), Jean met with representatives of Axovant and Eisai to discuss the companies’ research programmes and opportunities for collaboration in 2017.

On 12 and 13 December (Brussels, Belgium), Vanessa attended the Regional Consultation on the European Response to Chronic Diseases – the Role of Civil Society.

On 13 December (Munich, Germany), Jean attended a meeting with GE Healthcare to discuss the dissemination activities of the AMYPAD project.

On 14 and 15 December (Barcelona, Spain), Jean and Kate attended the launch meeting of the MOPEAD project.

On 4 January 2017 (Luxembourg, Luxembourg), Jean met with members of Alzheimer Europe member Alzheimer Uniti.

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**Members of the European Alzheimer’s Alliance**

*Currently, the total number of MEPs in the Alliance stands at 128, 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); Karin Kadenbach (S&D); Barbara Koppel (NI); Paul Rübig (EPP); **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brentem (ALDE).

**Bulgaria:** Andrey Kovatchev (EPP); **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomasić (ECR); **Cyprus:** Costas Mavrides (S&D); Eleni Theocarous (EPP); **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP).

**Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D); **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kylönen (GUE/NGL); Sirpa Pietikäinen (EPP); **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Charter (EPP); Gilles Pargneaux (S&D); **Germany:** Angelika Niebler (EPP); Udo Voigt (Ni); **Greece:** Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Speraki (EPP); Eleftherios Synadinos (Ni); Elissavet Vozomiarov-Vromionidi (EPP).

**Hungary:** Ádám Kósa (EPP); **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deidre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); **Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Stefano Mauelli (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Serragiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D); **Lithuania:** Vilija Blinkevičiute (S&D); **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP); **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP); **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP); **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybackska (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP); **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP); **Romania:** Cristian Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP); **Slovakia:** Miroslav Mikolásik (EPP); Ivan Stefanec (EPP); Anna Žabárska (EPP); Jana Žitnanska (ECR); **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricia Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP); **Spain:** Izaikun Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ernest Maragall (Greens/EFA); Pablo Zába Bidegain (EPP); **Sweden:** Åska Ruteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE); **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).
European Alzheimer’s Alliance
6 December: Members of the European Alzheimer’s Alliance participate in AE Lunch Debate

Alzheimer Europe (AE) would like to thank MEP Nessa Childers (Ireland) for hosting its Lunch Debate on “Comparing and benchmarking national responses to the dementia challenge” at the European Parliament in Brussels on 6 December. AE would also like to thank MEPs Heinz K. Becker (Austria), Deirdre Clune (Ireland), Sofia Ribeiro (Portugal), and Olga Sehnalová (Czech Republic) for their active and positive participation, as well as MEPs Karin Kadenbach (Austria), Stefano Maullu and Patrizia Toia (Italy) and Jana Žitňanská (Slovakia), who were represented at the meeting.

All nine MEPs present or represented are current members of the European Alzheimer’s Alliance (EAA) – a non-exclusive, multinational and cross-party group of MEPs supporting AE and its members in making dementia a public health priority.

The EAA currently has 128 Members from 27 Member States of the European Union and all seven political groups in the European Parliament.

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

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EU developments
28 November: European Commission convenes meeting of governmental experts on dementia

On 28 November, DG SANTE of the European Commission brought together governmental experts on dementia from a number of EU countries in Bratislava. The meeting, which was chaired by Herta Adam, Deputy Head of Unit “Health Programme and Chronic Diseases”, discussed the Council Conclusions on dementia adopted under the EU Presidency of Luxembourg which had highlighted a number of priority areas which should be discussed by the expert group, such as:

1. Exchanging information on national plans/strategies and programmes on dementia,
2. Promoting the rights of people living with dementia,
3. Improving the quality of information on dementia, including epidemiological information,
4. Exchanging best practices on:
   - Prevention, risk reduction and health promotion,
   - Dementia-friendly communities
   - Research
   - Early detection, timely diagnosis and post-diagnostic support
   - Quality of care
   - Support for carers
   - E-health and assistive technologies
   - Education of health professionals.

The experts discussed how best to follow up on these ambitious conclusions and which other stakeholders to involve in these activities. A tour de table of the different experts was also organised in which the national representatives presented their latest activities related to dementia.

The meeting was also an opportunity for Gillian Barclay from the Scottish Government to inform the group on the state of play of the second Joint Action on Dementia and for representatives of the OECD (Elina Suzuki) and WHO (Shekhar Saxena) to provide an update on the work of their respective organisations in the dementia field.

Jean Georges represented Alzheimer Europe in this meeting and Alzheimer Europe will be able to participate in future meetings of the group in an observer capacity.

29 November: Slovak Presidency of the European Union organises conference on Alzheimer’s disease

A conference “Alzheimer’s disease – epidemic of the third millennium: Are we ready to face it” was organised by the Slovak EU Presidency in Bratislava on 29 November. The conference brought together over 100 experts from different EU Member States and was an opportunity to highlight policy and research initiatives at global, European and national level.

The meeting was formally opened by Miroslav Mikolášik, a Slovak Member of the European Parliament who sits on the Committee on the Environment, Public Health and Food Safety and is also a Member of the European Alzheimer’s Alliance coordinated by Alzheimer Europe.

The programme was centred around four key themes which were discussed by four panels. The first panel was entitled “Dementia as a global health priority and scientific challenge” with presentations from Herta Adam, from the European Commission Unit “Health programme and chronic diseases” on “Dementia from a public health perspective at European level”, Prof. Bengt Winblad from the Karolinska Institute, Sweden on “What can the EU do for Alzheimer’s research” and Shekhar Saxena from the
World Health Organisation on "Dementia as a global public health priority".

The second panel looked at "Prevention and Intervention strategies in Alzheimer’s disease" with presentations from Simona Adamovičová from the Memory Centre, Slovakia on "Alzheimer’s disease prevention strategies", Serge Van Der Geyten from Janssen, Belgium on the "European Prevention of Alzheimer’s Dementia (EPAD)" project and Petr Novák from the Institute of Neuroimmunology, Slovakia on "Pharmacological and non-pharmacological strategies".

A third panel was dedicated to "National programmes and Action plans on dementia" with Jean Georges presenting Alzheimer Europe’s expectations for a "A pan-European dementia action plan", Michal Novák from the Slovak Academy of Sciences outlining Slovakia’s draft "National plan to conquer Alzheimer’s disease and other forms of dementia" and Justyne Caruana, Malta’s Parliamentary Secretary for Rights of Persons with Disability and Active Ageing and Charles Scerri, Focal Point for Dementia from Malta highlighting their country’s vision for dementia and Malta’s plans for the upcoming EU Presidency in 2017.

The final panel was entitled "Alzheimer’s disease trip through the EU Presidency" in which Gillian Barclay from the Scottish Government presented the EU Joint Action on Dementia, Martin van Rijn, State Secretary for Health, Welfare and Sports from the Netherlands highlighted the actions of its country when it had the rotating EU Presidency in the first half of 2016 and the country’s campaign to make the Netherlands more dementia friendly and Petra Brandoburová from the Memory Centre, Slovakia showed the results of a campaign to destigmatise Alzheimer’s disease.

29 November: Commission and EDF co-host conference for European Day of Persons with Disabilities

This year’s European Day of Persons with Disabilities, which marks the 10th anniversary of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), was the focus of a two-day conference, jointly organised by the European Commission and European Disability Forum (EDF).

The conference discussed and examined the progress that has been made in the European Union (EU) to promote the rights of persons with disabilities in line with the CRPD.

EDF also launched its first issue of a series of European Human Rights Reports. This first issue focuses on the 10th anniversary of the CRPD, giving an overview of the state of play and progress made with regards to the CRPD in Europe.

During the conference, the Commissioner for Employment, Social Affairs, Skills and Labour Mobility, Marianne Thyssen and EDF President Yannis Vardakastanis (pictured) announced the winners of the Access City Awards. This is a Europe-wide award, recognising cities for their efforts in becoming accessible to all. The winner of the 2016 Access City Award is Chester, UK.

A full report of the conference can be read here.

29 November: European Commission rewards British city Chester for enhancing accessibility in its city life

On 29 November 2016, the European Commission announced the British city of Chester as the winner of the Access City Award. Chester was chosen out of 43 cities from 21 EU countries, because of its inclusive measures for people with a disability in different sectors, in particular the tourism sector.

The award was granted in the framework of the International Day of Persons with Disabilities on 3 December and took place simultaneously with the yearly Conference European Day of Persons with Disabilities on 29 November. Rotterdam (NL), Jūrmala (LV), Lugo (ES), Skellefteå (SE), Alessandria (IT) and Funchal (PT) were also awarded for improving accessibility for the elderly and disabled citizens.

http://ec.europa.eu/social/main.jsp?langId=en&catId=1141&newsId=2682&furtherNews=yes

1 December: H2020 budget increase secured for 2017

On 1 December 2016, it was announced that the EU Council and Parliament have formally adopted the Union’s budget for 2017.

The 2017 budget includes an increase of EUR 50 million for the Horizon 2020 (H2020) research budget, bringing the total for 2017 to EUR 10.35 billion. Excellent news for EU-based research.

To see the detailed EU budget for 2017 please click here.

5-8 December: 2nd European Summit on Innovation for Active and Healthy Ageing held in Brussels

From 5 to 8 December 2016, the 2nd European Summit on Innovation for Active and Healthy Ageing was held in Brussels, looking at how digital innovation will "Transform the future of health and care in Europe" and how the Digital Single Market can turn demographic change into an opportunity for social development and economic growth in Europe.
The 2016 Summit built on the achievements of the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA), the Active and Assisted Living Joint Programme with Member States (AAL JP) and the EIT-KIC on Health and Active Ageing.

The Summit was organised by the European Commission together with the European Parliament (MEP K.H. Becker) and the European Committee of the Regions.

8 December: ENVI committee discusses amendments to draft report on EU options for improving access to medicines

On 8 December, the European Parliament’s Committee on Environment, Public Health and Food Safety (ENVI) held an exchange of views on amendments to the draft report regarding EU options for improving access to medicines.

The prices of new medicines have increased during the past few decades to the point of being unaffordable for many EU citizens, creating an unsustainable situation for health care systems.

In her draft opinion, rapporteur MEP Cabezón Ruiz Soledad (Spain) calls on the European Commission and the Council of Europe to explore new measures to control prices, and stresses the need for more transparency regarding the costs of development and clinical trials, which would lead to a fairer price.

The full report can be read here.

9 December: Draft Report on European Pillar of Social Rights adopted

The Draft Report on A European Pillar of Social Rights, with its 1,119 amendments, has been adopted by MEPs with 34 votes for, 14 against and 4 abstentions.

The rapporteur is MEP Maria João Rodrigues (Portugal).

The main goal of the “own-initiative” (INI) report will be to focus on the initiative launched by the Commission in relation to a European Pillar of social rights with a view to explore the EU social model and to adapt it best to the 21st century.


12-13 December: NCD Alliance and ECDA host meeting on role of civil society in response to chronic diseases

The meeting “The European Response to Chronic Diseases - the Role of Civil Society” was held on 12 and 13 December in Brussels, organised by the NCD Alliance and the European Chronic Disease Alliance (ECDA) and cosponsored by the WHO Regional Office for Europe.

The meeting had a mix of participants, strong content, good networking and animated discussions. With input and participation of all meeting participants the meeting concluded with an agreed-upon set of meeting recommendations, which will provide a good roadmap for the work ahead.

Some of the recommendations agreed upon were that noncommunicable disease civil society organisations (NCD CSOs) in the World Health Organisation (WHO) European Region should:

- Play an active role in the supporting the implementation of the WHO regional action plan for NCDs.
- Monitor progress to better NCD outcomes.
- Accelerate NCD prevention and control through awareness, advocacy access and accountability.
- Build public demand and political will for NCD policies and programmers.
- Hold Governments to account on national progress on NCD prevention and control.

A major outcome of the meeting will be a report, including: an outline of key priorities for joint action for the NCD CSO movement in the WHO European region, under the framework of the 2016-2025 WHO European action plan for the prevention and control of NCDs; key areas for collaboration between CSOs and the WHO Regional Office for Europe, the NCD Alliance and the ECDA; and key recommendations for strengthening the CSO movement in the region.

http://www.alliancechronicdiseases.org/home/

14 December: The Commission is running an online consultation on IMI

The European Commission is currently running an online consultation aiming to collect the views of the public about the implementation of IMI and the other Joint Undertakings (JUs) under Horizon 2020 for the period 2014 to 2016.

The outcome of this public consultation will provide input to the interim evaluation of the JUs, which is currently ongoing and covers the same period. The results of the interim evaluation will be used as a basis to improve the performance of the JUs and will be communicated to the European Parliament and the Council, national authorities, the research community and other stakeholders.

The deadline for responding to the consultation is 11 March 2017:
https://ec.europa.eu/survey/survey/JUsinterimevaluation

16 December: Commission releases Big Data Study outlining policy recommendations in 10 areas

A Study on Big Data in Public Health, Telemedicine and Healthcare, financed by the Commission’s Health Programme, was published on 16 December.

The study identifies examples of the use of Big Data in the area of Health, and puts forward recommendations covering 10 areas: awareness raising, education and training, data sources, open data and data sharing, applications and purposes, data analysis, governance of
In the context of this study, “big data in health” refers to large routinely or automatically collected datasets, which are electronically captured and stored. Using Big Data in health has many potential benefits. It may contribute to, for example, increasing the effectiveness and quality of treatments available for patients, widening possibilities for disease prevention by identifying risk factors at population, subpopulation, and individual levels, improving pharmacovigilance and patient safety, and reducing inefficiency and waste.

The study’s 10 recommendations are aimed at maximising opportunities Big Data can bring to public health in the EU - to improve the health of individuals as well as the performance of Member States’ national health systems. All recommendations are underpinned by principles such as the need to uphold ethical standards and the privacy or safety of citizens, and to include stakeholders such as patient advocacy groups, when implementing them.


16 December: Switzerland steps up research and innovation cooperation with the EU

On 16 December 2016, the Swiss Federal Council ratified the Protocol on the extension to Croatia of the Free Movement of Persons Agreement between the EU and Switzerland. This ratification was a condition for Swiss association to all areas of Horizon 2020, the European Union’s research and innovation funding programme. This means that as of 1 January 2017, Switzerland is fully associated to Horizon 2020 and Swiss researchers and organisations will therefore be able to fully participate, on equal terms with entities from EU Member States and other associated countries. Until now, Switzerland has only been associated to parts of the programme.

Commissioner for Research, Science and Innovation Carlos Moedas said: "Switzerland has now fulfilled the EU’s condition on free movement of people and can be fully associated to Horizon 2020. This is good news for Switzerland, and good news for the EU. It will further strengthen our scientific communities and our very substantial cooperation in research and innovation."


Members’ news

11 November: Association Luxembourg Alzheimer releases Memory Walk video

The  Association Luxembourg Alzheimer (ALA) has released a short video about its 2016 Memory Walk. The video, in Luxembourgish language, was made available on YouTube on 11 November 2016, and features commentaries from ALA Director Lydie Diederich and the Minister for Family and Integration Corinne Cahen.

https://www.youtube.com/watch?v=tBBZ-v0OXY

23 November: “Living with Dementia” project concludes in Slovenia

On 23 November in Celje, Slovenia, the conclusions of the project “Living with dementia” were held at a round table meeting. The guests were members of the project, representatives of the Ministry of Social Affairs, the Ministry of Health and Alzheimer Slovenia (Spominčica).

The general project objective was the improvement of services for people living with dementia and their relatives. The project wants to get as close to the needs of persons with dementia and their relatives as possible, by adjusting existing services and developing new ones; at the same time, it introduces a pilot multidisciplinary treatment by establishing a centre for dementia support.

The project was implemented in partnership with NGOs and public organisations from Slovenia, as well as one Norwegian partner:

- Institute for Research, Education and Sustainable Development Celje, Slovenia.
- University Medical Centre Ljubljana, Department of Neurology, Slovenia.
- Association for help with Dementia – Spominčica Šentjur, Slovenia.
- Social Work Centre Celje, Slovenia.
- Elderly home Savinja Celje, Slovenia.
- Stavanger University Hospital, Norway.

The project started in February 2015 and was scheduled to run until the end of December 2016, with financial support from the Norwegian Financial Mechanisms 2009-2014 and the programme operator in Slovenia, the Government Office for Development and European Cohesion Policy.

30 November: UK Alzheimer’s Society announces winners of its Dementia Friendly Awards 2016

People across the UK have been recognised for their remarkable efforts to make life better for people with dementia, at the Alzheimer’s Society’s 2016 Dementia Friendly Awards on 30 November 2016.

The awards celebrate organisations, communities and individuals making outstanding contributions towards improving the lives and experiences of people with dementia.

This year there were nine award categories, including four brand new awards with various sponsors across the different awards. The ceremony took place in...
Westminster, London and was hosted by Alzheimer's Society ambassador Angela Rippon.

Winners include Gatwick Airport for their work as a dementia-friendly airport and the East of England Co-Op, who won Dementia Friendly Organisation of the Year. 

http://ow.ly/6gaT306KEgC

5 December: Spominčica organises theatre performance about dementia: "Where was I?"

On 5 December 2016, Alzheimer Slovenia (Spominčica) organised a theatre performance about dementia called "Where was I?" in the Dance Theatre in Ljubljana. Close partners, stakeholders, sponsors and members of Spominčica were invited.

The performance interpreters developed the theme of dementia through two perspectives: personal and social. On one hand, the story is about an older lady, who is slowly losing her memory and is less aware of the environment she lives in. The world around her, which she knew for many years, is suddenly falling apart and every single day becomes a new vision of reality. On the other hand, it is a story about her caring son, standing beside her and helping her to cope with the problems she is facing each day.

The audience’s understanding of the world of the mother with dementia is supported through an interactive video scene, which shows a constant dialogue with her. The video scenes draw her new image of the world, revealing her memories and her feelings about the present.

The play is based on actual events and personal experience with family members with dementia. The performance can be also placed in a wider social context, because the number of people diagnosed with dementia in Slovenia is growing rapidly. The story embraces a wide variety of emotions, experienced daily by the person with dementia, as well as demonstrating ways to become more understanding as a caregiver.

The more-than-100-strong audience gave good feedback about the subject of the play.

The whole performance, given by a group of young artists with personal experiences with dementia, was touching and highlighted issues that people with dementia and their carers face every day. It has already toured Slovenia and has also been performed in Croatia. It will continue to tour in 2017, following its success so far.

The play will also be part of Spominčica’s programme at the upcoming Slovenian International Conference on Dementia, on 20-21 October 2017.

11 December: Jersey Alzheimer’a Association holds its first ever dementia-friendly Christmas carol service

The Jersey Alzheimer’s Association held its first ever dementia friendly Christmas carol service on 11 December 2016 at the St Helier Parish Church. The service, which took the form of a traditional service but was kept shorter, was followed by tea and mince pies in the Church Hall. It included well-known carols and readings and a “Musical Memories” slot, including old favourites such as Ding Dong Merrily on High. The Association hopes to repeat the service in 2017.

14 December: Alzheimer Society of Ireland wins Better Together award

The Alzheimer Society of Ireland (ASI) has won an award for its campaign video, featuring Kathy Ryan, a Vice-Chair of the Irish Dementia Working Group (IDWG), and her sons Matt and Andrew.

The video went viral, being viewed by over one million people.

Better Together is an annual campaign that aims to build support for community and voluntary organisations, clubs and associations across Ireland by encouraging the public to support good causes and make a difference in their communities.

The full list of 2016 winners can be seen here: http://www.bettertogether.ie/blog/hot-pieces-2016-better-together-winners-announced

16 December: Denmark has a dementia-friendly church

On 16 December, Danish Dementia Friends programme “Demensven” reported that the staff at Vesterkær Church in Aalborg, Denmark have all become Dementia Friends, so that the Church can offer as safe, secure and inclusive an environment for visitors with dementia as possible.

The Danish Alzheimer society, Alzheimerforeningen is encouraging people in Denmark to think of places where it might be beneficial for staff to become Dementia Friends, and to suggest them via www.demensven.dk/partnerskab

31 December: Alzheimer Uniti reports on its participation in a creative initiative in a train station in Rome

The year 2016 was declared a Jubilee Year and indeed there were many special events and celebrative activities. As the year closed, Alzheimer Uniti took part in a unique and artistic initiative: the creation of four paths of giant tiles on the floor of the Tiburtina train station in Rome. The four paths symbolised four thematic routes: the young, the sick and elderly, the
migrants and loneliness; tiles on each path represented volunteer associations and foundations. One hundred associations provided symbolic pictures with equally significant words, representing the theme of their mission.

The title of the initiative was “Non passarci sopra” (“Don’t tread on us”, figuratively “Don’t ignore us”), alluding to our busy lives, which prevent us from thinking about the hardship and suffering. Alzheimer Uniti also participated with its tile, thus giving support, significance and value to people with dementia and to their identity, for creating a friendly community.

Spotlight on: The Alzheimer Society of Finland (Muistiliitto)

The Alzheimer Society of Finland is a non-governmental organisation (NGO) aiming to raise awareness of all forms of memory diseases and dementia. It was formed in 1988.

We have in our network:

- 44 member associations
- around 270 employees
- around 1000 voluntary workers
- around 13 500 persons as members

In the central office, located in Helsinki but also in central and northern Finland:

- 13 persons are working in the central office.
- This year we are going to recruit four more: one development manager, one legal expert and two other experts of our field.

Our Board:
The Board consists of 1 chair and 8 members, including one person from the Working Group of Memory Activists made up of people with memory disorders and their informal carers. Three persons of our board are the members of Finnish Parliament from parties of right, centre and left.

We are funded mainly by Finland’s Slot Machine Association, called RAY.

We are not good at collecting money and donations, but we have succeeded in making grant applications to RAY. Our Memory network - the central office and member associations - are granted EUR 7 to 8 million by RAY, annually.

We coordinate the network of regional expert and support centres in order to ensure that centres follow common criteria, which include a commitment to network, customer orientation and evaluation of the work done. So far, a nation-wide network to strengthen voluntary work and cooperation regarding memory-related diseases has been created with it. As a result, services for people with memory disorders have improved. These centres ensure that people with memory-related diseases and their caregivers have the opportunity to influence and participate as full members in their own communities.

We publish our Memory magazine four times a year. We are also active on social media (Facebook, Twitter and Instagram)

We give statements, opinions and we publish news as well as making news.

We work closely with the Memory Club in the Finnish Parliament and participate in the working groups of the Ministry, like the key project of government which is focusing now on Home care and informal care. (Home care for older people will be developed and informal care enhanced in all age groups.)

In October 2016 the ministry for Social Affairs and Health granted EUR 14,8 million based on applications for eight projects on home care and informal care. Out of the eight granted, six involve our member associations.

We coordinate telephone and online help, guidance and support.

We have been developing and are piloting criteria of good care and support new guidelines to be published in Finnish.

Guidelines for the diagnosis and medical treatment of Memory diseases are updated every three years. The new guidelines will be published at the end of 2016. Creating positive attitudes, memory-friendly counties and cities, etc. is important work.

We are also a source of information:

Last year we did two studies, surveys: one was the Memory barometer 2015 and the other was survey of our member associations.

We publish our Memory magazine, and monthly newsletter in two languages - Finnish and Swedish.

We are also active in many projects of our own as well as several joint projects.

In 2012, we set up the Finnish Memory Activists, the Working Group of People with Memory Disorders and their informal carers. The group has been very active and productive.

Our annual Memory Conference was organised in November. Last year there were nearly 300 participants, including people with memory diseases and their carers, representatives of our member associations, healthcare professionals, academics and researchers, as well as policy makers.

These were just some aspects of our situation in Finland and at Muistiliitto. We have a lot of work to do in lobbying and advocacy in Finland.
**Policy watch**

**21 November: Bosnia continues to make progress on its National Dementia Strategy**

On 21 November, Association AiR reported further progress on the upcoming Bosnia and Herzegovina (B&H) National Dementia Strategy, in the form of a letter addressed to the association, from the Health Minister, in which he:

- Accepts that Association AiR should lead on the writing of the Strategy.
- Nominates two representatives from the Health Ministry to join the working group set up in October 2016.
- Fully supports the creation of a National Dementia Strategy.
- Accepts that the number of people affected by dementia in B&H is 105,000 (based on research in B&H by Association AiR’s centre for dementia)

http://demencija.org/o-nama/

**30 November: Luxembourg has a new National Dementia Centre**

On 30 November, the doors of Luxembourg’s new National Dementia Centre were officially opened, at 14a rue des Bains in the capital city of Luxembourg.

The centre is open to anyone seeking information about dementia and about supporting a person living with dementia in Luxembourg.

The hotline number is +352 26 47 00 and the centre can be found online too:
http://www.liewematdemenz.lu/online/www/content/homepage/FRE/index.html

**1 December: The Welsh Government is planning a new Dementia Strategy**

The Welsh Government is currently planning a new Dementia Strategy for Wales.

Members of the public have the opportunity to have their say on the things they feel are important about living with dementia and what they would like to see in this upcoming Strategy. The Alzheimer’s Society in Wales and the Dementia Engagement & Empowerment project (DEEP) are working together to include as many people as possible in this process, to ensure the best possible results for people living with dementia in Wales.

Five consultation events have already taken place, throughout November and December 2016.

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**Newsletter: December 2016**

A further five consultations events are planned:

- 12 January: 12:00 - 15:00 Bangor University.
- 18 January: 14:00 - 16:30 Metropole Hotel, Llandrindod Well.
- 19 January: 14:00 - 16:30 Plas Dolerw, Newton.
- 25 January: 11:00 - 14:00 Muni Arts Centre, Pontypridd.
- 8 February: 11:00 - 14:00 The Gate, St Clears, Carmarthenshire.

Places can be booked via Eventbrite

**6 December: The Swedish government moves one step closer to a Swedish National Dementia Strategy**

On 6 December 2017, The Swedish Ministry of Health and Social Affairs and the National Board of Health and Welfare held an international workshop in Stockholm. This provided an opportunity for the European Centre for Social Welfare Policy and Research (ECSWPR) to present the report on community care for dementia which had been commission by the Swedish Ministry. Dianne attended this workshop and had also been involved in the previous workshop organised by the ECSWPR which was responsible for the community care report. It was a very productive meeting with plenty of discussion between representatives from the Swedish government, the ECSWPR and the invited experts. The Swedish government described how it had involved numerous experts and relevant stakeholders in developing the Strategy, which was also briefly outlined, and declared that it hoped to launch the Swedish National Dementia Strategy mid-2017.

**8 December: UK regulator is first worldwide to set out guidelines on air travel for people with hidden disabilities**

New guidelines from the UK’s Civil Aviation Authority (CAA) on making air travel easier for people with hidden disabilities were published on 8 December, setting a new global benchmark in access to air travel.

The CAA is the first ever regulator worldwide to set out guidelines for operators, airports and airlines on how to meet the needs of passengers with hidden disabilities, which include, but are not limited to, dementia, autism, learning disabilities, anxiety issues, mental health impairments and hearing loss.

The ground-breaking document covers several key requirements set forth in the legal framework protecting the rights of disabled people traveling by air.

The CAA expects airports to ensure all customer-facing employees, including security staff, receive hidden disability awareness training. The regulator also asks airports to make information about the airport facilities and services available in a suitable and accessible format. Airports should also offer passengers with hidden disabilities the option to wear lanyards or wristbands to...
ensure staffs can identify and meet their needs without having to ask questions, the guidelines state.

Read or download the full document here: http://publicapps.caa.co.uk/docs/33/CAP%201411%20DEC16.pdf

14 December: Director announced to lead landmark UK Dementia Research Institute

On 14 December, the Director of the UK Dementia Research Institute (UK DRI) was named as Professor Bart De Strooper from the University of Leuven in Belgium.

Prof. De Strooper will lead the national Institute’s ‘Hub’ at University College London (UCL), recognised for its world-class dementia research and state-of-the-art facilities, which will closely link to a number of yet-to-be-announced centres across the UK.

A quarter of a billion GBP has been pledged towards the UK’s first ever DRI. In partnership with the Medical Research Council (MRC), the Alzheimer’s Society and Alzheimer’s Research UK, the pledge marks one of the single biggest financial commitments to dementia research in the history of both charities.

22 December: Two major reforms in Finland will impact NGOs there

There have been two reforms in Finland recently, which the Alzheimer Society of Finland (Muistiliitto) says will have a big impact on Finnish NGOs such as themselves.

The first reform involves one of the main sources of funding for Muistiliitto and many other NGOs: RAY - Finland’s Slot Machine Association. RAY grant funding is collected from slot machines and casino gaming operations and channeled into health and social welfare organisations. Funding is granted annually, based on applications.

Now in Finland the three Finnish gambling operators - RAY, the Finnish lottery for Finns (Veikkaus Oy) and Fintoto - will merge. The Government has set a goal that this new gambling entity will begin its operations at the start of 2017.

Muistiliitto is concerned about what kind of changes this merger will bring. It has been said that the revenue/earnings of the gambling operators will continue to be used for non-profit purposes and the merger does not affect the status of the beneficiaries. However, on 16 December RAY published a proposal, yet to be ratified by the Ministry in January, that Muistiliitto would be granted nearly EUR 1.8 million for 2017 and altogether Muistiliitto and its member associations nearly EUR 10 million. The sum is greater than in previous years.

The aim of the Government is to maintain the Finnish gambling system, which is based on the monopoly of national operators. The merger of the gambling operators will strengthen this monopoly, to help protect the country’s unique system against international gambling business, which collects profits rather than using them for non-profit purposes.

The second reform, which Muistiliitto finds more worrying involves a big reform package. The healthcare, social welfare and regional government reform package is one of the biggest ever administrative and operational overhauls in Finland. The reform impacts the jobs of hundreds of thousands of people and affects the services of every citizen in the country. It also has an effect on financial resources, steering and taxation of healthcare and social welfare services. The aim is to transfer the organisation of health care and social services and other regional services to autonomous regions as of 1 January 2019.

Social welfare and healthcare reform means that responsibility for providing public healthcare and social services will be assigned to autonomous regions that are larger than municipalities. Healthcare and social services will be brought together at all levels to form customer-oriented entities, and basic public services will be strengthened. Customers will have more freedom of choice in the services.

The objective is to reduce inequities in wellbeing and health between people, and to manage costs.

The target is that the reform will help to bridge a large part of the sustainability gap in general government finances.

The Government’s aim is to save EUR 10 billion, of which approximately EUR 3 billion should be covered through the reforms in the branch of government of the Ministry of Social Affairs and Health.

Besides structural reforms, the steering and operating models in healthcare and social welfare will be thoroughly modernised.

The aim is to achieve better services that are not only more customer-oriented, effective and cost-efficient than before but also better coordinated.

Public administration in Finland will be organised on three levels as follows: central government, autonomous regions and local government.

The existing division into regions will be used as a basis for dividing the country into autonomous regions. Responsibility for the organization of healthcare and social services will be transferred from joint municipal authorities and local authorities to the autonomous regions on 1 January 2019.

23 December: WHO revises Global Action Plan on the Public Health Response to Dementia


During the months of October and November 2016, Member States, UN agencies and non-State actors gave their feedback and a revised version was released on 23 December.

The plan emerged from the 139th session of the WHO Executive Board, which noted that "the response to the global burden of dementia can be greatly enhanced by a shared commitment among Member States and all other stakeholders to put in place necessary policies and
resources for care of people with dementia, to promote research, to find disease-modifying treatments or cure, and to give adequate priority to action against dementia in national and global political agendas.” The Executive Board decisions requested the WHO Director-General to develop a plan, with the full participation of Member States and in cooperation with other relevant stakeholders and laying out clear goals and targets.

The Zero Draft included the proposed vision, strategic action areas and a set of recommended actions. It was used as the basis for informal consultations with Member States, UN agencies and other non-State actors such as relevant private sector entities, philanthropic foundations, academic institutions and nongovernmental organisations, including Alzheimer Europe, which submitted a joint formal response together with Alzheimer’s Disease International, Dementia Alliance International (DAI) and the Global Alzheimer’s and Dementia Action Alliance (GADAA) on 31 October 2016.

A final version of the Plan will be considered by the 70th World Health Assembly (WHA70), through the 140th session of the WHO Executive Board, in May 2017.

More information about the process can be found here: http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/

Science watch

2 November: Loneliness might be a predictor of preclinical Alzheimer’s disease

On 2 November 2016, results from a study investigating the link between self-reported loneliness and brain amyloid burden were published in the journal JAMA Psychiatry. The study was conducted at the Johns Hopkins University School of Medicine, Maryland, US, following up on a potential predictor of Alzheimer’s disease (AD). Beta amyloid plaques are massively associated with the decrease of brain cells in AD.

In the scope of the newly introduced concept of Mild Behavioural Impairment (MBI) different changes in personality, behaviour and emotions are becoming more and more interesting for researchers in order to identify possible low-cost indicators of potential future cognitive impairment.

The researchers used data from the Harvard Aging Brain Study of 79 cognitively normal individuals between 68 and 89 years. Results showed that self-reported loneliness was associated with higher brain amyloid burden and that these associations were stronger in apolipoprotein Eε4 (APOEε4) carriers.

The small sample size and limited insight into the emotional state during the investigation heighten the need for long-term observations with bigger study samples before further interpretations can be made.

https://doi.org/10.1001/jamapsychiatry.2016.2657

14 November: Computerised cognitive training could improve cognitive functions and depressive symptoms in people with MCI

An analysis across various studies suggests that computerised cognitive training (CCT) could help to improve global cognition, attention, learning and memory, as well as psychosocial functioning - including depressive symptoms in people with mild cognitive impairment (MCI). MCI is a condition in which cognitive functions are worse than normally but do not interfere with activities of daily living.

The research, published on 14 November 2016 in the American Journal of Psychiatry, also compared the effects of CCT in people with dementia. Weak effects were found on overall cognition, but the researchers noted that they were limited to trials of immersive technologies.

Commenting on the research and envisioning future approaches, Dr Doug Brown, Director of Research and Development at the Alzheimer’s Society (UK), said: “Now, we need to work out how we could turn specially-designed brain training into activities that are widely accessible and available.” This way CCT could not only lead to better scores in neuropsychological tests but could also help maintain or even improve autonomy for people with cognitive impairment.

https://doi.org/10.1176/appi.ajp.2016.16030360

21 November: Study finds that age-specific risk of dementia may have declined

Evidence from a study published in the journal JAMA Internal Medicine on 21 November 2016 says that the prevalence of dementia in the US dropped between 2000 and 2012.

The investigation of 21,057 US adults over the age of 65 found that there has been a decrease in the prevalence from 11.6% in 2000 to 8.8% in 2012. It is expected that the total number of people with dementia will still rise due to the ageing of the population. The researchers also found an increase in education level, which they associated with some of the decline in prevalence. Until now the full set of factors such as social, behavioural and medical influences on dementia is still uncertain.

Comparable trends are under observation in other populations such as the UK. Using age and sex-specific prevalence estimations from a sample in 1991, researchers estimated that 664,000 people had dementia at that time. Considering the effects of the ageing population, it was expected that 884,000 people would have dementia in 2011, however the scientific staff observed a deviation of 214,000 fewer individuals, leading to a reduction of 24%.

While the scientific community is still uncertain why the prevalence of dementia is declining, more and more evidence points to education (which could potentially lead to a sort of cognitive reserve) and better heart health as a possible explanation.

In future, it will be important to continue monitoring changes and in the prevalence of dementia in order to
improve the understanding of the societal impact of dementia.

https://doi.org/10.1001/jama.neurol.2016.6807

7 December: Flickering lights may provide a new therapeutic target for AD

In a study published on 7 December in the journal Nature, scientists have described a possible new therapeutic target for Alzheimer’s disease (AD). They showed that mouse models exposed to a flickering light presented a reduction of the toxic molecule beta-amyloid.

Previous findings have underlined that gamma waves are reduced in people with AD. The role of gamma waves is not completely clear but they are thought to contribute to normal brain functions.

In the published study, researchers induced gamma oscillations using flickering lights, in the hippocampus brain region responsible for memory. Interestingly, they observed a decrease of 40%-50% of beta-amyloid proteins in the induced area. In addition, the team of neurobiologists also found that the flickering light could stimulate immune cells in the brain.

http://www.nature.com/nature/journal/v540/n7632/full/nature20587.html

7 December: Taking regular saunas may have a protective impact on risk of developing dementia

In a recent study, published on 7 December 2016 in the journal Age and Ageing, researchers at the University of Eastern Finland and the University of Bristol assessed whether the frequency of sauna sessions is associated with a reduction in the risk of developing dementia.

The scientific staff used a sample of 2,315 healthy men aged between 42 and 60 years collected between 1984 and 1989 with a follow-up of about 20 years. They then divided the participants into three groups, comparing men taking one sauna per week, two to three saunas and four to seven saunas.

Results showed that men who reported taking a sauna four to seven times per week were 66% less likely to develop dementia when compared with those taking only one sauna per week.

Commenting on the study, Professor Jari Laukkanen, who led the research, cautioned: “However, it is known that cardiovascular health affects the brain as well. The sense of well-being and relaxation experienced during sauna bathing may also play a role.”

https://doi.org/10.1093/ageing/afw212

8 December: Anavex announces positive 57-week update from AD drug phase 2a study

On 8 December, Anavex Life Sciences Corp reported a positive 57-week update from its phase 2a study in mild-to-moderate Alzheimer’s disease (AD), at the annual Clinical Trials on Alzheimer’s disease (CTAD) conference in San Diego, US. Its AD drug ANAVEX 2-73 targets cellular homeostasis.

At 57 weeks the phase 2a indicates cognitive as well as behavioural and functional benefits. The drug was found to be well-tolerated by participants with AD taking a daily oral dose and no severe side effects were observed.

The oral presentation of the findings is available in the publications section of the Anavex website.


8 December: Pfizer presents promising data about its novel experimental AD drug

On 8 December, the company Pfizer presented an experimental Alzheimer’s disease (AD) drug at the CTAD conference in San Diego.

The phase 1 study was conducted in healthy volunteers. They received the drug, which modulates the activity of gamma secretase. No major side effects were observed and interestingly a reduction in brain beta-amyloid (AB) level was noticed. The presented results revealed a reduction of the amount of Aβ42 by about 59% for people treated daily for two weeks.

The company said its experimental AD drug must be now tested in clinical trials involving people with the disease.


8 December: Biogen confirms promising results from a Phase 1b study of its experimental AD drug

A previous study published in the journal Nature by scientists from biotechnology company Biogen, reported the generation of a human monoclonal antibody called aducanumab against Amyloid Beta. This experimental treatment has been developed for use in early Alzheimer’s disease (AD). Pre-clinical results reported a reduction of amyloid plaques and appeared also to slow cognitive decline.

On 8 December, at the CTAD conference, Biogen presented data including results of its Phase 1b titration cohort and from the first year of the long-term extension of its experimental AD drug aducanumab. In the clinical trial, the major adverse event observed was amyloid-related imaging abnormalities. At 54 weeks, participants with AD showed a statistically dose-dependent reduction of amyloid plaques. Phase 1b long-term extension revealed no new cases of amyloid-related imaging abnormalities.

Currently, Biogen is advancing the clinical trial in two global Phase 3 studies to evaluate the safety and efficacy of its experimental treatment. The data presented at the conference support the ongoing Phase 3 studies.


9 December: AXON’s Alzheimer tau vaccine phase 1 study results published in Lancet Neurology

On 9 December, results from a first-in-man study of AXON Neuroscience’s active tau vaccine were published in the Lancet Neurology journal. The results demonstrated an excellent safety and immunogenicity profile of AXON’s
vaccine, AADvac1, which is intended to be the first disease-modifying tau treatment for Alzheimer’s disease (AD).

This first-in-man, first-in-class study was designed to assess safety and tolerability of the AADvac1 active vaccine in the treatment of patients with mild-to-moderate AD. The study was conducted in Austria with Professor Reinhold Schmidt from the Medical University Graz as the coordinating investigator.

http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(16)30340-4/fulltext

9 December: Neuronix announces positive cognitive results from its new therapy system

The company Neuronix, which develops new methods to promote a medical treatment for Alzheimer’s disease (AD) and to improve the quality of life of people with dementia, has announced results from a clinical trial testing its NeuroAD therapy system. The system is a non-invasive therapeutic device for the cognitive improvement of people with AD. It uses both magnetic stimulation and cognitive training.

Between October 2013 and March 2016, a multicentre clinical trial was conducted in nine centres in the US and one in Israel, in order to evaluate the effects of NeuroAD on the cognitive function of people with AD. All 131 patients included in the study were previously diagnosed with mild or moderate AD and were aged between 60 and 90. Participants received the therapy for six weeks, five times per week, during a one-hour session per day.

On 9 December, at the international conference on Clinical Trials for Alzheimer’s disease (CTAD) in San Diego, Neuronix presented positive results concerning its therapy system. The data presented seem to indicate cognitive improvement for people in the early stages of AD Indeed, a significant score change was observed on the AD assessment scale - cognitive subscale, which measures the severity of the most important symptoms of AD.


14 December: Protein in urine may be linked to increased risk of memory problems, study says

People who have protein in their urine, which is a sign of kidney problems, may also be more likely to later develop problems with thinking and memory skills or even dementia, according to a meta-analysis published on 14 December in the online issue of Neurology, the medical journal of the American Academy of Neurology.

Researchers looked at all available studies on kidney problems and the development of cognitive impairment or dementia. A total of 22 studies on the topic were included in the review. Five of the studies, which included 27,805 people, were evaluated in the meta-analysis on protein in the urine (known as albuminuria or proteinuria).

The analysis showed that people with protein in the urine were 35% more likely to develop cognitive impairment or dementia than people who did not have protein in their urine.

The reason for this apparent link needs to be further researched before any firm conclusions can be drawn.

https://www.aan.com/PressRoom/Home/PressRelease/1507

20 December: Phase II study of AD psychosis drug from Acadia shows positive results at 6 weeks but not at 12 weeks

Alzheimer’s disease (AD) affects an estimated 5.4 million people in the US and about 25-50% of them may develop some form of psychosis. However, no drug is currently approved by the US Food and Drug Administration (FDA) to treat AD psychosis. Interestingly, pimavanserin, a selective serotonin inverse agonist, has been approved by the FDA for Parkinson’s disease (PD) psychosis and the company Acadia Pharmaceuticals is conducting clinical trials of pimavanserin as an AD psychosis drug.

On 20 December, the company announced positive data from its Phase II exploratory study. In the clinical trial, performed in the UK, 181 patients were randomly assigned to receive 34 mg of pimavanserin or placebo once daily. The average age of participants in the study was 86.

After 6 weeks of treatment, a statistically significant reduction in psychosis with a 3.76 point improvement was observed in participants with AD psychosis, compared to a 1.93 point for those on placebo. In addition, the drug was well tolerated. However, Acadia revealed a not-statistically-significant decrease in psychosis after 12 weeks of treatment, compared to the placebo group.

The data analysis from the Phase II study is currently in progress and Acadia will present them at a future medical conference.


20 December: Odour identification test could be used as a supplementary means of screening in early AD

On 20 December 2016, results from a study investigating the association between the ability to smell and cognitive performance were published in the Journal of Alzheimer’s Disease. While further development of new cost-effective and reliable tests for the diagnosis of Alzheimer’s disease (AD) is essential, GPs still depend on a combination of both mental and physical examinations.

So far, different studies involving people with AD and mild cognitive impairment (MCI) have shown that the ability to smell declines with the progression of the condition.

Using this knowledge could lead to a more accurate diagnosis of AD. Researchers in the Department of Psychiatry at the University of Pennsylvania School of Medicine used a combination of both neuropsychological testing and an odour identification task.

The screenings were administered to 728 older adults, 292 of whom were healthy individuals, 174 had MCI and 262 had been diagnosed with AD. Results showed that the addition of the odour identification task was able to boost
the accuracy to detect people diagnosed with mild cognitive impairment (MCI) from 75% to 87%.

The test used – the Sniffin’ Sticks Odour Identification Test (SS-OIT) -was a simple test taking around five to eight minutes and consisting of 16 pens filled with liquid odorants to be identified. While odour identification is a useful supplementary screening tool, future plans for shorter tests are in progress, to encourage more neurology clinics to use this type of screening.

In order to find new techniques and identify earlier warning signs, the same research group now plans to investigate whether protein markers of AD can be detected in nasal fluid. These appear in the olfactory region of the brain before dementia manifests itself.

https://doi.org/10.3233/JAD-160842

Science – behind the headlines

12 December: Is dementia risk reduced by the use of statins? The Alzheimer’s Society comments

New research suggesting that the use of cholesterol-lowering statins may be associated with a reduced risk of dementia, has attracted quite a lot of media attention. The Alzheimer’s Society (UK) has commented on this research, emphasising that the effects were dependent on a person’s gender and ethnicity and that dementia risk also varied by type of statin used. The results, published online in the journal JAMA Neurology on 12 December 2016, still need to be confirmed in clinical trials, the Society stressed.

Commenting on the research, Dr Doug Brown, Director of Research and Development at the Alzheimer’s Society said:

“Previous research has attempted to find out whether using statins to lower cholesterol can alter a person’s risk of developing dementia but these studies have produced mixed findings. This new study goes some way towards clearing up this confusion by analysing large amounts of existing data of people who use different types of statins over a long period of time. Their refreshing approach highlights that ‘one size fits all’ is not always a suitable approach to healthcare and this is likely to be the case when it comes to ways people can reduce their risk of dementia. However, their data does not provide direct evidence that statins can influence dementia risk - this question will need to be answered by clinical trials.

“The results found cannot yet be applied to the doctor’s surgery, but could be used to improve the design of clinical trials that can help to answer the complicated questions around statin use and dementia risk.

“Currently there is not enough evidence that statin use can reduce your risk of dementia, but you should keep an eye on your cholesterol levels as keeping them in check will help to combat other conditions such as heart disease and stroke. We advise people to speak to their GP if they have any questions about cholesterol, statin use and dementia risk before making any decisions about their medications.”

Link to original study:
http://jamanetwork.com/journals/jamaneurology/article-abstract/2591317

Living with dementia

26 December: New EWGPWD member Idalina Aguiar introduces herself and tells us about her recent trip to 26AEC in Copenhagen

I have memory problems, however, some people support me to deal with this problem. Two of them are my psychologists, Lucília and Gonzalo, from Delegation of Madeira (Island from Portugal) of Alzheimer Portugal. They asked me if I was interested to participate in the EWGPWD. Initially I needed some help to understand what kind of group was this. They showed me some pictures and texts from the earlier EWGPWD. They even tried to teach me some English words and some images from Copenhagen. I was getting excited to participate and to share my ideas and thoughts about my own disease. I never forgot again that I was almost traveling to Copenhagen to participate in this meeting.

My daughter Nélida is my main support and it is through her that I can communicate and make the importance of my integration in society prevail.

I went to Copenhagen and they followed me through Nélida’s social network. When I came back they knew that I really enjoyed to be there and that I will have many challenges in coming future but that I am also enthusiastic to face them with their and Nélida’s support. Last week I gave them my feedback about Copenhagen meeting. Here’s what I said about it:

I enjoyed a lot to be in Copenhagen meeting and to be part of a working group that talked about Alzheimer’s disease with no complexes. I sympathised with the other members, even though I do not remember their names, but I certainly remember their faces and importance. I learned about Alzheimer’s disease and for sure, my experience will contribute to the future of this group.”

Idalina Aguiar, member of the EWGPWD
Dementia in society

23 November: Andrew Sachs dies aged 86 with Alzheimer’s dementia

On 23 November 2016, actor Andrew Sachs died at the age of 86 after a four year battle with Alzheimer’s dementia.

Born in Berlin, Mr Sachs and his family emigrated to London in 1938 to escape Nazi persecution. He made his name on British television and rose to fame in the 1970s for his portrayal of the Spanish waiter Manuel in the much-loved comedy series Fawlty Towers, a role for which he was BAFTA-nominated. He went on to have a long career in acting and voice-over work for TV, film and radio.

New publications and resources

2 December: King’s College London publishes policy paper “The dialectics of dementia”

On 2 December, King’s College London (KCL) announced a new publication, “The dialectics of dementia”, from its Social Care Workforce Research.

By way of introduction, authors Jill Manthorpe and Steve Iliffe write:

“Professional education about ways to respond to symptoms or to strengthen the support available to people with dementia (and their carers) does not always have multi-disciplinary content...and so loses the contribution that different perspectives can offer. There are few efforts to integrate understanding of the different theoretical approaches that underpin policy and practice, a situation which we hope to remedy in this report.”

They believe their dialectical analysis may be helpful in clarifying the positions taken by those with an interest in dementia, the reasons why they these are adopted, as well as the consequences for people with dementia, and for carers and services.

“The dialectics of dementia” sets out four theses:

- Dementia is a big and expensive problem and something must be done about it.
- Dementia is a disease process that deserves a medical solution.
- The medical solution is undermined by failure to recognise dementia, which must be put right.
- The care of people with dementia is primarily an individual or family responsibility.

For each thesis there is a counter-thesis, and a synthesis that attempts to resolve the polarity between thesis and counter-thesis.

8 December: Swiss publication promotes human rights-based approach in elderly policies, including dementia

Swiss NGO “humanrights.ch” has released a publication promoting a human rights-based approach in elderly policies, which includes the question of dementia. It makes reference to the work of Alzheimer Europe and also to the 26th Alzheimer Europe Conference (26AEC) in Copenhagen.

http://www.humanrights.ch/de/menschrechts-themen/alter/schluesselthemen/

12 December: New report focuses on feasibility study of a national dementia registry for Ireland

The report, commissioned under The Alzheimer Society of Ireland’s expert policy series, provides much needed information on the feasibility of developing a dementia registry within the Irish context.

The authors proactively engaged with leading experts both in the field of dementia and in patient’s registries more generally. They also, very importantly, met and engaged with people living with dementia; those whose information would be collected, stored and used in any future registry.

There is very poor recording and coding of dementia across all care settings. This study highlights the characteristics that a registry needs to have to be successful and the pitfalls to avoid.

A copy of the report can be read here.

13 December: UK report published on the issue of truth and lies in dementia care

On 13 December, the Mental Health Foundation, UK announced a new report it has published on a major inquiry about truth and lying in dementia care, “What is truth? An inquiry about truth and lying in dementia care”.

Carers often have challenging decisions to make when a person with dementia is “living with different realities and beliefs” - something that it says is the case for around half of people living with dementia and which increases as dementia progresses. Should they agree or contradict? What should they say? The report aims to provide some guidance and to examine the values we use when caring for and supporting people living with dementia.

https://www.mentalhealth.org.uk/sites/default/files/dementia-truth-enquiry-roe_0.pdf

14 December: Call launched for papers on palliative care in dementia

A call has been launched for papers for a special edition of the journal Palliative Medicine on palliative care in dementia.

Guest editors of the special issue, Julian C. Hughes, The RICE Centre, Bristol University, UK and Jenny T. van der Steen, Leiden University Medical Center and Radboud University Medical Center, Nijmegen, Netherlands, invite you to contribute.

The deadline for submissions is 31 March 2017.

http://journals.sagepub.com/doi/full/10.1177/0269216316672817
Education

13 December: INTERDEM Academy issues call for applications

The INTERDEM Academy enables Fellowships for early-stage researchers allowing them to attain experience in another INTERDEM research centre. Its grants cover expenses for travel and housing for a research exchange of 3-6 months. The salary of the fellow is not covered, and needs to be provided by the fellow’s institute.

There are two annual calls for INTERDEM Academy researchers to submit their applications – the next deadline is set on the 31 March 2017.

INTERDEM is a pan-European network of researchers collaborating in research on and dissemination of Early, Timely and Quality Psychosocial Interventions in Dementia aimed at improving the quality of life of people with dementia and their supporters, across Europe.

The INTERDEM Academy is part of the PRIDE project (PRomoting Independence in Dementia), which aims to identify how social and lifestyle changes may help reduce the risk of developing dementia and disability.

For more information about the Fellowships, including eligibility criteria and application forms, please see:


Contact Alzheimer Europe

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

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AE Calendar

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<td>6 January</td>
<td>Meeting with Roche (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<td>9-10 January</td>
<td>EPAD ethics work package meeting (Cambridge, United Kingdom)</td>
<td>Dianne</td>
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<td>10 January</td>
<td>ROADMAP Communication Meeting (Brussels, Belgium)</td>
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<td>20 January</td>
<td>PACE General Assembly meeting (teleconference)</td>
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<td>24 January</td>
<td>ROADMAP Steering Committee (Amsterdam, Netherlands)</td>
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<td>31 January</td>
<td>Meeting with World Dementia Council (London, UK)</td>
<td>Jean</td>
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Conferences

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<tr>
<td>2-5 February 2017</td>
<td>10th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PKA0) and 2nd Mediterranean Conference Neurodegenerative Diseases (McCuND)</td>
<td>Thessaloniki, Greece</td>
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<td>24-25 June 2017</td>
<td>3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a></td>
<td>Amsterdam, Netherlands</td>
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27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017

www.alzheimer-europe.org/conferences  #27AEC