Highlights in this issue

30 Oct: New EWGPWD meets for first time
31 Oct: AE has a new Board, Chair and 2 new members
31 Oct: AE hosts successful 26th Annual Conference
16 Nov: ROADMAP project is launched
23 Nov: Solanezumab fails to meet primary endpoint
24 Nov: Swiss Dementia Strategy prolonged

Table of contents

Editorial .......................................................................................................................... 1
Alzheimer Europe .......................................................... 2
EU projects .......................................................... 7
Alzheimer Europe networking 2016 ........................................ 10
European Alzheimer's Alliance ............ 11
EU developments .................................................. 11
Members’ news ................................................. 13
Policy watch ................................................... 20
Science watch .................................................. 22
Living with dementia .................................................. 25
New publications and resources .................................. 26
AE Calendar .......................................................... 26
Conferences .......................................................... 27

Welcome!

November saw a number of significant changes within Alzheimer Europe. I would therefore like to start this newsletter by paying a very special tribute to Heike von Lützau-Hohlbein for her fantastic contributions to Alzheimer Europe over the past 12 years as first a Board member, then as Honorary Treasurer and for the past 6 years as Chairperson.

At our Annual Meeting in Copenhagen, our members voted for Iva Holmerová from the Czech Republic to succeed her and I wish her every success in this new position. At the same time, I want to pay a very warm welcome to our newly elected Board, to our two new member associations from Albania and Hungary and to the new members and Board of our European Working Group of People with Dementia (EWGPWD).

You can find more details about all this news in pages 2-4 of this newsletter, which cover the different internal meetings we organised during our successful 26th Annual Conference (26AEC) in Copenhagen. We are delighted with the feedback received during and since 26AEC. Many thanks to our over 700 delegates for having been so positive and also for being so active on social media - the overall statistics are impressive, with over 20 million tweet impressions of the #26AEC hashtag! Let me also use this opportunity to congratulate the four prize-winners of the poster awards: Matthew Adams, Trine Nordby Skjeldestad, Deirdre Fetherstonhaugh and Wienke Jacobsen.

In November, we also launched our latest EU project, the ROADMAP initiative – Real world Outcomes across the Alzheimer’s Disease (AD) spectrum for better care: Multi-modal data Access Platform. We are delighted to be involved in another IMI collaboration.

On the policy front, we are pleased to announce that together with Alzheimer’s Disease International (ADI), Dementia Alliance International (DAI) and the Global Alzheimer’s and Dementia Action Alliance (GADAA), we have submitted a joint response to the WHO Zero Draft Global Plan on Dementia. Good news has also come from our friends in Switzerland that their national dementia strategy has been prolonged until 2019.

I am sorry that our newsletter is also reporting some negative news on the research front since Lilly’s drug solanezumab failed to meet its primary endpoint in phase 3. This is of course very disappointing for all the people with Alzheimer’s disease who were hoping for an innovative new treatment. However, we remain optimistic, in the knowledge that even failed trials increase our understanding and will bring us closer to the development of better treatments.

On a more positive note, AE is pleased to have collaborated with its continence care working group to publish a review of literature relating to the continence care of dwelling people with dementia in Europe in the Journal of Clinical Nursing. Congratulations Dianne Gove and colleagues!

Our December newsletter will be published on 6 January 2017. Until then, I wish you all an excellent festive season and a positive end to this busy and exciting year!

Jean Georges
Executive Director
The European Working Group of People with Dementia (EWGPWD) began its third two-year term of office at a meeting held on 30 October 2016 in Copenhagen. During this meeting, the group welcomed six new members and elected a Chairperson and two Vice-Chairpersons to the new Executive Board.

**Members of the EWGPWD (2016-2018)**

Chairperson: Helen Rochford Brennan (Ireland)

Vice-Chairperson: Alv Orheim (Norway)

Vice-Chairperson: Chris Roberts (UK – England, NI, Wales)

Members: Amelia Hajric (Bosnia), Nina Baláčková (Czech Republic), Ib Holger Hegner (Denmark), Markku Parkkisenniemi (Finland), Helga Rohra (Germany), Idalina Aguiar (Portugal), Karin Gustafsson (Sweden) and Carol Hargreaves (UK, Scotland).

The EWGPWD was launched by Alzheimer Europe and its member associations in early 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with members electing their own Board and setting an agenda of activities. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe with full voting rights. During the group’s first two terms of office (2012-2014, 2014-2016), the members of the EWGPWD have actively participated in the Alzheimer Europe conferences and gave keynote presentations in the European Parliament. They have contributed to several consultations for different European projects where AE is involved and to the work that AE develops. Members of the group have also contributed to research conducted by external organisations on topics such as outcome measures that are meaningful to people with dementia and their carers, social health and people with dementia as peer-researchers. They attended various international dementia events and also gave numerous interviews, both in their countries and internationally.

Old and new members of the group participated in the meeting of 30 October and jointly planned their involvement on the activities of the upcoming AE conference in Copenhagen. Members also contributed to a consultation on Public and Patient Involvement (PPI) in research. The new members from Denmark (Ib) and Scotland (Carol) sent their apologies as they could not be present in this first meeting of the group.

The EWGPWD wishes to thank outgoing members Raoul Grönqvist (Finland), Hilary Doxford (UK – England) and Agnes Houston (UK - Scotland) for their strength, enthusiasm and determination during the second term of office of the group.

Jean Georges, Dianne Gove and Ana Diaz attended the meeting.

**31 October: Alzheimer Europe holds Board meeting in Copenhagen**

The members of the Alzheimer Europe Board held a meeting on 31 October in Copenhagen, Denmark. They discussed various financial and operational matters, including final preparations for the Annual General Meeting that took place later in the day.

This was the last meeting of the 2014-2016 Board. The members of the new Alzheimer Europe Board (2016-2018) will hold their first meeting in Brussels on 5 December 2016.

**31 October: Alzheimer Europe holds Annual General Meeting**

Alzheimer Europe held its 2016 Annual General Meeting in Copenhagen, Denmark on 31 October 2016. The meeting was attended by representatives from 27 full and three provisional member associations, as well as various guests.

The delegates reviewed and adopted AE’s 2015 Annual and Financial reports and also voted in favour of accepting Alzheimer Albania and the Hungarian Cluster Association as new provisional members of Alzheimer Europe. They also discussed and adopted new statutes for dealing with multiple full member associations from a single country. This was followed by a vote that successfully elevated Alzheimer Uniti ONLUS to full member status. In addition, the delegates elected new members to the Alzheimer Europe Board for the period 2016-2018. Finally, delegates reviewed and approved AE’s 2017 Work Plan and Budget.

The next Annual General Meeting will take place in Berlin (Germany), which is also the venue for the 27th Alzheimer Europe Conference on 2-4 October 2017.

www.alzheimer-europe.org/AlzheimerEurope/Who-we-are/Our-members

**31 October: Alzheimer Europe has a new Chairperson, new Board and two new members**

Following its AGM, AE is pleased to announce it has a new Board, new Chairperson and two new member associations as well as having elevated one of its provisional members to the status of Full Member.

The Office holders and members of AE’s new 2016-2018 Board are:
• Chairperson: Iva Holmerová (Czech Republic)
• Vice-Chairperson: Charles Scerri (Malta)
• Honorary Secretary: James Pearson (UK - Scotland)
• Honorary Treasurer: Maria do Rosário Zincke dos Reis (Portugal)
• Members: Stefanie Becker (Switzerland), Marie-Odile Desana (France), Sabine Henry (Belgium), Sabine Jansen (Germany), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Štefanija Lukšič Zlobec (Slovenia).

The Office holders and Members of the Board were elected by representatives from Alzheimer Europe’s full member associations that took part in the Annual General Meeting. They are joined by Helen Rochford Brennan (Ireland), new Chairperson of the EWGPWD and an ex-officio Member of the Board with full voting rights. The new AE Board will serve a two-year term and will hold its first meeting in December 2016.

AE would like to thank Heike Holmerová (pictured, left) for 12 outstanding years of service on the AE Board, six of which she served as Chairperson (2010-2016) and bids her a fond farewell.

AE also says a warm welcome to Iva Holmerová (pictured, right), its new Chairperson.

AGM delegates also voted unanimously in favour of accepting Alzheimer Albania and Hungary’s Social Cluster Association as new provisional members.

They also voted in favour of elevating Italy’s Alzheimer Uniti ONLUS to Full Member status. Alzheimer Europe now has a total membership of 39, with 35 full members and four provisional members in 34 countries.

31 October-2 November: Alzheimer Europe holds successful 26th Annual Conference

The 26th Alzheimer Europe Conference (26AEC) was held on 31 October - 2 November 2016 in Copenhagen together with Alzheimerforeningen, Denmark's national Alzheimer association. This year’s theme was “Excellence in dementia research and care” and the conference attracted over 730 delegates - including 35 people with dementia - with a programme featuring some 200 speakers and 160 poster presentations. The event was organised under the Honorary Patronage of Her Royal Highness Princess Benedikte of Denmark, who was also the first speaker at the Opening Ceremony.

Her Royal Highness welcomed the delegates with a special mention for the people with dementia and their carers, whom she particularly admired for their spirit and commitment. She was followed by Sophie Lahde, Danish Minister for Health and the Elderly. Ms Lahde focused on Denmark’s new national action plan on dementia, explaining that it aims to make the entire country a dementia-friendly society. Heike von Lützau-Hohlbien, outgoing Chairperson of Alzheimer Europe, noted that the conference would once again be a showcase of many great achievements in improving the lives of people with dementia. She also referred to the need for more and better cooperation among countries, inviting the delegates to attend the plenary session that would specifically address this topic. The next speaker was Birgitte Vælund, Chair of Alzheimerforeningen, who spoke of the Danish association’s work to eliminate all the taboos and stigma that still affect public awareness. She was followed by Merete Lind Larsen, a Danish nurse who is living with dementia. Ms Larsen was pleased to see the conference taking place in Denmark, as this would raise awareness of dementia and its many challenges. The keynote lecture was delivered by Gunhild Waldemar, Professor of Clinical Neurology at Rigshospitalet, University of Copenhagen. Her presentation “Improving the quality of health care for people with dementia” highlighted the importance of an accurate and timely diagnosis, access to local programmes for treatment and the education and competences among physicians and professional carers.

On 1 November the first plenary session, “A rights-based approach to dementia” was chaired by Jim Pearson, Director of Policy & Research at Alzheimer Scotland and Honorary Secretary of AE. The first speaker was Tina Leonard, Head of Advocacy & Public Affairs at the Alzheimer Society of Ireland, who presented “Putting people with dementia first: promoting a rights-based approach in national dementia strategies.” She was followed by Christine Swane, Director of EGV Foundation (Ensomme Gamles Værn) in Copenhagen with a talk on balancing the perspectives of persons with dementia and caregivers. Adrian Ward, a legal consultant for the Council of Europe, spoke about the Council’s activities on legal capacity and proxy decision-making. The final speaker was Richard Milne from the Institute of Public Health at the University of Cambridge. He presented the latest aspects of ethical challenges in contemporary Alzheimer’s disease clinical trials and research.

The second plenary session took place on the same day, in the form of a round table discussion with five global, European and national officials with an interest in dementia, moderated by Nis Peter Nissen. Mr Nissen asked each speaker in turn for a statement on their work, which was then discussed with members of the audience. Herta Adams, Deputy Head of the Health Threats Unit at the European Commission’s DG Health and Food Safety spoke about how the EU can support Member States in their efforts to address dementia. Tarun Dua, from the Department of Mental Health and Substance Abuse at the World Health Organization, explained that the WHO continues to increase its dementia activities, such as supporting countries to set up national dementia strategies. Mogens Harder, Professor at the Department of Public Health, University of Southern Denmark, spoke about the activities of the JPND - the EU Joint Programme on Neurodegenerative Disease Research, which gathers researchers from all over Europe and helps to locate and fill research gaps in specific countries. Anne Calteux, Senior Policy Advisor for the Luxembourg Ministry of Health, explained the principles behind the rotating EU Presidency and how Luxembourg made dementia a health priority during its EU Presidency term in the second half of 2015. The fifth speaker on the panel was Hilary Duxford, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and Board Member of the
She explained that the WDC’s role is to identify areas that may be overlooked and to share knowledge from developed countries with those who are in need.

The third plenary session took place on 2 November and was moderated by Charles Scerri, General Secretary of the Malta Dementia Society and Vice-Chair of AE. The first speaker was Helen Rochford Brennan, Chair of the EWGPWD, who spoke about the impact of receiving a diagnosis of dementia. She was followed by Craig Ritchie, Professor of the Psychiatry of Ageing at the University of Edinburgh. He explained how the European Prevention of Alzheimer’s Dementia (EPAD) project aims to improve the chance of successful prevention and to gain a better understanding of early aspects of AD before dementia develops. The next speaker was Steen Hasselbalch, Consultant Neurologist for the Danish Dementia Research Centre at Rigshospitalet. Prof. Hasselbalch showed how an early and accurate diagnosis leads to better-targeted pharmacological and non-pharmacological treatments. Finally, Henry Simmons, Chief Executive of Alzheimer Scotland, showed how national dementia strategies can help to transform the rights to choice, power and control for people with dementia and their carers.

The final plenary session was chaired by Prof. Hasselbalch. Alexander Kurz, Professor of Psychiatry, Technische Universität München began by discussing perspectives for the future treatment of AD. Geoff Huggins, Director for

Health and Social Care Integration in the Scottish Government followed with a presentation on the 2nd European Joint Action on Dementia. “DEM 2” will promote the implementation of coordinated actions to improve the situation of people living with dementia and their carers in EU countries. He was followed by Frans Verhey, Professor of Old Age Psychiatry and Neuropsychiatry at the University of Maastricht. He showed how the “Actifcare” project is helping to improve access to formal dementia care. The final speaker was Prof. Iva Holmerová, Director and Consultant Geriatrician at the Centre of Gerontology in Prague and newly elected AE Chairperson. She presented the results of PALLIARE and DEMDATA, two projects dealing with long-term care for people with dementia.

In addition to the four plenaries, delegates at 26AEC had the choice of 30 different parallel sessions on specific legal, ethical, scientific and human aspects of living with dementia.

The conference ended with an invitation by Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft - the German Alzheimer Association - to attend the 27th Alzheimer Europe Conference (27AEC) in Berlin in 2017.

The 26th AE Conference in Copenhagen received funding under an operating grant from the European Union’s Health Programme (2014-2020).
31 October - 2 November: Six special symposia held during 26AEC in Copenhagen

During the 26th Alzheimer Europe Conference (26AEC) in Copenhagen, six special symposia were held:

**SS1 - Living well with dementia**

This session, held by the European Working Group of People with Dementia (EWGPWD), was chaired by Alv Orheim of Norway, newly elected Vice-Chairperson and a member of the group since 2015.

The session started with former group Chairperson Helga Rohra of Germany and her son Jens giving a speech on “Change in dementia: the mother-son relationship”. Ms Rohra also said a heartfelt thanks to Alzheimer Europe “for helping raise up the voices of people with dementia via the EWGPWD”.

They were followed by former group member Agnes Houston of Scotland, speaking about “How people with dementia can contribute to participate in research”. She made a special mention of her daughter and carer, Donna, who was with her on stage and without whom “I just wouldn’t be here talking to you”.

The final speaker was the group’s newly elected Chairperson, Helen Rochford-Brennan from Ireland, who kicked off her presentation on “How the CRPD can enhance my life living with dementia” with Bob Dylan’s “Blowing in the Wind”, to “get everyone in the mood to talk about rights”.

The packed session was also attended by Her Royal Highness Princess Benedikte of Denmark, who graciously agreed to pose with the group for a photo after the session (pictured).

**SS2 - Changing how we communicate about Alzheimer’s disease**

This session, held by the European Prevention of Alzheimer’s Dementia (EPAD) project, was chaired by Sean Knox, medical affairs director within global neuroscience franchise at Novartis Pharmaceuticals.

The session was well attended by a mixture of researchers, healthcare professionals, caregivers, persons with dementia and many more. Presentations were given by Prof. Craig Ritchie, EPAD Co-coordinator and Professor of the Psychiatry of Ageing at the University of Edinburgh, Dr Richard Milne, University of Cambridge, UK and Jean Georges, Executive Director, Alzheimer Europe (AE), Luxembourg. Following this, a very constructive discussion emerged with the audience. Questions such as “does focus on prevention means we abandon progress on symptomatic treatment?”, “based on the AE survey, it seems many persons do not want to know their risk status, does this endanger ‘earlier’ populations trials to be successful?” and “What does it actually mean to be ‘at risk’ – and how do we need to interpret risk profiles?” were discussed.

**SS3 - Living well with dementia and social health**

This session, chaired by Prof. Myrra Vernooij-Dassen, principal investigator at the Radboud University Medical Centre Nijmegen, Netherlands, was held by INTERDEM – 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.

Speakers were: session Chair Prof. Vernooij-Dassen, who spoke about “Social health and living well with(out) dementia”; psychologist and sociologist Dr Vjenka Garms-Homolová, Germany, who spoke about “Social and functional health of home care clients with different levels of cognitive impairments”; Jonathan Serbsker, DZNE, Germany on “Concepts of autonomy in person-centered dementia care and its relevance for social health”; Prof. Bob Woods, Co-Director of the Dementia Services Development Centre, Wales, UK, on “Charting new territory: measuring outcomes that have meaning” and finally Prof. Rose-Marie Dörs, VU University Medical Center, Amsterdam, Netherlands talked about “Social health in dementia: operationalization of the concept and directions for research and practice”.

**SS4 - The EADC (European Alzheimer Disease Consortium)**

The EADC is a fully functional network of European centres of excellence working in the field of Alzheimer’s disease (AD) research and care. It consists of over 60 European centres of clinical and biomedical research excellence working in the field of clinical research on AD and related dementias.

The first speaker at this session was EADC Chairman Prof. Bengt Winblad, Center for Alzheimer Research, Division for Neurogeriatrics, Karolinska Institutet, Stockholm, Sweden gave an overview of the Consortium.

Second speaker Prof. Frank Jessen, Director of the Clinic for Psychiatry and Psychotherapy, University Hospital Cologne, Germany spoke about the newly initiated project on subjective cognitive decline (SCD) “Euro-SCD” (funded by EU-JPND), which he directs.

Up next was EADC Principal Investigator Prof. Flavio Nobili, Clinical Neurophysiology Unit of the University of Genoa, Italy, who told the audience about the ongoing EADC-PET project (EAPP – The European Alzheimer’s Disease Consortium PET project), which he leads.

The second last speaker at the session was Prof. Patricia Meccoci, department of Gerontology and Geriatrics, University of Perugia, Italy, who presented the background of Tau-directed interventions and outline the status of the ongoing clinical trials.

The final speaker was Prof. Lutz Frölich, Head of the department for Geriatric Psychiatry, Central Institute of Mental Health, Mannheim, Germany, who relayed recent
LMTX Phase III trial results, previously presented at AACIC2016.

SSS - Can we move the Alzheimer’s Disease environment towards an earlier diagnosis?

This session, chaired by Dr Mercè Boada, founder and medical director of Fundació ACE, Spain, was sponsored by Lilly and presented the upcoming MOPEAD project (Models of Patient Engagement for Alzheimer’s Disease), which will officially launch on 14 December. MOPEAD is designed to assess different Patient Engagement models across Europe, to identify efficient approaches of earlier identification of mild AD dementia and prodromal AD patients. It has the potential to contribute to move the AD Environment towards earlier diagnosis to improve identification of appropriate patients for disease modifying therapies.

The first speaker was Hilary Doxford, former Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and member of the World Dementia Council. Ms Doxford shared her own experience of diagnosis and stressed the importance of a timely diagnosis.

The second speaker, Dr Octavio Rodriguez spoke about “When to suspect Alzheimer’s Disease: from Subjective Cognitive Decline to MCI”.

Up next was session Chair Dr Boada, who gave the audience an overview of the MOPEAD project and its aims and hopes. She was followed by final speaker Annette Dumas, who gave more details about the project and about how it will inform EU action on dementia.

SS5 – Understanding the Family and Caregiver Impact of Alzheimer’s Disease

This session, chaired by independent health consultant and Policy Lead for the European Brain Council Jean Mossman, focused on the results of a survey sponsored by Roche.

The first speaker was Christin Bexelius, International Payer Strategy Leader at Roche. She showed how impact on caregivers increases as the disease evolves. Concurrently, the progression degrades quality of life. Ms Bexelius also noted that the indirect and informal costs of AD rise dramatically as the disease progresses: the survey show a fourfold increase in informal costs between the lowest and highest levels of dependence.

Mario Possenti, National Coordinator at Federazione Alzheimer Italia (FAI), spoke next, giving specific examples of the challenges faced by caregivers in Italy. FAI operates a telephone helpline for carers of people with dementia. In 2016, 19% of all calls came from carers dealing with behavioural and psychological symptoms (BPSD) of their loved ones with dementia. Mr Possenti also showed a table of symptoms affecting carers, developed during a related study. They include both psychological signs such as anger and despair, but also physical burdens such as exclusion from social relations and the sacrifice of personal interests.

The presentations were followed by a discussion session with the audience.

31 October: ADI submits response to WHO Zero Draft Global Plan on Dementia together with AE and others

On 31 October, Alzheimer Europe (AE), Alzheimer’s Disease International (ADI), Dementia Alliance International (DAI), and Global Alzheimer’s and Dementia Action Alliance (GADAA) submitted a joint formal response to the World Health Organization (WHO) Zero Draft Global Plan on the Public Health Response to Dementia.

A final version of the Plan will be considered by the 70th World Health Assembly (WHA70) in May of next year.

Read the response to the plan by AE, ADI, DAI and GADAA here.

2 November: Euractiv news talks to members of the EWGPWD about diagnosis and living with dementia

During the 26th Alzheimer Europe (AE) Conference (26AEC) in Copenhagen Euractiv journalist Sarantis Michalopoulos interviewed Helen Rochford Brennan and Hilary Doxford (pictured), members of the European Working Group of People with Dementia (EWGPWD), as part of a special series of reports on Alzheimer’s disease: Is Europe ready for Alzheimer’s? The full article was published online in Euractiv on 2 November 2016.

3 November: Euractiv news talks to our Executive Director about the state of dementia policies in Europe

Mr Michalopoulos also interviewed Alzheimer Europe Executive Director Jean Georges as part of a special series of reports on Alzheimer’s disease: Is Europe ready for Alzheimer’s? The full article was published online in Euractiv on 3 November 2016.

7 November: AE article on continence care published in the Journal of Clinical Nursing

AE represents the interests of people with dementia and carers across Europe and is fully committed to promoting the rights, dignity and autonomy of people with dementia; rights which are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.
Over the last 25 years, the issue of providing continence care at home, without adequate and appropriate support and guidance, has frequently been raised at AE conferences and in meetings. This lack of support, combined with the risk of premature institutionalisation, was considered an important threat to rights, dignity and autonomy and as inequity in the provision of health care to people with dementia compared to other groups in society. Having recognised a shared interest in improving the continence care of community-dwelling people with dementia, in 2014, Alzheimer Europe (AE) and global hygiene company SCA worked together with a group of experts in the field of continence care and policy to produce a detailed report on "Improving continence care for people with dementia living at home".

Subsequently, AE has collaborated with its continence care working group to complete a review of literature relating to the continence care of community-dwelling people with dementia in Europe. "Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges" was published online in the Journal of Clinical Nursing on 7 November, with open access.


18 November: AE Foundation awards prizes for 26AEC posters

Following Alzheimer Europe’s 26th Annual Conference #26AEC, the Alzheimer Europe Foundation has awarded a prize to the top four poster presentations, as voted by conference participants via poster evaluation forms. The winner for each day of the poster presentations (1 and 2 November) has been awarded EUR 750 and the runner-up for each day was awarded EUR 250.

The two winners and two runners up were:

- 1 November runner-up: Trine Nordby Skjellestad (Norway), “Who will see me? – Children who have a parent with dementia”.
- 2 November winner: Deirdre Fetherstonhaugh (Australia), “Sex might be a taboo subject but we need to get it right! Resources to assist residential aged care staff and family carers”.
- 2 November runner-up: Wienke Jacobsen (Germany), “Farm as a place for people living with dementia”.

Congratulations to all four!

The Foundation has also awarded a free subscription for the 2017 conference in Berlin to one lucky participant, drawn at random from the submitted poster evaluation forms: Congratulations to Aase Marie Ottesen (Denmark) - we look forward to welcoming you to Berlin for #27AEC!

The Alzheimer Europe Foundation would like to thank all 123 conference delegates who voted and all poster presenters for their excellent contributions at the conference.

EU projects

25 October: AETIONOMY project welcomes new partner from Barcelona

As of 25 October, the AETIONOMY project is pleased to welcome a new project partner - the BarcelonaBeta Brain Research Center (BBRC).

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

25 October: EU Project PredictND holds general assembly meeting in London

On 25 and 26 October, the research project “From Patient Data to Clinical Diagnosis in Neurodegenerative Diseases” (PredictND) held its 6th team and management board meetings at GE Healthcare in Amersham, UK. The project finished its baseline data collection in June 2016 and is currently analyzing the collected data. There will also be 12-month follow-up data collection with the same subjects. The collected prospective data will allow scientific research for improvements in early detection of the neurodegenerative diseases.
The meetings focused on designing the data analyses and forthcoming publications. A risk analysis workshop was also held to map the whole consortium view on possible risks involved in use of the PredictND tool, now that there is experience on its use in the study. In addition to data analysis, the PredictND tool is still being developed further. For example, the user interface has been improved and reporting functionality is being added.

The PredictND project has received funding from the European Union’s Seventh Framework Programme for research (FP7), technological development and demonstration under grant agreement no 611005. The project team consists of nine European institutes: VTT Technical Research Centre of Finland Ltd. (Finland, co-ordinator), GE Healthcare Ltd (UK), Imperial College London (UK), University of Eastern Finland (Finland), Rigshospitalet/Region Hovedstaden (Denmark), VU/VUmc (The Netherlands), University of Perugia (Italy), Alzheimer Europe (Luxembourg), and Combinostics Ltd. (Finland).

Alzheimer Europe Executive Director Jean Georges and Director for Projects Dianne Gove participated in these meetings.

31 October: INTERDEM members meet in Copenhagen

The INTERDEM group met on 31 October in Copenhagen prior to Alzheimer Europe’s annual conference.

New members made short presentations about their research interests and work and were welcomed to the group.

This was followed by the INTERDEM business meeting which focused on possible future collaboration between members in new projects, INTERDEM website and post-doctoral training. In addition, there were 10 short “laptop presentations” which allowed focused debates (‘think tank’) between presenters and participants.

In the afternoon, Prof. Frans Verhey chaired a session on new insights in dementia research which was followed by an update of the ongoing INTERDEM projects.

Alzheimer Europe Project Officer Ana Diaz and Director for Projects Dianne Gove attended the meeting.

10 November: EPAD conference held in Switzerland

On 10 November 2016, the European Prevention of Alzheimer’s Dementia (EPAD) initiative held a public conference in Geneva, Switzerland, in collaboration with Hôpitaux universitaires de Genève (HUG).


The six eminent speakers included Prof. Frederick Barkhof, Professor of Neuroradiology, Department of Brain repair & Rehabilitation, Institutes of Neurology and Biomedical Engineering, UCL, London and Department of Radiology & Nuclear Medicine, VU University Medical Centre, Amsterdam. Prof. Barkhof’s presentation was on “EPAD and AMYPAD: the future of Alzheimer’s care is today”.

Organisers were Neurologist Prof. Giovanni B. Frisoni, Professor of Clinical Neuroscience and Head of Memory Clinic, HUG and University of Geneva, Switzerland and Dr Idris Guessous, Head of Epidemiology, HUG and University of Geneva. Dr Guessous chaired the conference.

Acknowledgement: This work has received support from the EU/EFPIA Innovative Medicines Initiative Joint Undertaking EPAD grant agreement nº 115736.

http://www.hug.ge.ch/geriatrie/programme-conference-prevenir-maladie-alzheimer

11 November: INDUCT project publishes winter 2016 newsletter

The INDUCT project has published its second newsletter. The winter 2016 edition contains:

- Introducing our Early Stage Researchers (ESRs).
- A Word from the Induct Coordinators.
- Message from the Induct Ombudsman.
- Alzheimer Europe Conference 2016, Copenhagen.
- Involving people with dementia in research.

INDUCT (Interdisciplinary Network for Dementia Utilising Current Technology) is a four year project under the Marie Skłodowska-Curie Actions Programme. The main aim of INDUCT is to develop a premier quality multi-disciplinary, multi-professional and intersectorial education and training research framework for Europe aimed at improving technology and care for people with dementia, and to use the coherent themes and interrelated Early Stage Researchers ESRs within INDUCT to provide the evidence to show how technology can improve the lives of people with dementia.

Download the newsletter here:
http://www.dementiainduct.eu/newsletters/

16 November: ROADMAP project paves way for sustainable platform for generation and analysis of real world evidence in AD

On 16 November, the members of the ROADMAP initiative - Real world Outcomes across the Alzheimer’s Disease (AD) spectrum for better care: Multi-modal data Access Platform - announced the start of a new collaborative pan-European research effort. Its aim is deliver a series of scalable, transferable data integration methods and tools for patient outcomes, developed and tested through pilot projects, which will provide the foundation for a Europe-wide RWE platform on AD. In parallel, ROADMAP will develop tools for stakeholder engagement and for better understanding of the ELSI
(ethical, legal and social implications) context and health economics impact of a RWE approach in AD.

Successfully delivering therapies to people with AD will also depend on building a sustainable global payer strategy to address challenges around drug access to markets. This will be dependent on the integration of RWE in health care systems to support approval as well as HTA/payer evidence. The development of a sustainable global payers strategy is one of ROADMAP’s objectives.

As the result of an ageing population, rising costs and more specialised treatments, Europe is now facing an acute healthcare challenge. In no area is this more apparent than in AD and dementia. The European Union (EU), with the world’s most diverse and sophisticated health care systems, is uniquely placed to develop and exploit technologies to support RWE; addressing operational issues of data access, integration and security, alongside hypothesis testing, ELSI, health economic (HE) and budget impact, at a level of detail and complexity not possible elsewhere.

ROADMAP, led by the University of Oxford and Novartis (on behalf of EFPIA), has been designed to combine active participation of stakeholder representatives with exemplar pilot exercises in different settings that allow the identification of the opportunities and threats for widespread adoption of RWE and to enhance clinical and health policy decision-making in AD.

It also addresses the challenge of how to best inform clinical and health policy decisions by conceptualising the entire population as the decision-making laboratory and building a population-based integrated data environment which is optimised for precision and personalised medicine. By developing tools enabling this laboratory to conduct hypothesis specific in-silico experiments, ROADMAP provides a context for identifying and addressing the many unknown challenges of AD. In this process, the interests of healthcare providers, industry, regulators, payers, patients and governments can be addressed transparently, leading to shared best practice, greater efficiency and responsiveness to increasingly fine-grained healthcare questions.

In order to achieve its objectives, ROADMAP has been designed as a highly pragmatic initiative. It combines active stakeholder participation (with special emphasis on patients, HTA, regulators and payers) with the application of established technologies across diverse data types and across healthcare systems, to optimise the use of RWE in AD.

ROADMAP aims to provide the foundation for a much-needed integrated data environment and framework for RWE in AD including: 1) The development of consensual key outcome measures across stakeholder groups; 2) Enabling data integration tools for dataset characterisation and outcome classification, data standards, data sourcing, software application repository; 3) Guidelines on the handling and interpretation of RWE data.

In addition, the following priorities have been identified: Outcome measurement; Identifying the best natural history model; Identifying the best pharmacoeconomic modelling strategy; Using short-term data to model long-term effects; Using short-term data to model long-term economic impact; Association between cognition, QoL (quality of life) and function over the AD spectrum; Identifying combination markers for diagnosis in asymptomatic patient population; Identifying combination markers for prognosis; and consolidating the regulatory/HTA/payer evidence requirements.

ROADMAP is mainly sponsored by the European Union’s Horizon 2020 research and innovation programme and the European pharmaceutical industry (via EFPIA) under the auspices of the Innovative Medicines Initiative (IMI) 2 Joint Undertaking.

For more information, check out [www.roadmap-alzheimer.org](http://www.roadmap-alzheimer.org)

Jean Georges, Dianne Gove and Ana Diaz attended the kick-off meeting on behalf of Alzheimer Europe (AE). AE will co-lead Work Package 7 on communication and patient/healthcare provider engagement, and will also contribute to most of the WPs of the project, particularly to the definition of real world outcome measures for Alzheimer’s disease that are relevant to people with dementia and their families and to the discussions of ethical and social implications of the project.

22 November: EPAD paper reviews effects of disclosing AD biomarker results to healthy individuals

Current Alzheimer’s disease (AD) research initiatives focus on cognitively healthy individuals with biomarkers that are associated with the development of AD. It is unclear whether biomarker results should be returned to research participants and what the psychological, behavioural and social effects of disclosure are. A systematic review by the European Prevention of Alzheimer’s Dementia (EPAD) initiative has examined the effects of disclosing genetic and nongenetic AD-related biomarkers to cognitively healthy research participants.

A systematic literature search in eight scientific databases was performed. Fourteen studies met the inclusion criteria and were included in the data synthesis. Results extracted from the included articles were aggregated and presented per effect group. None of the identified studies examined the effects of disclosing nongenetic biomarkers. All studies but one concerned the disclosure of APOE genotype and were conducted in the US.

Study populations consisted largely of cognitively healthy first-degree relatives of people with AD.

The EPAD reviewers concluded that in cognitively healthy research participants with a first-degree relative with AD, disclosure of genetic biomarkers does not lead to elevated anxiety and depression levels, but does increase test-related distress and results in behaviour changes concerning insurance and health. They did not find studies reporting the effects of disclosing nongenetic biomarkers and only one study included people without a family history of AD.

“Empirical studies on the effects of disclosing nongenetic biomarkers and of disclosure to persons without a family history of AD are urgently needed” they concluded.

Alzheimer Europe networking 2016

On 31 October-2 November (Copenhagen, Denmark), AE staff attended the 26th Alzheimer Europe Conference (26AEC).

On 1 November (Copenhagen, Denmark), Jean met with representatives of France Alzheimer for an exchange of views on the discussions in France regarding the reimbursement of Alzheimer medicines.

On 1 November (Copenhagen, Denmark), Jean met with Lilly representatives to discuss AE’s plans for 2017 and the collaboration on IMI funded projects MOPEAD and ROADMAP.

On 1 November (Copenhagen, Denmark), Jean and Vanessa met with representatives of MSD to explore possible areas for collaboration in 2016 and 2017.

On 1 November (Copenhagen, Denmark), Dianne and Ana met with members of INTERDEM to discuss collaboration on PPI position paper.

On 2 November (Copenhagen, Denmark), Dianne and Ana participated in the INTERDEM Masterclass.

On 2 November (Copenhagen, Denmark), Jean met with Myrra Vernooij-Dassen to explore ways for closer collaboration between Alzheimer Europe and the INTERDEM network.

On 2 November (Copenhagen, Denmark), Jean met with representatives of Roche to update them on the organisation’s Carers’ survey project and discuss collaboration opportunities in 2017.

On 2 November (Copenhagen, Denmark), Jean met with representatives of the European Alzheimer’s Disease Consortium to explore areas for collaboration between the two organisations.

On 2 November (Copenhagen, Denmark), Jean met with representatives of AbbVie for an introductory meeting.

On 3 November (Copenhagen, Denmark), Jean participated in a meeting of WP6 (Dissemination) of the EPAD project.

On 4 November, Dianne participated in the EPAD ethics work package telephone meeting.

On 7 November, Dianne participated in the PACE GA telephone meeting.

On 8 November (Brussels, Belgium), Jean participated in a European Parliament meeting dedicated to European research on dementia hosted by Ernest Maragall, MEP (Spain) and organised by the Innovative Medicines Initiative.

On 10 November (Luxembourg, Luxembourg), Gwladys attended an HRG event for clients and suppliers.

On 14 and 15 November (London, UK), Jean participated in a workshop on big data opportunities organised by the EMA.

On 16 and 17 November (Barcelona, Spain), Ana, Dianne and Jean attended the kick-off meeting of the ROADMAP project.


On 22 November, Dianne participated in a telephone conference with Karen Riisgaard re the Human Brain Project Subproject 12.

On 22 November, Ana and Dianne took part in a telephone conference with the AD-Sensor project proposal.

On 24 November (Luxembourg, Luxembourg), Ana and Dianne had a meeting with Isabelle Tournier re the MinD project.

On 25 November, Kate, Ana, Dianne and Jean took part in a telephone meeting for the SMART4MD project.

On 25 November, Kate and Jean participated in a MOPEAD project WP5 telephone meeting.

On 28 November (Bratislava, Slovakia), Jean attended the meeting of government experts on dementia convened by DG SANTE of the European Commission.


On 28-29 November (Brussels, Belgium) Vanessa attended an EDF event at the European Commission for The European Day of Persons with Disabilities (EDPDP).

On 29 November (Brussels, Belgium) Vanessa attended the “Public private partnership: a successful experience” event at the European Parliament.

On 29 November (Bratislava, Slovakia) Jean, Iva and Charles participated in the conference of the Slovak EU Presidency “Alzheimer’s disease – epidemic of the third millennium”.

On 29 November (London, UK), Dianne took part in the EMA training session.

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 Brempt (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomatić (ECR). **Cyprus:** Costas Mavridis (S&D); Eleni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Merja Kylönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (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 Mitsitis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyrali (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg (NI). **Hungary:** Ádám Kósa (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Catherine Stihler (S&D); Roberto Gualtieri (EPP). **Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Stefano Mauro (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). **Lithuania:** Vilija Blinkevičiutė (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybacka (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 (S&D); Daciana Octavia Sarbu (S&D). **Slovenia:** Angelika Niebler (EPP); Udo Voigt (NI). **Spain:** Sofia Nina (S&D); Marifran Del Olmo (EPP); Ricardo Mufíl (NI). **Sweden:** Johanna Olofsson (S&D); Anna Östberg (NI). **Turkey:** Barış Akarsu (NI). **United Kingdom:** Therese Comodini Cachia (ALDE); Jean Marinescu (EPP); Izaskun Bilbao Barandica (ALDE). **Croatia:** Bogut (NI); Milica Šunj (NI); Nina Gracin (NI).

European Alzheimer’s Alliance

23 November: Spotlight on: Karin Kadenbach, Member of the European Alzheimer’s Alliance

Following her recent membership of the European Alzheimer’s Alliance we asked Austrian MEP Karin Kadenbach why she joined the EAA and what should be done at European level to tackle the impact of Alzheimer’s disease and other dementias.

“Due to the demographic changes in the European Union we are facing new challenges to our healthcare system. Approximately 130,000 people live with dementia in Austria. In the European Union around 22% of the inhabitants are older than 60. This number will double in 30 years."

The elevation of the aging population is leading to an increased incidence of the incurable disease dementia and its sub forms. We have to tackle this disease on different levels. The EU-level can only set broad policy frameworks.

I joined the EAA to bring more attention to dementia and especially Alzheimer’s disease. We need to integrate the patient agenda into the policy agenda. At European level we should focus on health literacy, investing in research and building up awareness to mention just some of the keywords.”

Ms Kadenbach also recently participated in the special symposium “Facing the challenge of Alzheimer’s and other dementias” (pictured) at the European Health Forum Gastein (EHFG) where she met Helen Rochford Brennan, Chair of the European Working Group of People with Dementia (EWGPWD).

http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance/Members/Kadenbach-Karin

EU developments

7 November: IMI appointments new Scientific Committee

On 7 November 2016, the Innovative Medicines Initiative...
(IMI) formalised the two-year appointment of its Scientific Committee members.

The IMI Scientific Committee includes internationally acclaimed experts from highly specialised medical fields, including bioinformatics, cancer, microbiology, molecular biology, neurology, pharmacology, proteomics and public health.

The 11 members of the IMI Scientific Committee, including one ad-hoc member are: Isabelle Bekerdedjian-Ding, Andreas Bernkop-Schnur, Maria Blasco, Dolores Cahill, Anna Chioti, Maria Beatriz Da Silva Lima, Hans-Georg Eichler, Markus Perola, Torsten Schwede, Tanel Tenson and Annamaria Vezzani.

The Scientific Committee provides strategic science-based recommendations to IMI and advises on the continued relevance of the Strategic Research Agenda and the scientific priorities, which are the basis for the Call topics. The Committee is appointed upon suggestions made by the States Representatives Group.

http://www.imi.europa.eu/content/scientific-committee

8 November: IMI organises roundtable discussion on challenges of Alzheimer’s disease

On 8 November, the Innovative Medicines Initiative (IMI) organised a roundtable discussion in the European Parliament in Brussels, on the challenges of Alzheimer’s disease (AD) for patients. The discussion was an opportunity to share the progress and results delivered by the IMI Alzheimer’s Disease Platform and its global collaboration and synergies with other EU projects in the field.

The roundtable, hosted by MEP Ernest Maragall (Spain), brought together patient advocates, academia, pharmaceutical companies, IMI projects and other EU-funded consortia, as well as research organisations. Executive Director Jean Georges represented Alzheimer Europe (AE) at the meeting. In particular, the spotlight was on the collaboration between the IMI projects EPAD, EMIF and AETIONOMY – each of which is involved in - under the IMI Alzheimer’s Disease Platform and its collaboration with other high-level initiatives in the field of dementia.

The event presentations are available for download from the event webpage.

15 November: EMA proposes safety-improving changes to current guideline on first-in-human clinical trials

The European Medicines Agency (EMA), in cooperation with the European Commission and the Member States of the European Union (EU), is proposing changes to its existing guideline on first-in-human clinical trials, to further improve the safety of trial participants. The revised guideline is open for public consultation until 28 February 2017. Comments should be sent to FHH-rev@ema.europa.eu using the template provided.

Between July and end of September 2016, EMA released for public consultation a concept paper, which outlined the major areas needing to be revised, to reflect the evolution of practices in the last ten years.

The consultation of the concept paper served as the basis for the revision of the guideline, which was carried out by an EU-wide group made up of experts from the national competent authorities who authorise clinical trials in the EU. The draft revised guideline was adopted this month, by the EMA’s Committee for Medicinal Products for Human Use (CHMP).

EMA will make available all comments received, both on the concept paper and the revised guideline, after the final guideline is released. The aim is to publish a final revised guideline for the conduct of first-in-human clinical trials in the first half of 2017.


15 November: JPND announces upcoming Joint Transnational Call for Research Proposals

The EU Joint Programme – Neurodegenerative Disease Research (JPND) will shortly launch a call for “Multinational Research Projects for Pathway Analysis across Neurodegenerative Diseases”.

There is clinical, genetic and biochemical evidence that similar molecular pathways are relevant in different neurodegenerative and other chronic diseases. Therefore, JPND will launch a call for multidisciplinary proposals to perform network analyses across such diseases and to elucidate the underlying mechanisms involved. Research proposals may:

- Combine experimental approaches from fundamental, pre-clinical and/or clinical research.
- Perform network analyses in different neurodegenerative and/or other chronic diseases to elucidate the underlying common and differing mechanisms in the investigated diseases.
- Add value to existing research by analysing diseases across traditional clinical boundaries, technologies and disciplines, thereby gaining deeper understanding of the patho-physiological mechanisms of neurodegenerative diseases.

The following neurodegenerative diseases are included in the call:

- Alzheimer’s disease and other dementias
- Parkinson’s disease and PD-related disorders
- Prion diseases
- Motor neuron diseases
- Huntington’s disease
- Spinocerebellar ataxia (SCA)
- Spinal muscular atrophy (SMA)

Cross-disease analysis may solely comprise different neurodegenerative diseases or include other chronic...
diseases (e.g. chronic mental or physical disorders). Up to six research groups from at least three different countries may collaborate within a consortium.

This will be a two-step call, expected to be launched in early January 2017. Final call information will be published on the JPND website www.jpnd.eu

17 November: European Patients Forum holds Policy Advisory Group meeting

On 17 November, the European Patients Forum (EPF) held a Policy Advisory Group (PAG) meeting in Brussels.

The European Disability Forum (EDF) presented its 2017 work plan, after which there was a group discussion.

The group also reviewed the EPF draft survey on electronic health records and was given updates on the following policy dossiers: European Parliament own initiative report on access to medicine; Update on discussions for lay summaries of clinical trials results; EPF’s briefing for patients and patient organisations on data protection.

Daniela Morghenti, EU Policy Advisor from the European Federation of Allergies and Airways (EFA) presented the EFA’s experience on how to run a campaign on a Written Declaration.

Alzheimer Europe Policy Officer Vanessa Challinor attended the meeting.

23 November: European Commission/OECD launches Health at a Glance Report

On 23 November, Commissioner Andriukaitis launched “Health at a Glance: Europe 2016”, a European Commission/OECD joint report which shows the state of health provision across the EU. The publication is the result of a renewed collaboration between the OECD and the European Commission under the broader “State of Health in the EU” initiative, designed to support EU member states in their evidence-based policy making.

The flagship report provides comparisons of health status, risk factors to health, health expenditure, access to care and quality of care in 36 European countries. The 2016 edition also includes chapters analysing the links between population health and labour market outcomes as well as the need in all EU countries to strengthen primary care systems. The report is a first step in the Commission’s new State of Health in the EU cycle.

The full report can be read here.

Members’ news

2 October: Dementia represented in theatre production in Malta for the first time

On 2 October, the Malta Dementia Society in collaboration with the University of Malta and HSBC Call Centre (Malta) staged a theatre representation on dementia. This was the first time that dementia was represented as a theatre production in Malta.

Il-Masgar tal-Allat Siekta (The Grove of the Silent Gods) centres on a family of three who, in their own way, are grappling with the diagnosis and aftermath of Alzheimer’s disease. There is a focus on the various stages of disease progression starting with diagnosis, denial, anger and finally acceptance. The various monologues contained also reflect society’s stigma against mental diseases including dementia.

According to the author, the main objective of this socio-cultural-educational representation of Alzheimer’s disease was that of creating more awareness of this particular disease, which affects thousands of Maltese individuals.

A one-hour discussion on dementia by the audience followed the staging of the play.

5 October: Ireland receives huge response to “Dementia Care Begins at Home” campaign

The Alzheimer Society of Ireland (ASI) received a huge response to its Pre-Budget Campaign, “Dementia Care Begins at Home”, with over 25,000 people signing a petition calling on the Irish Government to invest in home care supports for people with dementia.

In addition to the petition a wonderful campaign video made by Kathy Ryan, a Vice-Chair of the Irish Dementia Working Group, and her sons Matt and Andrew went viral and was viewed by over one million people.

While funding was provided for an additional 950 generic home-care packages in the Irish Budget, this is not enough to meet the needs of the thousands of families trying to support a loved one with dementia to remain living at home and this is an issue the ASI will continue to highlight.

More information on this campaign is available on www.alzheimer.ie

Pictured L-R: Minister Helen McEntee and Pat McLoughlin, ASI CEO, at the handover of the ASI petition on 5 October 2016.
12 October: Federazione Alzheimer Italia member inaugurates "Casa Viola" project

The Association Goffredo de Banfield is a voluntary non-profit organisation, active in Trieste since 1988. A part of Federazione Alzheimer Italia since 1995, it works in favour of people in conditions of extreme fragility with or without dementia, helping them to live at home as long as possible and to postpone institutionalisation.

There are numerous studies and research about the condition of stress, loneliness and isolation experienced by caregivers. All these conditions, together with the psychological burden, bring a deterioration in both the stress and emotional tension of the caregiver influencing also the cognitive performance of the person with dementia, who happens to live better in an environment quiet and free from confrontation.

In order to be even more effective in accompanying and supporting family members in their care commitment, on 12 October 2016 the Association inaugurated its new "Casa Viola" (Purple Home). This is a unique project in Italy: a tailor-made space for family members, welcoming, open to meeting and all kind of sharing; a centre where you can find a wide range of informational, recreational and psychological activities to support caregivers.

The proposal of the activities to be carried out within the "Casa Viola" - designed like a real house with a kitchen and living area - range from the possibility for family members to receive support through mutual-help groups and personalised psychological support, to activities dedicated to the promotion of well-being - such as exercise classes, cognitive stimulation, sewing, weaving and art laboratories.

The "Casa Viola" project makes use of the important support of Federazione Alzheimer Italia, the collaboration of the Municipality of Trieste and of the Health University of Trieste. It also relies on the professional contribution of a scientific committee composed of experts, and stands as an important reference point for the collection of valuable scientific data, analysis and enhancement of the role of the caregiver.

The project includes a psychologist dealing with the compilation and collection of data through questionnaires, to help establish whether there is an actual positive result from participation in these activities for caregivers, and whether the stress level and psychological burden is reduced.

27 October: Alzheimer Switzerland participates at OECD Workshop in Lausanne

The yearly workshop, organised under the auspices of the Organisation for Economic Cooperation and Development (OECD) and which was first held in 2014, convened international stakeholders in Lausanne to promote innovative strategies in Alzheimer’s research, regulation and access to treatment. The workshop is supported by the State Secretariat for Education, Research and Innovation (SERI), Switzerland, The Global CEO Initiative on Alzheimer’s Disease (CEOi) and Alzheimer’s Disease International (ADI).

Anna Munk, a nurse on the Swiss Alzheimer’s national helpline, presented a talk on dementia-friendly communities in theory and in practice as a part of the introductory session dedicated to the theme "What’s driving our efforts? Supporting people living with Alzheimer’s disease". In her talk, she gave an overview of the numerous aspects that add up to make a society dementia friendly. She underlined the dichotomy between a society, which tends to patronise or ignore people with dementia, who might be felt to be disruptive or bothersome, as opposed to being inclusive of those same people, along with other minorities, because society is about caring for the needs of as many of its members as possible, and ideally of all of them. Ms Munk concluded her talk on the fact that awareness still needs to be raised, as participation can only be a natural attitude for people with dementia if they are truly welcome to participate, but that people living with dementia do have crucial observations to share with us. This is why Alzheimer Switzerland decided to choose “My life with dementia” as its motto for 2017, putting the voices of people with dementia at its heart.

2 November: Alzheimer Croatia holds 2nd edition of “EdukAl” conference


The discussion focused on the issues of dementia and society and adopted several decisions: to increase the public fight against stigma, to initiate the adoption of a national dementia plan, to improve education of all who come into daily contact with people with dementia, to recognise family caregivers as formal caregivers and to improve standards in nursing homes catering for people with dementia. The need for development of dementia-friendly communities and to support Alzheimer Croatia to lead all these changes were also noted.

During the two-day conference participants took part in workshops on methods of early diagnosis and on person-centered care for people with dementia.

EdukAI 2016 was held under the auspices of the Ministry of Health and the Ministry of Demography, Family, Youth and Social Policy of the Republic of Croatia and the City of Zagreb. It was also supported, again, by Alzheimer Europe, Alzheimer’s Disease International (ADI), the Mediterranean and Croatian Alzheimer’s Alliance and the chambers of medical doctors, nurses, therapists, psychologists and social workers.
3 November: Solidarity, support and personal growth in Danish “folk high school” courses for people with dementia

Recently, the Folk High School pedagogy has been developed in Denmark in two projects for people with dementia in the early and middle stages. One was conducted by The Danish Alzheimer Association (Alzheimerforeningen) in week-long courses at three of the schools. The other was conducted by a local branch of the Association, Alzheimerforeningen Østjylland, consisting of activities once a week for six months at a former seaside hotel.

In both projects, there were activities including physical exercises - in the open air when possible, singing, storytelling, arts and other creative courses. “For some a new challenge, for others skills long forgotten, for all days of joy and togetherness”, writes former Alzheimerforeningen Chairperson Anne Arndal.

The participants with dementia experienced support and sympathy in social groups and an enhanced quality of life, says Ms Arndal. They felt accepted and acknowledged by the other participants and by therapists and staff. The relatives got a much-needed break and some time to themselves, in the knowledge that their loved ones were in good hands and enjoying themselves.

The knowledge gained during both projects is important to the continuation of current courses and to the implementation of high school pedagogy in new settings of dementia care.

“It was the best week of my life – at least as far as I remember it”, “You are the best friends I ever had” (participants’ remarks).

7 November: Slovenia runs successful poster campaign

On 7 November, Alzheimer Slovenija (Spomincica) announced an awareness campaign consisting of 300 “citylight” posters, which appeared all over Slovenia for 8 days. This is a campaign to raise awareness about dementia.

The advertising agency used, Eurolaplat has since agreed to continue the campaign, retaining the posters in several prime locations, such as entrances to shopping centres.

The poster (pictured) - designed by a leading design, consultancy and communications company, Pristop – will also be published in a national design magazine.

11 November: UK Alzheimer’s Society launched a new blog

This month, the Alzheimer’s Society (UK) launched a blog, where it will be posting Alzheimer’s Society news, dementia research updates and personal stories, among others.

For example, in a first blog post Pam (pictured) shares her story about caring for her mum who was diagnosed with Alzheimer’s disease aged 73.

13 November: 185 runners in Istanbul Marathon support Alzheimer Turkey

The Vodafone 38th Istanbul Marathon, which took place on 13 November, is unique in the sense that it is inter-continental. The number of participants was limited to 10k for 42km, 12.5 k for 15 km and 12.5k for 10 km races. After the races began, thousands more started a “public run/walk” for 8 km.

There were 90 top athletes this year from Turkey, Belarus, Eritrea, Ethiopia, South Africa, Kenya, Russia and Ukraine. Evans Kiplagat from Azerbaijan came first, while Shura Kitata Tola from Ethiopia finished second and Peter Kiptoo Kiplagat from Kenya came third. For the women, Agnes Jeruto Barsosio from Kenya took gold and Sechale Adugna Dalasa and Rahma Tusa Chota, both from Ethiopia, took silver and bronze respectively. A total of USD 887,000 was awarded the high rankers.

Adim Adim (Step by Step in Turkish) is a platform established in 2007. The aim of the platform is to create resources and awareness through charity runs in Turkey, for NGOs that agree with absolute transparency. Between 2008 and 2015, 13,000 runners have raised TRY 14.5 Million by collecting small donations from 111,000 donators across 8 NGOs, changing the lives of 70,000 people.

This year the platform opened up to accept more NGOs into its community, so the figures reached a huge 24,927 volunteer runners, 179,763 donators and TRY 20,628,561 collected for all the NGOs in the pool, with roughly 100,000 people benefiting from this effort in some way, through scholarships, wheelchairs, etc.

Through this enlargement process, Türkiye Alzheimer Derneği (Alzheimer Turkey) joined the platform to raise awareness and gain some money for our “homecare service for bedridden Alzheimer patients” project. We were lucky to get 185 volunteer runners to sign up with our Association. It was a very enjoyable connection, to run in identical Alzheimer t-shirts, waving Alzheimer flags and sharing the experience with our supporters who had been sending messages, mails, tweets, etc. to all their connections just to be our voice.
15 November: Alzheimer Slovenia reports on a new project in which it is involved - AD-GAMING

The kick off meeting of the AD-GAMING project took place on 15-16 November in Valencia, Spain. AD-GAMING aims to increase the technological and digital skills and ICT literacy of people with Alzheimer’s dementia, their families and caregivers, allowing them to use “serious games”, with the purpose of improving their Quality of Life (QoL).

There is strong evidence that stimulation of cognitive abilities helps slow the loss of functions and abilities, consistently improves cognitive functions and is also associated with benefits of QoL and communication. To promote these impacts and to overcome the existing barriers, AD-GAMING is launched with the main objective of increasing the competences (attitudes, skills, knowledge) of the collective around persons with mild and moderate Alzheimer’s dementia (persons, families and caregivers) about how to exploit serious games for increasing their QoL, through an innovative training programme

The project has the following specific objectives:

- To create awareness and motivation about the importance and possibilities of serious games as a tool for improving QoL for persons with Alzheimer’s dementia.
- To inform and make available a prioritised selection of serious games for their application to the specific needs of each person.
- To train persons, families and professionals on how to play serious games for therapeutic purposes.
- To develop digital and technological skills, which allow persons with Alzheimer’s dementia and their carers to properly exploit ICT-based serious games.
- To involve professionals and families in the training process in order to be able to support persons with Alzheimer’s dementia.
- To increase the social inclusion of persons with Alzheimer’s dementia, through the participation of their families in serious games in domestic environments.

The AD-GAMING Project is being developed by a consortium of different entities from 5 countries and complementary backgrounds (user associations, university and technological centres). Project partners are: Asociacion Familiares Enfermos Alzheimer Valencia (Spain), Instituto di Biomecanica de Valencia (Spain), Bournemouth University (UK), Spomincica Alzheimer Slovenija (Slovenia), Societatea Romana de Sfirijn a Varstnicilor si a Suferintilor cu Afectiuni de tip Alzheimer (Romania) and Elliniki Etaireia Nosoy Alzheimer Kai Syggenon Diatarachon Somateio (Greece). The AD-GAMING project will run until August 2018.

This project has been funded with support from the European Commission under the ERASMUS+ initiative (project number 2016-1-ES01-KA204-025313).

17 November: Jersey Alzheimer’s Association reports on 26AEC

In the November edition of its Friendship Group newsletter, the Jersey Alzheimer’s Association reported on its experience of Alzheimer Europe’s 26th Annual Conference, 26AEC:

“Brian Snell and I reflected on our recent trip to the Alzheimer Europe Conference in Copenhagen which took place between 31 October and 2 November which Jim also attended as Chairman of the charity. The overall theme for the Conference was ‘Excellence in dementia research and care’.

Brian spoke about the Award which had been presented at the Conference to his wife Rozel, who is living with dementia, in recognition of Rozel’s contribution to the Alzheimer Europe Working Group over many years.

I then highlighted some of the many highlights of the Conference at which a large number of the speakers were people living with a diagnosis of dementia and care providers.

The main message which I brought back was the necessity to start any discussion about the help and support that is required by people with dementia and carers with those individuals directly affected. ‘Nothing about us without us’ as is said in Scotland. Over and over again this point was made in both plenary and workshop talks.

Each year the Conference consists of an AGM on the first day followed by the official Opening Ceremony in the evening, then two full days of presentations and posters on display, all promoting the latest best practice across Europe. This year there were delegates and speakers from the USA and Australia as well as the many member countries of Alzheimer Europe.

Language is critically important and one speaker who herself has dementia said that if you use the phrase ‘a person living with dementia’ it automatically excludes any care providers. Therefore it is better to speak of ‘people affected by dementia’ and so be more inclusive.

The good news is that well co-ordinated and well-funded research is currently underway to find effective treatments for the symptoms of dementia. Quite a few of the main talks centred on ethical issues around public participation in research. Large numbers of people are needed in order to produce effective results from which drugs can be developed. Typical timescales for research projects are 10-15 years, so beware of Newspaper headlines offering cures today.

I learned about a number of wonderful person-centred initiatives involving art and dementia, including artists in residence in a region of the UK, working in a number of Care Homes; ‘I come alive when I go to the group’ said one participant. ‘Armchair tours’ of Chatsworth House are happening thanks to links made possible by the latest technology. These ideas ‘value a continued zest for life’ for
those who take part. An Italian project involved a dialogue between people with dementia and professional musicians playing violins. One member of the group likened handling a violin for the first time to holding a newborn baby.

Perhaps the most powerful - and effective - talk which I heard was given by Helen Rochford-Brennan from Ireland. She spoke of the impact of receiving a diagnosis of dementia. Helen had worked in the arena of disability rights before herself receiving a diagnosis of dementia; she described very movingly what she felt on learning that she had dementia and the support she eventually found thanks to charities and the European Working Group of people with Dementia for which she now campaigns. Helen said that the ‘deepest darkest grief descended’, ‘hope is all I had’ and ‘I am the same person before and after the diagnosis’.

Overall the Conference was very informative and encouraging with many courageous and determined people with dementia and care providers talking about their own personal experiences as well as scientists and healthcare professionals.

Once again Scotland’s brilliant rights-based Dementia Strategy was described. In Scotland an individual receives a full year’s support from a Link Worker immediately following the receipt of a diagnosis of dementia. It is time for Jersey to adopt its own Dementia Strategy, in common with the vast majority of the Alzheimer Europe member countries.”

Pictured: Brian receives plaque for Roze for its support to charities and the European Working Group of People with Dementia (EWGPWD).

23 November: UK Alzheimer’s Society writes “How campaigning can change the face of dementia right now”

While we wait for a cure for Alzheimer’s disease and other types of dementia, the Alzheimer’s Society (UK) believes that we can change the quality of care people are receiving right now for the better.

That’s why we launched the Fix Dementia Care campaign: a series of investigations into the state of dementia care at hospitals, care homes and homecare. We want people living with dementia and their families to be treated with dignity and not as second-class citizens.

Supporters are helping us get there

Since the launch in January 2016, the campaign has been a great success.

After 10,000 people emailed the CEO of NHS England, calling on him to make sure all hospitals publish an annual dementia statement, he pledged his support:

“NHS England will be encouraging trusts to publish an annual dementia statement, to set out the quality of the care they provide. Additionally, we are exploring, with the Department of Health, ways in which we could require hospitals to publish an annual dementia statement.”

Now our Policy team is leading on the development of a statement for hospitals.

20,000 supporters also helped us call on the Health Minister to end unfair charging of care homes by GP practices. We’ve met with the Minister with responsibility for dementia to discuss our recommendations and we are closer than ever to stopping this unfair practice.

Behind the scenes

Our Hospitals investigation highlighted how thousands of people with dementia are being discharged from hospitals every year, between the hours of 11pm and 6am. Our team presented the evidence to a cross-parliamentary committee, which concluded that night discharges are “potentially dangerous” for patients and called on the Health Secretary to take action.

The Alzheimer’s Society will keep campaigning tirelessly until every person with dementia has the care they deserve, and until we find a cure.

23 November: Bosnian dementia centre becomes a member of the DANDEC group

The DANDEC project was initiated in 2013 to generate a sustainable improvement of treatment and care for older people with dementia and their carers in six countries on the Danube River: Bulgaria, the Czech Republic, Germany, Romania, Slovenia and the Ukraine. The Center for dementia in Bosnia and Herzegovina (B&H) has now also become a member of the DANDEC group, during a recent visit by Prof. Alexander Kurz - a main driver of DANDEC.

During his visit, Prof. Kurz met future project participants, the Board of the Center for dementia and the Udruženje AIR association, the Chairperson of the Medical Chamber for B&H, the Vice-Dean of the Faculty of Philosophy, the Assistant Minister of Health and the Assistant Minister of Labour and Social Policy.

It was a very successful visit, with all participants agreeing to support future activities to help carers, GPs, psychologists and sociologists, and to transfer knowledge within DANDEC countries.

23 November: Alzheimer Bulgaria writes about its new report on access to health and social services for people with dementia

The report seeks to identify major barriers to providing access to health and social services for people with Alzheimer’s disease and other forms of dementia in Bulgaria, as well as the first feasible steps in addressing those barriers. Based on objective indications as well as survey data (collected among health and social service providers), we identified the following barriers: lack of information and data, general ignorance in the social service sector, procedural constraints, lack of coordinating mechanisms, and lack of infrastructure for social service provision.
The crux of the problem lies in the fact that service providers are not familiar with the target group – they don’t know how many the dementia patients are, who they are, where they live and what their needs are. Furthermore, service providers have little to no contact with the target group. As a result, access to both health and social services is seriously hindered.

We recommend that general medical practitioners, being in close proximity and regular contact with people aged 65+, be involved in early diagnosis and prevention, medical monitoring and data collection. We further insist that employees and administrators in the social service sector be educated on dementia-related issues. We suggest training personal and social assistants for working with people with dementia. We also propose a number of normative and procedural changes, most notably the delineation of people with dementia as a target group separate from the larger group of people with disabilities.

23 November: First Alzheimer Café held in Bosnia and Herzegovina

For the first time ever in Bosnia and Herzegovina, an "Alzheimer Café" has been held, at the Holiday Inn in the centre of Sarajevo. The café topic was “A dilemma – whether to use dementia therapy or not”, reports AE member Udruženje AiR. The guest lecturer was Prof. Zvezdan Pirtolek from Slovenia.

There were many participants – families, people with dementia, carers and GPs. Everyone enjoyed the wonderful lecture and wants to come to the next Alzheimer Café. "The cafe is a reflection of the friendship between Slovenia and Bosnia".

24 November: Alzheimer Hellas holds theatre lessons as cognitive training therapy for people with MCI

Alzheimer Hellas has created a cognitive training therapy for people with Mild Cognitive Impairment (MCI). The primary aim is the enhancement of executive function parameters. Secondary aims are, as a generalisation, the improvement of verbal and visual memory, language, perception, functional performance and quality of life. The programme begins with theatre workshops resulting in a theatre show for the public. Preliminary results have shown improvement in learning ability, selective attention and language.

On 24 November, Alzheimer Hellas organised the third performance of its theatrical group. The play was based on Molière’s “Le Malade Imaginaire” and was performed in a theatre Thessaloniki city center, to an audience of 250 people. The audience gave great reviews on this initiative and the actors (members of Alzheimer Hellas’ theatrical therapy group) were delighted with the experience.

28 November: Local police in Abbiategrasso attend dementia support training

A training course to teach local police how to support people in the early stages of dementia was held in Abbiategrasso, near Milan, Italy. Abbiategrasso is Alzheimer Italia’s pilot dementia-friendly community project, launched in July 2016.

The goal of such trainings is to increase knowledge about and awareness of dementia in order to avoid the marginalisation and isolation of people who are already in the early stages of dementia – experiencing disorientation and memory lapses, and therefore finding it more difficult to move around town alone.

In order to create a friendly community, communication between people living with dementia and local police officers plays a key role in restoring a person’s active role within the urban context, by not incurring the stigma that often surrounds dementia. This project was born and developed from the direct and immediate request of the local police to acquire tools and knowledge to be able to provide an appropriate response in situations where a person with dementia may have forgotten the way home or got confused.

Practical advice and knowledge that can allow them to interact, help and support citizens in difficulty, without creating additional anxiety and agitation are the main points addressed in the training, as well as an insight into different means of communication with people with dementia.

To date, two cycles of such training courses have been completed, to involve the largest possible number and meet the demands of shift work. The participants have shown real interest and involvement and a result of the success of this training, another training for civil servants and library employees will be organized shortly, to allow a larger number of citizens the possibility to learn to relate not only to with people with dementia but to all categories of vulnerable people.

28 November: Alzheimer Uniti writes about its involvement in the aftermath of recent devastating earthquakes in Italy

The strong earthquakes of August and October 2016 that devastated some towns in central Italy had a serious effect on all inhabitants, including people with dementia and their families living in those areas and on the very associations that look after them. Alzheimer Uniti has associations in the areas where the earthquake struck, such as Rieti and Macerata (which is coincidentally also the hometown of the new president) and it has been a difficult time for all.
To help people with dementia and their families in those areas affected by the earthquake, a 24-hour toll-free phone line was activated to give information to families in the affected area and also to help family members in other parts of Italy contact their relatives in the earthquake zone.

In the Marche region, a network of services has been designed to identify people with dementia who have survived the earthquake. Those people were then placed together in makeshift shelters to make it easier to link them with professionals in the field, to support them in their time of loss and anguish.

Recently, the presidents of the local associations of Alzheimer Uniti gathered in the town of Recanati, despite continuing aftershocks, to express their solidarity with their colleagues from the affected areas and also to discuss and plan future actions. Some participants from the recent Alzheimer Europe (AE) meeting in Copenhagen were also in Recanati, relaying topics of interest from the AE meeting.

29 November: Panhellenic Federation reports on two recent conferences in Greece

As part of the celebrations for World Alzheimer’s Day (WAD) and for the International Day of Older Persons, the Alzheimer’s Society for Heraklion “ALLILENGI” (SOLIDARITY) organized two successful conferences: the 5th Pancretan Interdisciplinary Congress on Alzheimer’s Disease and Related Disorders; and the 1st National Conference on Active and Healthy Ageing. The scientific meetings took place at the Galaxy Hotel in Heraklion, from 22 to 25 September, attracting international participation.

Distinguished speakers presented their work on the newest developments in the diagnosis and treatment of Alzheimer’s disease (AD), supporting patients and carers, preventing physical and mental vulnerability in the “third age” and the promotion of good health. References were made to modern treatments that, while still being tested, show promise.

On the last day of the conference the results of the Programmes “THALES” and “THOUGHT” were presented. These programmes were completed in the county and the city of Heraklion during the last two years by the University. The first data evaluated the potential impact of a multitude of factors on the mental functions of the elderly, such as nutrition, the presence of other diseases, sleep problems and emotional disorders.

Finally, during the conference, the importance of a holistic and interdisciplinary care of the elderly person and the person with dementia, and also the strength and value of volunteering - especially nowadays - were highlighted.

Spotlight on: Alzheimer Sverige

Alzheimer Sweden is a nationwide patient and relative organisation located in Lund, in the south of Sweden, which started in 1986. We have 3 employees and 14 local organisations with voluntary workers around the country, who helps us to spread information about dementia.

Sweden, with a population of approximately 10 million is calculated to have about 160,000 people living with Alzheimer’s disease and other causes of dementia. About 9,000 of these are younger people (under 65 years old). Every year the total number of cases increases by about 25,000. That is 71 new cases every day! About 600,000 relatives are related to people with dementia.

Telephone Helpline

One of Alzheimer Sweden’s most important tasks is our telephone helpline. It started in 1998. Until today we have received around 80,000 calls from patients and their relatives. The employees working with this have their own experiences, being relatives and carers of people with dementia themselves. Normal questions we get are: "How can I get my mum to a doctor?", "where can I find help?”, "how long will my father be able to drive his car?"; what support can I ask the society to give?”, is it genetic?”. Our staff speaks several languages: Swedish, Danish, Farsi and Bosnian.

World Alzheimer’s Day

As a member of Alzheimer’s Disease International (ADI) we highlight and celebrate World Alzheimer’s Day every year on 21 September. We alternate between the three biggest cities in Sweden - Stockholm, Gothenburg and Malmö for our plans. This year, we were in the concert hall in Malmö, where we gave lectures and organised entertainment. Professor Agneta Nordberg, Karolinska Institutet, Stockholm and Professor Elisabet Londos, Skånes Universitetssjukhus, Malmö, alongside two famous Swedish entertainers, Mikael Neumann and Tommy Juth, helped us make our event a success this year. 500 people came to listen to us! We also held smaller events around the country, together with our local organisations. So, all in all we gathered an audience of almost 1,500 on the day!

Café Memory

We have 15 meeting points called “Café Memory”, in different places around the country, for people with dementia and their relatives, nursing staff, politicians and other interested parties. Each Café meets once a month - same place, same time, same day every month, in a relaxed environment. The aim of these meetings is to break isolation and stigma, and to raise awareness of Alzheimer’s and other dementias. Café Memory was inspired from the Dutch concept “Alzheimer Café”. We gather around 1,400 persons each month and it is free for everyone. The Cafés are run together with different partners like the Red Cross, Ersta Diakoni and some adult educational associations. We also have a well-developed link with a number of scientists and doctors, who give the lectures. This year, we celebrate 10 years of Memory Café work and are proud to have won prizes for the best activity of the year in this field several times!

Membership

Our members in Alzheimer Sweden receive our magazine Minnesvärt (Memory) four times per year. Minnesvärt looks at and highlights the problems that people with dementia and their relatives are facing. We also follow
Science, politics and advice on education, lectures and other things we organise. Above all we want to spread faith and safety with our magazine. The membership fee is EUR 20/year and we currently have about 5,000 members.

Alzheimer Sweden wants to influence and form opinion and policy. We attend decision-making meetings held by The National Board of Health and Welfare and other national organisations related to dementia. We also are involved in upgrading and complementing the national guidelines on dementia. One of our most important aims is to make our politicians, journalists and society at large aware of dementia, so that Sweden will introduce a dementia plan. We constantly need to point out that more resources are needed, especially for science, so that the long-awaited medical treatments that hopefully can halt and even cure Alzheimer’s disease will come. In Sweden, we also need a lot more community care spaces and more resources to minimise the impact dementia has on relatives.

It is our opinion that society can save money by using resources in better ways. By investigating and giving more diagnoses, and with the right medical treatments we can increase the quality of life of people with dementia and also postpone the need for home care services and accommodation in a dementia care home.

We try hard to make media of all kinds aware of dementia. We tell them to stop talking only about elderly people and dementia because in Sweden, the common interpretation of society is that it is only elderly people get dementia and that it is a normal part of ageing!

The National Board of Health and Welfare in Sweden has stated that only 30-40% of all people with dementia receives a complete memory investigation and a symptom-managing treatment.

For many years, Alzheimer Sweden has been a member of Alzheimer Europe and is proud to also be represented in the European Working Group of People with Dementia (EWGPWD) since many years. Our Swedish representative is nowadays Karin Gustafsson from Gothenburg. The work those people do in the group is very important for those of us working in the dementia field. It enables us to continue our work for a “Dementia Friendly Society”.

Beyond the actual cardholders, the card will also be beneficial to service providers who, with the assistance of the information contained on the cards, will be able to adapt their service provision to suit the cardholder’s specific communication needs.

The project is a collaboration between many of the Island’s disability charities and groups, as well as some States of Jersey Departments. It is hoped that if the pilot is successful, funding will be achieved to launch the scheme to a wider number of people.

Senator Paul Routier, Assistant Chief Minister with special responsibility for disability issues, said: “The Connect card has the potential to improve the lives of many, by facilitating simple and everyday interactions. I believe the scheme will benefit the community as a whole – from service users to essential service providers such as the hospital and the police, and indeed local businesses too.”

For more information about the Connect Card see http://connectcard.je/ or contact the Jersey Alzheimer’s Association.

26 October: All-Party Group on Dementia Launched in Irish Parliament

Ireland’s first All-Party Oireachtas Group on Dementia was launched on 26 October. This group - co-convened by Deputy Mary Butler from Co. Waterford and Independent Senator Colette Kelleher - will be run in partnership with The Alzheimer Society of Ireland (ASI).

The aim of the group is to build understanding, consensus and cross-party support for long term planning and increased investment to support people with dementia and their carers in Ireland. The All-Party Oireachtas Group and the ASI delivered the first dementia awareness session for members of the Irish parliament on 23 November.

To find out more about the All-Party Group please contact: allpartygroup@alzheimer.ie

Pictured L-R: Senator Colette Kelleher and Deputy Mary Butler at the launch of the All-Party Oireachtas Group on Dementia on 26 October 2016.

27 October: Third annual OECD workshop held in Lausanne

On 27 and 28 October, the Organisation for Economic Cooperation and Development (OECD) held its third annual Lausanne workshop – Lausanne III, focusing on “The Road to 2025: Delivering next generation Alzheimer’s treatments / Increasing understanding and collaboration between industry, regulators and payers”.

The workshop brought together Alzheimer’s disease (AD) experts from government, industry, patient advocacy, regulation, public policy and academia to challenge traditional paradigms, taking a patient-centric and interdisciplinary approach to overcome key treatment, regulatory and market access barriers in AD.
The prevalence of AD and other dementias is projected to double over the next twenty years. “This is currently one of the biggest challenges for our health systems - and it remains poorly understood and highly stigmatised. That’s why it is critical to put those living with Alzheimer’s and other dementias and those caring for them at home, in the hospital and in our communities at the centre of our efforts,” said Tania Dussey-Cavassini, Vice-Director General of the Swiss Federal Office of Public Health and Switzerland’s Ambassador for Global Health.

Critical to ensuring that new drugs make it to market and reach those most in need is the integration of new technologies and patient-reported outcomes to inform the regulatory review process. The good news is that regulators are already having open conversations with key stakeholders in AD, a collaborative spirit reinforced by the panel of distinguished regulators from the United States, Canada, Switzerland, European Union and Japan.

Taking action was a top priority in Lausanne, and the conference closed with several action items to accelerate advances in 2017, including:

- Expand the scope and reach of Lausanne to other critical themes, to create a truly global and ongoing Lausanne dialogue.
- Engage finance ministers, treasuries, parliamentarians and municipalities – stakeholders who drive budget decisions and public investment in AD.
- Focus efforts to speed the development of a validated surrogate biomarker that could transform clinical trial design duration and costs.
- Break down the silos between AD and other disease areas to draw out lessons and best practices.
- Take a disciplined and systematic look at the ways to mitigate the age-related incidence of the disease.
- Leverage The Big Ideas Alzheimer’s Platform for critical real-world evidence insights needed by payers.
- Initiate country-level “Lausanne Dialogue” series to increase engagement around regulatory and access solutions.


11 November: German parliament passes law changing conditions for dementia research

On 11 November, Germany's lower house of parliament, the Bundestag voted in favour of a new law, changing the conditions researchers must meet to conduct clinical research on people lacking capacity, including many people with dementia. 357 supported the new law, 164 voted against and 21 abstained. As is typical with votes concerning ethical matters, members of parliament were not called upon by party leadership to cast ballots along party lines.

The new law will allow doctors to conduct more expansive clinical research on people with dementia. Previously, doctors were only permitted to test new medication to specifically treat themselves, but under the new framework, doctors can test a wider array of medicinal products that may not be catered to the person but are rather designed to treat future patients.

The requirement of consent to any future trial medicines being given before dementia progresses to a stage at which the person is deemed to lack capacity remains unchanged and potential participants must also receive the counsel of a doctor. The law also specifies that studies must have a minimal negative impact (burden) on the participant, and must be approved by a medical ethics commission.

16 November: Dementia is on the school curriculum in Northern Ireland

The Alzheimer’s Society (UK) has worked with the Council for the Curriculum, Examinations and Assessment (CCEA) to put dementia on the school syllabus in Northern Ireland, with the aim of creating the first ever “dementia-friendly generation”.

On 16 November, the Alzheimer’s Society launched educational resources in English and Irish language, which will form part of the Northern Ireland Curriculum, to help children between 5 and 16 better understand what dementia is and how to deal with their personal experiences of it.

In a statement supporting the launch, Northern Ireland Education Minister Peter Weir said:

“I welcome the launch of this important resource for schools...Schools provide children with a wide-ranging and broad education helping them to become well-rounded individuals. It is right that as part of their education they learn about issues such as dementia and learn the skills needed to best take care of and help family members and friends who have the condition.”

You can view the informational video and educational resources here:

https://www.alzheimers.org.uk/youngpeople

24 November: Switzerland has prolonged its National Dementia Strategy until 2019

On 24 November 2016, the Confederation and cantons decided to prolong the National Dementia Strategy until 2019. Alzheimer Switzerland supports the prolongation, even though only two of the expected four years were approved. The strategy makes an important contribution to better understanding of dementia among the population and to acceptance of those concerned within society.

Projects that began in the first phase of the National Dementia Strategy are already beginning to bear fruit. All essential national stakeholders in the dementia field are involved. Consequently, the subject of dementia is becoming less of a taboo, and more open interaction with those affected is being encouraged. The prolongation of the Strategy makes it possible to bring the current projects to a conclusion and to launch work not yet begun - for in the everyday life of those concerned there has long been
too little support. There continues to be an urgent need for action. It is also necessary to take a closer look at the situation of caregiving relatives, for whom the support of people with dementia is a major strain on their time and their emotions. Within its framework, the National Dementia Strategy indeed provides for respite services for day and night care to relieve caregiving relatives. However, the corresponding projects have not yet been started.

With increasing life expectancy dementia is becoming more and more of a social and political challenge, as age is the number one risk factor for dementia. Alzheimer Switzerland continues its efforts – also in the context of the National Dementia Strategy – to improve the everyday life of people with dementia and their families.

Alzheimer Switzerland strives for a dementia-friendly society, aiming at affording people with dementia and their families a better quality of life. Together with its 21 cantonal sections it provides information, counselling and support for those with dementia, their relatives, carers, doctors, hospitals, old people's homes and other occupational groups catering for people with dementia. Alzheimer Switzerland represents the interests of those concerned on the political and social level.

Science watch

18 October: Researchers reveal how neurodegenerative diseases spread through the brain

Synapses, the place where brain cells contact one another, play a pivotal role in the transmission of toxic proteins. This allows neurodegenerative diseases such as Alzheimer's disease (AD) to spread through the brain, says new research led by Professor Patrik Verstreken of Katholieke Universiteit Leuven, in collaboration with Janssen Research & Development. Their research paper was published on 18 October in the journal Cell Reports.

During neurodegenerative disease, including AD, toxic proteins are known to spread throughout the brain. As the disease progresses, more and more brain areas are affected.

The researchers now offer proof that synapses (pictured) are critical to mediate the transmission of toxic protein species and reveal the mechanisms behind this process. They show that the toxic proteins cross from one brain cell to the next by being engulfed by vesicles (pictured), small bubbles in the receiving brain cell. The vesicles burst and release the toxic proteins.

Prof. Verstreken said the new research also shows how familial history has an impact on this process:

“There are known genetic factors in the human population that increase the risk to develop Alzheimer's and we show that one of the more common genetic variants, dubbed 'BIN1', directly affects the transmission of toxic proteins at synapses. BIN1 'improves' the transmission at synapses but in doing so, it enables the spread of toxic proteins.”

These findings may open new perspectives for the treatment of neurodegenerative diseases. By understanding how toxic proteins are passed between brain cells, researchers may also be able to identify therapeutic avenues to block this process or to shuttle the toxic proteins to the cellular "waste bins". Also, the work done in this study was based on in vitro experiments, so it will now be important to put these models to the test in in vivo models of AD.

http://www.cell.com/cell-reports/fulltext/S2211-1247%2816%2931131-5

7 November: Study of memory function in early midlife period pinpoints changes linked with menopause

Women have a two-fold higher risk of developing Alzheimer's disease (AD) than men, yet strikingly little is known about how changes in brain function promote this difference - and how early in midlife those changes can be detected. Now, in a population-based study involving more than 200 healthy women and men ages 47 to 55, a team of researchers led by the Brigham and Women's Hospital reveals specific changes in memory function that correspond to sex and menopausal stage, rather than chronological age. The work implicates key areas of the brain that are vulnerable to age-related decline and highlights the importance of ovarian hormones in maintaining memory function. The new study appeared in the online issue of the Menopause – The Journal of The North American Menopause Society on 7 November.

"For years, the dominant thinking in the field was that women were at higher risk of Alzheimer's disease simply because they tend to live longer," said senior author Dr Jill Goldstein, Director of Research at the Connors Center for Women's Health and Gender Biology at BWH. "But that idea was perpetuated by research that looked late in life - not at middle age, when key hormonal transitions take place and when changes in memory begin to surface."

Age-related cognitive decline impacts both men and women, with people reporting forgetfulness and a lack of mental clarity (so-called "brain fog") as they age. While women in general tend to fare better than men on tests of verbal memory and men have a higher rate of mild cognitive impairment later in life, women are disproportionately affected by AD.

Dr Goldstein and her colleagues seized an opportunity to examine how and why these sex differences unfold when one of their long-studied community cohorts, known as the New England Family Study, began entering their later-40s and 50s. That allowed the researchers to carefully examine what happens to memory function in healthy, middle-age women over time as menopause unfolds - spanning the pre-, peri-, and post-menopausal periods - and to compare those findings to healthy, age-matched men.

Because the individuals studied showed no signs of dementia or obvious memory loss, standard tests of memory function were not challenging enough to detect changes. So the team turned to a series of...
neuropsychological tests, refined by Dr Dorene Rentz, senior neuropsychologist in the Department of Neurology at BWH and a lead author on the paper. These tests rigorously evaluate different forms of learning and memory, offering a finer-grained view that could identify even early, age-related cognitive deficits.

The researchers found that, when compared to age-matched men, the women scored significantly higher on all categories of memory function assessed by the tests, with one notable exception: Post-menopausal women performed at roughly the same level as their male counterparts (and worse than the other women) on tests of initial learning and retrieval of information. The finding suggested changes in frontal areas of the brain, known for their roles in short-term memory and so-called “executive functions” - advanced cognitive abilities, like organising, structuring and evaluating information. In addition, hormone measurements revealed that across all women studied, higher estradiol levels (the form of estrogen that has the greatest effects on the brain) correlated with better memory performance.

When taken together with other recent work, both from Dr Goldstein’s group and others, the paper helps paint a picture of the memory circuits in the brain that begin to change with age - in both males and females - and underscores the importance of steroid hormones, especially estradiol for women, in maintaining memory function.

http://journals.lww.com/menopausejournal/Abstract/publishahead/Sex_diff erences_in_episodic_memory_in_early-97879.aspx

8 November: Dementia diagnosis delayed by complex referral criteria

Complex and time-consuming memory clinic referral criteria are contributing to delays in the diagnosis of dementia, according to a paper published in the Journal of the Royal Society of Medicine on 8 November.

Currently general practitioners (GPs) in the UK are responsible for referring patients for assessment and diagnosis by specialists, usually in dedicated memory clinics, which set referral criteria. There is considerable variation in referral criteria, with requirements set by some memory clinics that exceed UK guidelines. Requirements can include different combinations of cognitive tests, laboratory blood tests, urine tests and physical examination that vary between clinics.

Lead author Dr Benedict Hayhoe, of the School of Public Health at Imperial College London, says: “GPs have difficulty assessing patients with memory problems in strict accordance with guidance within a 10-minute consultation; in our experience a significant proportion of available consultation time can be taken up by carrying out just one of the brief cognitive tests.” He went on to suggest that, with current workload pressures on primary care, complex criteria involving multiple investigations are likely to provide a significant disincentive for referral.

The authors set out alternative approaches to help speed up diagnosis. Dr Hayhoe said: “A primary care led process, perhaps staffed by practice nurses carrying out assessments according to protocols, may speed up diagnosis while reducing pressure on GPs and specialists.” He added that it may also be appropriate to allow people with memory concerns direct access to memory clinics.

http://jrs.sagepub.com/content/109/11/410.full

10 November: Probiotics may boost learning and memory in people with AD, study finds

A research team from Iran has completed a study, showing that a daily dose of probiotics for three months could help improve memory and thinking abilities in individuals with Alzheimer’s disease (AD). Senior study author Prof. Mahmoud Salami, from Kashi University in Iran, and colleagues published their findings in the journal Frontiers in Aging Neuroscience on 10 November.

The researchers found that participants with AD, who consumed milk enriched with beneficial live bacteria every day for 12 weeks, showed significant improvements in cognitive functioning.

Probiotics are defined as live microorganisms that have a positive effect on human health. These include bacterial groups such as Lactobacillus and Bifidobacterium, as well as yeasts, including Saccharomyces boulardii.

Previous animal studies have also shown probiotics to improve learning and memory - an association that has been attributed to beneficial alterations in the gut microbiome that affect the brain. Whether probiotics have the same effect in humans, however, has been unclear.

For this latest study, Prof. Salami and team set out to determine the effects of probiotics on the cognitive functioning of 52 men and women aged 60-95 who had been diagnosed with AD.

Participants were randomised to one of two groups. One group was required to drink 200 millilitres of normal milk every day for 12 weeks, while the other group drank 200 millilitres of milk containing four probiotic bacteria: Lactobacillus acidophilus, Lactobacillus casei, Lactobacillus fermentum, and Bifidobacterium bifidum.

Before and after, researchers collected blood samples from the participants, and the subjects’ cognitive functioning was assessed using the Mini-Mental State Examination (MMSE) scale. Compared with participants who consumed the untreated milk, those who received the probiotic-enriched milk demonstrated significant improvements in cognitive functioning, the team reports. Participants who consumed the treated milk saw average MMSE scores increase from 8.7 to 10.6 (out of a possible 30) during the 12-week study period, while scores dropped from 8.5 to 8.0 for those who drank the untreated milk.

The researchers stress that all participants remained severely cognitively impaired, but their findings are the first to show that probiotics might lead to some cognitive improvements.

12 November: Understanding psychological dimensions of dementia can improve care, says British Psychological Society

To help people live well with dementia we need a better understanding of its psychological impact, says a new report from the British Psychological Society (BPS). The report stresses that dementia affects a person’s sense of identity, how they think and behave, their mood and their personal relationships. Improving people’s experience of dementia, therefore, requires improving the support they receive to process how they feel about and understand the condition, their future and the impact it has on their relationships.

Dr Linda Clare, Chair of the BPS Dementia Advisory Group, said: “Maintaining a sense of control, identity and connection is a key focus as dementia progresses. Without it there is a risk that the person will experience a sense of isolation and dislocation at a time when the resources to protect against this threat are lacking.

“That’s why we say putting the person at the centre of care is vital to help people to live well with dementia.”

The report highlights a number of areas where action is needed to improve understanding and care, and makes recommendations for commissioning services.

The recommendations include:

- People with dementia should be supported in making their own decisions as far as possible.
- Care and treatment should be individually tailored to each person’s needs and circumstances.
- Dementia care plans must cover all the person’s needs, including equal access to the right healthcare for other mental or physical health needs.
- Families and carers should be included in care planning at all times and have access to psychological support.


14 November: Dementia is leading cause of death in UK for the first time

New figures published by the Office for National Statistics (ONS) in the UK show, for the first time, that Alzheimer’s disease and dementia are now the leading cause of death in England and Wales.

In 2015, more than 61,000 people in England and Wales died of Alzheimer’s disease and dementia, totalling 11.6% of all recorded deaths. Dementia therefore replaces ischaemic heart disease as the leading cause of death and is related to an ageing population as well as better dementia diagnosis rates.

The Office for National Statistics report can be viewed here: https://goo.gl/63mxPv

22 November: Anavex announces positive 41-week update from AD drug Phase 2a study

On 22 November, Anavex Life Sciences announced a positive 41-week update from its Phase 2a study in mild-to-moderate Alzheimer’s disease (AD). Its drug, ANAVEX 2-73 targets cellular homeostasis.

At 41 weeks, participants with AD taking a daily oral dose of the drug in the exploratory, not yet dose-optimised Phase 2a trial, showed a stabilisation of cognitive and functional measures. The drug was well tolerated and no participants discontinued treatment due to adverse events.

The full data will be presented at the Clinical Trials on Alzheimer’s Disease (CTAD) meeting on 8 December.

22 November: Neurotrope completes enrollment in Phase II clinical trial for moderate to severe AD

On 22 November, Neurotrope, a company focused on developing drugs to treat neurodegenerative diseases including Alzheimer’s disease (AD), announced that it has initiated dosing in the final participant in its randomised, double-blinded, placebo-controlled, Phase II clinical study in moderate to severe AD. The primary endpoint of the trial is the Severe Impairment Battery (SIB) and the secondary endpoints are the Mini Mental State Exam (MMSE), Activity of Daily Living (ADL) and Neuropsychiatric Inventory scale (NPI).

Top line results from the study are expected to be announced in April 2017. Patients meeting the MMSE enrollment criteria score of 4-15 were enrolled in the study. Two doses of bryostatin, 20ug and 40ug, vs. placebo for 12 weeks are being tested. A total of 148 patients were enrolled into the study.

22 November: Occupational therapy fails to aid functioning in people with Alzheimer’s dementia, US study finds

A US study has found that home-based occupational therapy (OT) may not be as effective as hoped in slowing down functional decline in people with Alzheimer’s disease (AD). A team of researchers from the Indiana Center for Aging Research and the Regenstrief Institute in Indianapolis, US, led by Dr Cristopher M. Callahan, the Cornelius and Yvonne Pettinga professor of medicine at Indiana University’s School of Medicine, and the founding director of the Indiana University Center for Aging Research, designed a randomised, controlled clinical trial for the study. Their results were published in the journal Annals of Internal Medicine on 22 November.

180 participants were divided into two groups. Both groups received collaborative care for dementia from the Healthy Aging Brain Center, in collaboration with the primary care practices from the Eskenazi Health Center. The researchers had previously shown that their primary care practices reduced caregiver stress and improved behavioural symptoms for people with dementia. In this new study, one of the two groups also received OT for 24 months, in addition to collaborative care, but at the end of the two-year period, both groups showed a similar decline in
everyday functions, such as walking, eating, bathing, and toileting.

"Persons with dementia face a steady decline in function that we found is not slowed by home-based occupational therapy," said Dr. Callahan.

"The participants in the study declined both mentally and functionally as the neurodegeneration of the brain continued. This is a disappointing outcome because previously published, but shorter-term studies had suggested these interventions might be able to slow the physical decline that leads to nursing home placement," he concluded.


23 November: Lilly’s experimental Alzheimer’s drug solanezumab fails to meet primary endpoint in large study

Eli Lilly’s experimental Alzheimer’s drug solanezumab, which had previously shown promise in slowing the deterioration of thinking and memory in people with mild dementia due to Alzheimer’s disease (AD), has failed in its Phase III clinical trial, the company announced on 23 November.

Trial participants treated with solanezumab did not experience a statistically significant slowing in cognitive decline compared to patients treated with placebo. While the study results, including many secondary clinical endpoints, directionally favoured solanezumab, the magnitudes of treatment differences were small.

Lilly will not be pursuing regulatory submissions for solanezumab for the treatment of mild dementia due to Alzheimer’s disease.

Lilly will present further findings from the study at the Clinical Trials on Alzheimer’s Disease (CTAD) meeting on 8 December. The presentation will be shared live via webinar from the meeting. To access the webinar, please visit http://www.ctad-alzheimer.com.

Dear friends,

I want to write you about me and the activities of our Association “AIR” in Bosnia and Herzegovina.

I spoke about our stay at the Alzheimer Europe conference and about my election in European Working Group of People with Dementia (EWGPWD) at a meeting of our Association and the meeting in the Center for dementia.

The first Alzheimer Café in my country was held on 12 November for two days, at the Holiday Inn. This was a wonderful beginning for future maintenance of Alzheimer Cafés in many cities in Bosnia and Herzegovina.

Esteemed Professor Doctor Zvezdan Pirtosek from Slovenia spoke on the courses and treatment of dementia.

For me this was an opportunity to tell everyone about our stay in Copenhagen. I told them about my internment into the EWGPWD. I also said how many new people I met and how many new insights I got from people with dementia and from lectures. It was a beautiful and useful socialising experience.

In the last week activities have been continued by our “AIR” association:

We had very important meetings with people from the Ministry of Health and the Ministry of Social Policy. For me
it was again an opportunity to convey to people from these Ministries the experience of our delegation in Copenhagen, of which I was a member.

I presented my election to the working group EWGPWD and talked about the importance of this election and my presence in this group in the next two years.

I described the work of the group EWGPWD from the first day, when there was a shift of the old and the election of new members.

Yours, Amela Hajrić, member of the EWGPWD.

New publications and resources

5 October: Irish Hospice Foundation publishes seven dementia palliative care guidance documents for healthcare staff

As part of The Irish Hospice Foundation’s Changing Minds programme, a suite of seven guidance documents were developed to support healthcare staff working with people with dementia from all care settings in addressing specific aspects of dementia palliative care.

Each guidance document is accompanied by a factsheet, all of which are available to download by clicking on the pictures below.

These comprehensive documents were launched last month at University College Cork, Ireland.

21 October: ADI publishes booklet to help Alzheimer associations influence public policy

Alzheimer’s Disease International (ADI) has published a booklet, Influencing public policy, in an effort to support Alzheimer associations around the world to undertake campaigns aiming to influence public policy in their country, region or community.

The booklet gives examples of successful advocacy campaigns, including Alzheimer Europe’s Glasgow Declaration.

29 November: Young Dementia Network launched

YoungDementia UK is excited to announce the launch of the Young Dementia Network, launched at the recent “Young Onset Dementia: Different Impact, Positive Solutions” conference.

Tessa Gutteridge, Director of YoungDementia UK said “We know first-hand the impact of dementia on younger people and their families and how isolating it can be. We believe that everyone affected should be well informed, feel connected to others and enabled to live life to the full.

“So we are creating a Network. A community that includes people living with young onset dementia, their family and friends, as well as organisations and professionals who work in the fields of dementia and social care.”

The Young Dementia Network aims to provide opportunities for members to share experience, knowledge and to learn from each other and to encourage improved young onset services across the UK and influence and inform national and local policies.

https://www.youngdementiask.org/young-dementia-network

DONATE NOW!
Help us make dementia a priority

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

Alzheimer Europe Board
Chairperson: Iva Holmerová (Czech Republic); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: James Pearson (UK - Scotland); Honorary Treasurer: Maria do Rósario Zincke dos Reis (Portugal); Members: Stefanie Becker (Switzerland), Helen Rochford Brennan (Ireland), Marie-Odile Desana (France), Sabine Henry (Belgium), Sabine Jansen (Germany), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Štefanija Lukči Zlobec (Slovenia).

Alzheimer Europe Staff
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Policy Officer: Vanessa Challinor; Project Officer: Ana Diaz; Director for Projects: Dianne Gove; Conference and Event Coordinator: Gwladys Guillory; Finance Officer: Stefanie Peulen; Director for Communication: Alex Teligadas; Administrative Assistant: Grazia Tomasoni.
## AE Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 December</td>
<td>AETIONOMY General Assembly (Paris, France)</td>
<td>Dianne and Jean</td>
</tr>
<tr>
<td>5-6 December</td>
<td>AE Board meeting (Brussels, Belgium)</td>
<td>AE Board and staff</td>
</tr>
<tr>
<td>6 December</td>
<td>AE European Parliament Lunch debate (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
</tr>
<tr>
<td>6 December</td>
<td>AE Company Round Table (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
</tr>
<tr>
<td>6 December</td>
<td>Workshop organised by Swedish National Board of Health and Welfare, Swedish Ministry of Health and Social Affairs, and European Centre for Social Welfare Policy and Research (Stockholm, Sweden)</td>
<td>Dianne</td>
</tr>
<tr>
<td>6-7 December</td>
<td>AE Alzheimer’s Association Academy (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
</tr>
<tr>
<td>8 December</td>
<td>EPPIA Think Tank (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>8 December</td>
<td>Board Meeting for the Covenant on Demographic Change (by Skype)</td>
<td>Dianne</td>
</tr>
<tr>
<td>8-11 December</td>
<td>Clinical Trials on Alzheimer’s disease CTAD (San Diego, USA)</td>
<td>Jean</td>
</tr>
<tr>
<td>12-13 December</td>
<td>Regional Consultation on the European Response to Chronic Diseases - the Role of Civil Society (Brussels, Belgium)</td>
<td>Vanessa</td>
</tr>
<tr>
<td>12-14 December</td>
<td>EWGPSW meeting (Brussels, Belgium)</td>
<td>Ana and Dianne</td>
</tr>
<tr>
<td>13 December</td>
<td>AMYPAD WP6 Meeting (Munich, Germany)</td>
<td>Jean</td>
</tr>
<tr>
<td>14-15 December</td>
<td>MOREAD Kick-off meeting (Barcelona, Spain)</td>
<td>Jean and Kate</td>
</tr>
</tbody>
</table>

## Conferences

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 December</td>
<td>MinD Project 1st Symposium, <a href="https://www.eventbrite.co.uk/e/mind-project-1st-symposium-tickets-2772802261">https://www.eventbrite.co.uk/e/mind-project-1st-symposium-tickets-2772802261</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>9-11 December</td>
<td>2016 IPA Asian regional meeting, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>Taipei, Taiwan</td>
</tr>
<tr>
<td>2-5 February</td>
<td>10th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PICAD) and 2nd Mediterranean Conference Neurodegenerative Diseases (MeCoND)</td>
<td>Thessaloniki, Greece</td>
</tr>
<tr>
<td>24-25 June</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>
</tr>
</tbody>
</table>
27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017
www.alzheimer-europe.org/conferences  #27AEC