I trust that 2017 was a good year for you all and that 2018 is treating you well so far. As for the Alzheimer Europe team, I am personally proud of our achievements over the past 12 months and I would like to express our gratitude to everyone who contributed to our continuing efforts to ensure dementia is firmly on the European agenda: the European Working Group of People with Dementia (EWGPWD), which helps ensure that our activities reflect the priorities and views of people living with dementia (“Nothing about us without us!”); the AE Board; our 40 national member associations from across the European region; our Expert Advisory Panel; our strategic partners, project partners and sponsors; the Alzheimer Europe Foundation; the 123 MEPs in our European Alzheimer’s Alliance (EAA); and, of course, the EU and its health and research programmes supporting our activities and projects, without which our work would not be possible.

December began in Brussels for the AE team with our final series of meetings for the year, including a lunch debate at the European Parliament, on the topic of improving the diagnosis of Alzheimer’s disease through European research collaboration. It was hosted jointly by MEPs Heinz Becker (Austria) and Olga Sehnalová (Czech Republic) and I would like to thank them both for their gracious contributions, highlighting the importance of continued and increased EU collaboration in this field, and for their continued commitment to our EAA and to the dementia field. Other meetings in Brussels included our Board meeting and Company Round Table, as well as the 3rd edition of our Alzheimer’s Association Academy.

The EWGPWD also congregated in Brussels for its quarterly meeting. During this visit, members were delighted to be invited to the 4th edition of the European Parliament of Persons with Disabilities (EPPD), co-organised with the European Disability Forum and the European Parliament. Vice-Chair Chris Roberts was asked to speak on behalf of the group at this event, which was a fantastic opportunity to have their voice heard on such an important European stage.

Lastly, I am delighted to bring you news of the launch of the World Health Organisation’s web-based platform, the Global Dementia Observatory. This is a knowledge hub for dementia, providing data analysis, epidemiological trends, policy formulation and adoption, country implementation through health and social care systems, partnerships and research. AE was invited by the WHO to work on this initiative back in 2016 and we are delighted to see it come to fruition now.

On that positive note for international dementia policy and research, I wish you all an excellent start to the New Year!

Jean Georges
Executive Director
At its meeting of 4 and 5 December in Brussels, the Alzheimer Europe Board reviewed the different 2017 activities and approved the organisation’s Yearbook on care standards in residential homes and the Ethics report on the recognition of dementia as a disability. The Board also reviewed the evaluation of the participants of the Alzheimer Europe Conference in Berlin and welcomed the positive assessment of the conference’s scientific and social programme and the organisational aspects. The Board was particularly pleased to see that 96.43% of conference participants said that they would recommend the Alzheimer Europe Conference to a colleague.

The Board also congratulated the AE Director and his team for the successful application to the EU health programme for a framework agreement covering the organisation’s core activities for the next 4 years. The completion of annual operating grants will allow AE to continue its high degree of activities. The Board therefore also unanimously adopted the 2018 Work Plan and Budget of the organisation.

Finally, the Board approved a memorandum of understanding with the European Academy for Neurology which highlights the future collaboration between the two organisations including the participation of the AE Director in the review of the EAN guideline.

On 5 December Alzheimer Europe (AE) held a successful lunch debate in the European Parliament co-chaired by MEPs Heinz K. Becker (Austria) and Olga Sehnalová (Czech Republic) which focused on improving the diagnosis of Alzheimer’s disease thanks to European research collaboration. The lunch debate gathered over 95 people including MEPs Nessa Childers (Ireland) Marian Harkin (Ireland), Lambert van Nistelrooij (Netherlands). Peter Kouroummnashev (Bulgaria) and Keith Taylor (UK). The audience included representatives from 24 Alzheimer Europe member associations, several pharmaceutical companies plus all members of Alzheimer Europe’s European Working Group of People with Dementia (EWPWD) and their supporters.

Heinz K. Becker MEP, opened the lunch debate and welcomed all participants. Mr Becker stressed the need for more political will at European level to help solve the dementia problem and address the needs of the growing elderly population. By 2060 28% of the population will be aged over 65 and 12% aged over 80. According to figures the number people currently living with dementia are 8.7 million in European Union and this number is expected to at least double by 2040. In light of these figures Mr Becker called for better coordination at European level and the need for a high level European coordinator for dementia.

This lunch debate looked at the advances and improvements through European research in diagnosing AD. However, despite these advances, it is estimated by Alzheimer’s Disease International (ADI) that only a quarter of people with dementia worldwide and half of people in high-income countries have received a formal diagnosis.

The first speaker, Prof. Philip Scheltens, (VU University Amsterdam, Netherlands) said that thanks to biomarkers there has been a paradigm shift in diagnosing Alzheimer’s disease and Alzheimer’s dementia. Prof. Scheltens gave a very interesting historic overview of the diagnosis of AD. For a long time, a diagnosis of Alzheimer’s disease (AD) could only be confirmed post-mortem after a brain autopsy. One of the undoubted key advances in AD research is the emergence of biological measures (biomarkers) and imaging techniques which allow a definitive diagnosis of Alzheimer’s disease in living persons. Biomarkers can be assessed by neuroimaging i.e. MRI and PET scans or cerebral spinal fluid (CSF) analysis which are also increasingly being used to diagnose Alzheimer’s disease in research studies and specialist clinical settings.

Prof. Scheltens highlighted the fantastic progress in diagnosis, illustrating that being able to detect brain changes early, now gives a better window of opportunity to help identify new treatments to prevent Alzheimer’s dementia. He said it is easier now through the discovery of amyloid to give a preclinical diagnosis of AD even if there are no symptoms. This in effect means that AD can be diagnosed before the onset of dementia.

The second speaker Prof. Pierre Krolak-Salmon (University Hospital of Lyon, France) presented the 2nd European Joint Action on Dementia – Act On Dementia. Prof. Krolak-Salmon highlighted the fact that diagnosis is often too late and post diagnosis support is insufficient as well as inappropriate in many European countries. To address these challenges he introduced a diagnostic framework centred on primary care detection which could promote and enhance a timely diagnosis of Alzheimer’s disease and other neurocognitive
disorders thanks to a better collaboration between general practitioners and specialists.

In order to redeem today’s great promises of big data and artificial intelligence to change and support clinical practise the third speaker Dr Jyrki Lötjönen, (Combinostics, Helsinki, Finland) introduced the PredictND project’s clinical decision support tool. Currently the time from symptoms to diagnosis can take an average of 20 months in Europe and less than 50% of people get the diagnosis. This new tool uses brain scans and compares them to support clinicians in their decision making for an accurate diagnosis. In the PredictND prospective study, the clinical decision support tool was evaluated with 800 patients from four European memory clinics. Dr Lötjönen emphasised that artificial intelligence can support clinicians in decision making and the results show that the confidence of clinicians increased on their decisions, enabling earlier diagnosis. In his conclusion Dr Lötjönen said that having more efficient diagnostics is essential in solving the huge challenge of dementias.

The final speaker Dr Elisabetta Vaudano from the Innovative Medicines Initiative (IMI) talked about the IMI portfolio of AD projects supporting research in the diagnosis of Alzheimer’s disease, and how IMI is supporting disease areas with high unmet needs. As well as IMI, the European Union also supports a number of different research efforts on the diagnosis of Alzheimer’s disease and other neurodegenerative disorders through various programmes including the EU health programme, Horizon2020 and the Joint Programme for Neurodegenerative Diseases Research (JPND).

The two IMI projects that focus on diagnosis are AMYPAD (Amyloid imaging to prevent Alzheimer’s disease) which looks at the diagnostic value of amyloid imaging and MOPEAD (Models of patient engagement for Alzheimer’s disease) which compares different approaches to engage potential Alzheimer’s disease patients.

MOPEAD identifies four strategies to detect memory complaints at their initial stage and provide timely diagnosis. Dr Vaudano also highlighted some barriers to this diagnosis which include: misidentification of early stages of dementia as “normal” part of ageing (a lot of “hidden disease”), denial by patients and/or families and social stigma associated with diagnosis and a lack of definitive screening and diagnostic testing.

AMYPAD aim is to explore the impact of amyloid PET imaging on diagnostic thinking in the work-up of patients with SCD-plus MCI, and dementia to improve the understanding, diagnosis and management of Alzheimer’s disease through the utilisation of 8-amyloid PET imaging. The AMYPAD initiative further aims to improve the diagnostic work-up of people suspected to have Alzheimer’s disease and their management, to understand the natural history of the disease in a pre-symptomatic stage and select people for treatment trials aiming at preventing Alzheimer’s disease.

Dr Vaudano stressed the need for collaboration at European but also at global level to address the dementia challenge, amongst patients, scientists, industry and healthcare professionals. Dr Vaudano said that despite the fact we still do not have a cure diagnosis remains critical to stress the importance of diagnosis: improve access to medical and support services; to provide an opportunity to make legal, financial and care plans while affected individual is still capable; reduce health care costs by delaying placement in a nursing home and current treatments may only work if started early.

This lunch debate showed there has been huge progress in the development of new tools including the discovery of novel biomarkers for the diagnosis of AD at its earliest stages. It is possible that ultimately it will lead to new and better treatments and better disease management. However more and better collaboration is necessary to impact decision making where it matters most for patients. In her concluding remarks, Olga Sehnalová said that it was important to bring the issue of Alzheimer’s disease to the European Parliament and that the new trend in diagnosis gave us hope for a future cure. She then handed over to Iva Holmerová, Chairperson of Alzheimer Europe who thanked everyone for coming including the sponsors of the event, Eisai, GE Healthcare, GSK, Lilly, MSD, Pfizer and Roche.

5-6 December: AE organises its third Alzheimer’s Association Academy

On 5 and 6 December 2017, Alzheimer Europe (AE) hosted its third annual Alzheimer’s Association Academy. Participants included 24 representatives from AE member organisations; 4 company representatives and 4 AE staff members. There were 14 expert speakers including a representative of the European Working Group of People with Dementia (EWGPWD and topics were defined based on a survey of participants at the 2016 Academy and AE members.

The first day began with a session on “The role of biomarkers in the diagnosis of Alzheimer’s disease/dementia” and was moderated by Charles Scerri, from the Malta Dementia Society. This session included presentations by Mariana Boccari from the University of Geneva, Switzerland, Pierre
Krolak-Salmon, from the Institut du Viellissement, Lyon, France and Richard Milne from the University of Cambridge, UK. This interactive session built on the presentations provided at the European Parliament lunch debate earlier in the day on “Improving the diagnosis of Alzheimer’s disease thanks to European research collaboration. During their presentations the speakers addressed the key questions: How have biomarkers impacted the diagnosis of Alzheimer’s disease/dementia? How do national organisations communicate about the changing definition of Alzheimer’s disease/dementia? What are the implications for clinical practice of new research criteria? How can Alzheimer’s association support communication activities on the meaning of biomarkers and risks of developing dementia.

The second session of the day was on “EU research collaboration on timely diagnosis – Opportunities for collaboration with Alzheimer’s associations” and was moderated by Iva Holmerová, Chairperson, Alzheimer Europe. This session included presentations by Laura Campo from Lilly, who presented the key aims of the MOPEAD (Models of patient engagement in Alzheimer’s disease) project and Isadora Alves (VUMC, Netherlands) who presented the key aims of AMYPAD (Amyloid Imaging to Prevent Alzheimer’s disease) project. Both speakers illustrated how the projects can support earlier diagnosis of Alzheimer’s disease and dementia.

Day two of the Academy began with a session on “Patient and public involvement in dementia research” which was moderated by Jean Georges, Executive Director, Alzheimer Europe. This session included presentations by Helen Rochford Brennan Chairperson of the EWGPWD and Dianne Gove, Director Project, Alzheimer Europe who presented “The experience of Alzheimer Europe in involving the European Working Group of People with Dementia in Research. Wendy Werkman from Alzheimer Nederland, Netherlands presented “The experience of Alzheimer Nederland in involving carers in research” and Stina Saunders from the University of Edinburgh, UK presented “The participant panel in EPAD (European Prevention of Alzheimer’s dementia) as a model of involving research participants in research”. All speakers helped give delegates a deeper understanding of how Alzheimer associations can involve people with dementia and carers in research projects and how research can benefit from this input.

The second morning session, was on Real World Evidence in dementia research and was moderated by Chris Bintener from Alzheimer Europe. The session focused on the ROADMAP project. Catherine Reed from Lilly, UK presented “The aims of the ROADMAP (Real world outcomes across the Alzheimer’s disease spectrum for better care: multi-modal data access platform) project”. Marije Dekker from the Medicines Evaluations Board, Netherlands presented “The use of real world data and evidence in regulatory and health technology assessments” and Andrew Turner from the University of Oxford, UK presented “Ethical issues raised by big data and real world evidence projects”. This session introduced the aims and objectives of the ROADMAP project and showed how real world data can support the development process of new medicines and looked at the question of how do big data projects address ethical issues.

The final session of the Academy was moderated by Vanessa Challinor, Alzheimer Europe. It was dedicated to EU programmes and their relevance for Alzheimer associations. The first two speakers were from the European Commission, Andor Urmos presented “Funding opportunities for national activities from the European Regional Development Fund and the European Social Fund” and Isabel de la Mata presented “The European Solidarity Corps and opportunities for national Alzheimer’s associations”. The final speaker of the Academy Christine Marking from Eurocarers presented “The European Social Pillar and its implications and relevance for carers of people with dementia”. This session provided an opportunity for national Alzheimer Associations to learn more about a number of key European programmes and initiatives and how these can support national organisations and carers.

The two-day Academy was a highly interactive event, with lots of time for questions after presentations and plenty of lively and thought-provoking discussion. Given the success of its Academies, AE plans to organise a fourth in December 2018.

5-7 December: EWGPWD has its last meeting of the year in Brussels

Members of the EWGPWD and their supporters met in Brussels from 5 to 7 December for a series of consultations and events during their quarterly meeting.

The meeting kicked off with their attendance at Alzheimer Europe’s lunch debate at the European Parliament, followed in the afternoon by a consultation for the PACE project on palliative care for older people in care and nursing homes in Europe. The consultation was organised and co-moderated by Ana and Dianne from Alzheimer Europe together with Sheila Payne from Lancaster University, Nhu Tram from AGE Platform and Sébastien Libert from the INDUCT project. The results of the discussion will be carefully analysed in the coming months but initial findings include confirmation from both people with dementia and their supporters of the tendency to associate palliative care with cancer, end-of-life care and pain. However, there was also
agreement on the need for better training of staff in nursing homes and for recognition that palliative care is equally important for people with dementia and their supporters. The involvement of the EWGPWD in this project will continue in 2018, the input from this and future consultations being part of an overall task to develop, together with the PACE researchers, guidelines for policy makers on palliative care in nursing homes.

The following morning the group had the opportunity to provide feedback on the work that has been developed by two Work Packages of the Joint Action Act on Dementia, on the topics of relevance to timely diagnosis and residential care (person-centred care, end-of-life care, behavioural and psychological symptoms of dementia and the use of antipsychotics). Members of the EWGPWD then turned their attention to the issue of empowerment. They shared the associations they had with certain terms to be used in the context of the SPAN+ project which will start in January 2018. They will be consulted again next year in connection with this project but it was important at this stage to share their perspective on the terminology which is fundamental to the project. Alzheimer Europe was pleased to have been invited by Annemie Bielderman and Debby Gerritsen (the project leaders from Radboud University Medical Centre, Nijmegen, the Netherlands) to participate in this project and consider this a very good example of Patient and Public Involvement spanning various stages of a research project.

The EWGPWD then rushed off back to the European Parliament to join the 4th European Parliament of Persons with Disabilities at which Chris Roberts, Vice Chair of the EWGPWD, gave a presentation and emphasised that people with dementia also experience disability and that the United Nations Convention on the Rights of Persons with Disability is equally applicable to dementia and people with dementia. Alzheimer Europe and the EWGPWD greatly appreciated the warm welcome and assistance provided by staff from the European Disability Forum, especially Lucia D’Arino.

The final day of the rather hectic quarterly meeting was taken up with a consultation for the ROADMAP work package on ethical, legal and social issues, which is led by Andrew Turner from Oxford University. Andrew, Ana, Dianne and Sébastien co-moderated focus group discussions (with two separate groups, one comprised of the people with dementia and one comprised of their supporters). The two groups discussed their perceptions of health data and issues surrounding data sharing, both of which are central to the ROADMAP project. Recurring themes in the discussion included trust, transparency and a broader understanding of health data. The findings of this consultation will be transcribed and analysed. This consultation follows on from the group’s recent contribution to the work package addressing outcome measures. Work will continue on data sharing and outcome measures, with publications planned for next year in peer reviewed journals.

A new member from Slovenia, Tomaz Grzinić joined the EWGPWD at this meeting. This was the last meeting for Alv Orheim, from Norway who has been a member of the group since 2015 and is currently Vice Chair. The EWGPWD wishes to thank Alv Orheim for his strength, enthusiasm and determination during these years of work with the group and also to his wife, Berit, for her support and involvement in the group.

6 December: Chris Roberts, Vice Chair of the EWGPWD speaks at the European Parliament of Persons with Disabilities

On 6 December, the 4th European Parliament of Persons with Disabilities (EPPD) took place in Brussels. More than 600 persons with disabilities from all over Europe attended the event and engaged in discussions about the right of persons with disabilities to vote and participate in political and public life, the next European Disability Strategy and the European Union being a global leader on inclusive Sustainable Development. During the EPPD, a manifesto on European elections 2019, a resolution on the next European Disability Strategy and an emergency resolution on the European Accessibility Act were adopted by the delegates. In the afternoon, delegates also discussed the Sustainable Development Goals and the importance of taking people with disabilities on board in their implementation. The Vice Chair of the EWGPWD, Chris Roberts, was one of representatives from different disability organisations to give a speech during this session.

“My name is Chris Roberts. I was diagnosed with mixed dementia, Alzheimer’s and vascular five years ago. I represent Alzheimer Europe’s European Working Group of People with Dementia which has been established since 2012 (http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia). Dementia ‘IS a disability’, it is covered by disability discrimination legislation. And at a domestic level, that means the Equality Act. At an international level, the equivalent is the Convention on the Rights of Persons with Disabilities (the CRPD). Both these laws talk about reasonable adaptations and...
adjustments, that can be made to ensure that people with dementia and other disabilities, are included and not excluded, ‘doing with and not for’. We need to make sure that the public services that do exist, are more enabling to help reduce the anxiety and agitation, that people affected by dementia, feel on a daily basis, and not to forget their families that are also affected. A quarter of people in hospitals and prisons have a form of dementia: what are we doing to make their experience easier? And yet despite dementia being recognised as a disability, good practice is not widespread or fully promoted as the law dictates, any training and awareness that does exist to try and improve this is very weak, tokenistic and inconsistent. People affected by dementia still face numerous challenges in realising their rights and encounter continual stigma and prejudice. There still remains a total lack of understanding about the dementias, as well as multiple discriminations on so many grounds, including age and gender, compounded with bad care, abuse and, mostly non-existent services. The legislation which is there to protect and uphold our rights has been poor, variable, and in some European countries, has been trampled on, or even worse, not considered at all! People affected by dementia are not receiving the protection that these laws are supposed to provide. Dementia is mostly, until the late stages, a hidden or invisible illness. So perceptions of this illness and what the person requires often prevails over the person’s actual needs, which can vary hugely depending on the type of dementia, the environment, the country they reside in, their age, and the support around them (or lack off)! Furthermore, the “social model of disability” which should be applied to dementia, is continually overridden by the “medical model”. This must change! And finally, I would like to say thank you to all of you that have stayed to listen and have “not left us behind”! ‘Nothing about us without all of us’.

12 December: European Neurological Review magazine features Alzheimer Europe’s new report the “European Dementia Monitor”

Alzheimer Europe’s report the “European Dementia Monitor 2017” is featured in the winter edition of European Neurological Review - Leading the Debate on the Advances in Healthcare.

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The full article was published online on 12 December 2017.


EU PROJECTS

20 November: EPAD LCS has been selected as one of the finalists for the APM Social Project of the Year

The Association for Project Management (APM) was formed in 1972 and is committed to developing and promoting project and programme management. The association is a registered educational charity in the UK, with over 23,000 individual and 570 corporate members, making it the largest professional body of its kind in Europe.

On 20 November, IQVIA, Synapse and The University of Edinburgh representatives (pictured) attended the APM Awards evening, held in London at Old Billingsgate. This is the pinnacle event of the APM and was attended by almost 2000 project management and industry professionals from all over the UK for a formal, sit down dinner & presentation night. The EPAD project had been selected, from a huge number of entries, as a finalist and it was one of 6 finalists for the “Social Project of the Year” award. This was a tremendous achievement as all the other finalists – in every category – were from the construction and / engineering fields. EPAD was the only one representing a project in the medical / scientific area. Unfortunately, the project did not win the award – but it is truly delighted to have raised the EPAD profile to all involved in the APM and represented our medical industry and EPAD in such a prestigious event.

To learn more about the APM Awards program and to see the list of winners, visit the APM website.

28 November: BBRC holds its first EPAD Research Participant Panel meeting

The Barcelonaβeta Brain Research Center hosted the first meeting of the Research Participant Panel of the European Prevention of Alzheimer’s Disease Consortium (EPAD) in Barcelona. The panel is composed of 8 members who will represent and ensure the interests of the Spanish participants in the project.

Their mission is to suggest ideas in order to improve their experience in the study, to discuss topics of their interest, to review the information provided to the participants, and to act as an independent board between participants and the international scientific board of the study.

The next meeting will take place on spring of 2018, and will be focused on the topics that they will present at the EPAD General Assembly. With more than 110 cognitively healthy participants, the BBRC is leading the recruitment of the EPAD
project, which has now recruited over 400 participants within 10 European Trial Delivery Centres.

29 November: AETIONOMY partners meet in Basel for Steering Committee meeting and General Assembly

Members of the Steering Committee Partners of the AETIONOMY project met in Basel from 29 November to 1 December 2017.

The focus of the GA was on issues related to recruitment, knowledge mining and plans for the analysis of data in the context of a range of hypotheses e.g. in the domains of genomics, proteomics, methylation and neuro-inflammation. Participants also discussed plans for a neurodegenerative diseases conference which will be held towards the end of 2018.

Simon Lovestone from the University of Oxford gave a keynote speech on the big data in Alzheimer’s disease. Marc Stauch (University of Hannover) from the legal and ethics work package, in which Alzheimer Europe is involved, gave an update on relevant provisions in the new GDPR which will come into force next May.

8 December: The MinD project works on the design concept development

At the end of this year, the designing for people with dementia mindful self-empowerment and social engagement (MinD) project hosted two secondments in November and December 2017, one at INTRAS in Valladolid, Spain, and the other at the Technische Universität Dresden and Alexianer St Hedwig Hospital in Berlin, Germany.

The aim of the secondments was to start with the concept development and realisation of the two design ideas selected with the help of people with dementia and healthcare experts in October. The two secondments in Spain and Germany continued the thread of consultation and co-design with people with dementia and with healthcare experts: Two co-design sessions were held by INTRAS with 12 people with dementia and with care professionals; and one expert feedback session was held at the Alexianer Hospital. Both sessions provided vital feedback on the two designs: The ‘Good Life Kit’ and the ‘Social Engagement Map’.

The ‘Good Life Kit’ aims to be able to help people with dementia to deal with their condition constructively and openly, especially at the point of the diagnosis when there can be a feeling of loss and uncertainty about the future. The ‘Social Engagement Map’ aims to help people with dementia stay socially connected and engaged. It responds to findings that elderly people in general have fewer social connections, and that people with dementia in particular may find it difficult to maintain or establish social connections.

During the design work, designers, technologists and psychologists from the MinD team worked together to develop the format and content for the different parts of the designs. The team created visual examples and models to discuss how the designs will look, how they will work, and when and how they can be used. The feedback from the co-design and expert groups provided vital feedback to help further develop these ideas in the New Year to make the designs fit for purpose.

In addition to the design development, visiting researchers participated in local events and training sessions, e.g. taking the Snoezelen VR test for people with dementia, they also worked on the completion of data analysis and publications related to the data collection phase.

11-12 December: New H2020 project kicks off

On 11 and 12 December the kick-off meeting of the H2020 project SoCaTel was held in Tarragona (Spain). The SoCaTel project aims to improve the accessibility, responsiveness, efficiency, transparency and transferability of social and care services by developing a multi-stakeholder platform for the co-creation, and later, deployment of long-term care services. The platform will be designed through a co-creation process, which will allow and encourage users to interact with ICT in a straightforward way. In this project, AE is a member of the Advisory Board.

15 December: MEETINGDEM project comes to a close, reports successful outcome

The MEETINGDEM project, funded by the Joint Programme Neurodegenerative Diseases (JPND), ran from 2014 to 2017 in three EU countries (Italy, Poland, United Kingdom). Rose-Marie Dröes, PhD, is professor of psychosocial care for people with dementia at the department of Psychiatry, VU University medical center in Amsterdam, Netherlands, and is project coordinator of MEETINGDEM. Prof. Dros reports on the success of the project, at its close in December 2017, on behalf of the MEETINGDEM Consortium:

The JPND-MEETINGDEM project aimed to implement and validate the successful Dutch Meeting Centres Support Programme (MCSP) developed by the VU University medical center (research group Prof. Rose-Marie Dröes) for community dwelling people with dementia and their family carers.

MCSP provides activities and person-centred interventions for people with dementia, information meetings and discussion groups for their carers, and individual consultations and plenary (social) centre meetings for both, with the main scope to support people in dealing with the changes dementia brings in their lives. In Italy, the project was carried out by the University of Bologna (lead Prof. Rabih Chattat) and Don
Gnocchi Foundation in Milan (lead Dr Elisabetta Farina), in Poland by Wroclaw Medical University (lead Prof. Joanna Rymaszewska) and in the UK by the University of Worcester (lead Prof. Dawn Brooker).

After exploring pathways to care, each country established initiative groups of organisational collaborators and user representatives; inventoried country/region specific facilitators/barriers to implementing MCSP; and developed an implementation plan, practical guide and toolkit, utilising and adapting existing Dutch materials. Staff were trained and nine Meeting Centres (MC) were established (five in Italy, two in Poland and 2 in the UK), with another six MC coming later in the project (four in Italy and two in Poland).

The first nine MC participated in the controlled pre/post study into MCSP’s impact on people with dementia (behaviour, mood, quality of life/QoL) and carers (sense of competence, mental health, loneliness, distress, experienced burden) compared to Usual Care, its cost-effectiveness and user satisfaction.

Positive (moderate to large) effects were found on several QoL aspects (feelings of belonging, positive affect and self-esteem). Carers reported less experienced burden and carers in Italy experienced less distress from behavioural and mood symptoms of the person with dementia, compared to carers who received Usual Care. The attendance at MCSP was high and participants (both the people with dementia and the carers) were highly satisfied with the programme. Evidence suggests that MCSP may be cost-effective for several QoL measures.

In conclusion, the study shows that MCSP is transferrable across countries, well accepted by its users, and has quality of life and mental health benefits for people with dementia and carers, taking into account reasonable additional costs. Dissemination of MCSP in Europe and beyond is recommended by the project consortium.

www.meetingdem.eu

2 January 2018: ROADMAP reports on recent progress, submits two deliverables

As we reached the end of 2017 and start 2018, the ROADMAP communication team is happy to provide a brief overview and update of what has been happening across the project in recent months.

The Coordination team has been responsible for convening the 4th ROADMAP GAM, which was held in Barcelona from 16-18th October. This was a major meeting attended by ROADMAP staff, the next will be held on 25-26 April 2018. The team has also been organising the forthcoming Big Data for Better Outcomes (BD4BO) group meeting, which will be held in Stockholm on 29-30th January and attended by ROADMAP representatives, focusing on issues relating to regulators, HTA bodies, and patients in relation to research about better outcomes in Alzheimer’s disease (AD).

The Outcomes Definition team has been simultaneously conducting a systematic literature review (SLR) of relevant outcome prioritisation literature and designing a study, which will commence early in 2018 involving AD patients and their carers. Across the SLR the team has screened the relevant citations and progressed to full-text screening and data extraction, which it will conclude in January 2018. Across the survey, the team has prepared the final version and translated it into Spanish and Catalan, such that data collection via a Girona memory clinic is now underway. This will be followed by data collection in Oxford and Edinburgh memory clinics in January 2018, for which ethics application forms have been submitted. Interviews and workshops with the professional stakeholder group have also been prepared and will likewise commence in the New Year. Data collected from workshops with patients and carers has been completed and analysis of this is underway. Finally, the team has produced two interim reports on their recent work, both of which are available on the ROADMAP website.

The Real World Evidence (RWE) identification team has been focusing on several important tasks. They have identified data for disease modelling studies through the Dementias Platform UK (DPUK), European Medical Information Framework (EMIF), Electronic Health Records and AD catalogues. In conjunction with the Disease Modelling and Simulation team, they have been exploring the feasibility of a distributed data access and analysis network model. The RWE team has also continued work on the ROADMAP Data Cube, scheduling meetings with representatives of the other ROADMAP teams for January 2018 to discuss and further refine the current outcomes and information. In addition to this, the team has initiative development of a Data Sharing Agreement Template for ROADMAP to support data custodians when they are sharing data for ROADMAP studies.

Within the Disease Modelling and Simulation team, work has been ongoing to validate the first model produced, and information about the outcome of this validation will be forthcoming once this process has been completed. The team has also begun a second literature review of disease prediction models, and is exploring several new data sets, including the recently joined Memento cohort. Finally, model validation plans for other AD case studies have been submitted via the RWE team to owners of relevant data, and access to real-world data (RWD) is being processed by several owners of such data. Systematic reviews have been the primary focus of attention for the Health Economics team. They are conducting three – on resource use and costs, quality of life, and economic modelling. Protocols for each of these have been approved by ROADMAP and are being published as three separate manuscripts in BMJ Open.

The regulatory issues and Health Technology assessment team have focused largely on reviewing regulatory experiences with
RWE in AD. Led by the Medicines Evaluation Board, the team has now produced an initial draft for internal review by ROADMAP colleagues, which will be finalised and completed for wider dissemination in 2018.

Next is an update about the recent work of the Ethical, Legal, and Social Implications (ELSI) team. In December, members of the team conducted a focus group in collaboration with Alzheimer Europe, speaking to members of the European Working Group of People with Dementia (EWGPWD) and their carers. The focus group explored concerns about the sharing and re-use of real world data. The results of this work will be reported in 2018 and will provide important stakeholder input into the ELSI framework requirements.

Finally, the Communication team has been disseminating information about the important work being delivered by ROADMAP team, ensuring that all the relevant information is accessible and made widely available to the dementia, scientific, and policy communities, as well as the general public. In addition, they will attend a meeting with BD4BO on 16 January in the EFPIA office (Brussels) to discuss communications and outreach activities between the disease specific project representatives and BD4BO’s Communication team.

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- AETIONOMY – grant agreement 115568
- EPAD - grant agreement 115736
- ROADMAP – grant agreement 116020

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**Alzheimer Europe Networking**

On 28 November Dianne took part in the AMYPAD/EPAD ethics work package telephone meeting.

On 29 November (Basel, Switzerland) Dianne attended the Steering Committee meeting of the AETIONOMY project.

On 30 November-1 December (Basel, Switzerland) Dianne and Cindy attended the AETIONOMY GA meeting.

On 4-5 December (Brussels, Belgium), the AE Board met.

On 5 December (Brussels, Belgium) Heinz K. Becker, MEP (Austria) and Olga Sehnalová, MEP (Czech Republic) hosted the Alzheimer Europe lunch debate.

From 5-7 December (Brussels, Belgium), Dianne and Ana attended the EWGPWD meeting and provided support to the group.

On 6 December (Brussels, Belgium) the EWGPWD, Dianne and Ana attended the 4th European Parliament of Persons with Disabilities.

On 6 December (Brussels, Belgium), AE organised a company round table meeting with its corporate sponsors.

On 6 and 7 December (Brussels, Belgium), AE organised its Alzheimer’s Association Academy with capacity building workshops for its national member organisations.

On 11 December (Brussels, Belgium) Vanessa took part in the #EU4Health meeting.

On 11-12 December (Paris, France), Cindy attended a Human Brain Project seminar on data governance and informed consent.

On 11 and 12 December (Geneva, Switzerland), Jean attended the launch of the Global Dementia Observatory of the World Health Organisation.

On 11-12 December Ana participated in the online kick-off meeting of the project SoCaTel, representing AE as member of the Advisory Board.

On 13 December, Dianne and Ana participated in the ROADMAP ethics work package telephone meeting.

On 13 and 14 December (Lausanne, Switzerland), Jean participated in the Workshop “The road to 2025 – Building the ecosystem for Alzheimer’s innovation”.

On 18 December, Jean participated via telephone in the Programme Board meeting of the 2nd European Joint Action on Dementia.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 123, 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 Kappel (NI); Paul Rübig (EPP). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brentem (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni 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 Jätteenmäki (ALDE); Mapestra Kumpula-Natri (S&D); Merja Kylänén (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Dominique Bide (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:** Costas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyriko Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); María Spyrauki (EPP); Eleftherios Synadinos (NI); Elisavet Vozemberg (EPP). **Hungary:** Ádám Kösa (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Cathy (ALDE); Áine Cleary (S&D). **Italy:** Gianni Del Bello (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke 'Ming' Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairéad McGuinness (EPP); Diannò Ni Riain (GUE/NGL). **Lithuania:** Vilius Blink vi centyte (S&D). **Luxembourg:** Georges Bach (S&D); Frank Engel (S&D); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Lukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wentka (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian Siliviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP); Daciana Octavia Sarbu (S&D); Claudia Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolásik (EPP); Ivan Stefanc (EPP); Anna Zaborska (EPP). **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (S&D). **Sweden:** Jiří Havel (ALDE); Monika Huemer (S&D); Roberta Metsola (EPP); Alfred Sant (S&D). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).

**EU DEVELOPMENTS**

**6 December: 4th European Parliament of Persons with Disabilities takes place in Brussels**

On 6 December more than 600 persons with disabilities from all over Europe including members of Alzheimer Europe’s Working Group of People with Dementia (EWGPWD) met at the 4th European Parliament of Persons with Disabilities (EPPD). The EPPD was co-organised by the European Disability Forum (EDF) and the European Parliament. The President of the European Parliament, Antonio Tajani, and EDF President, Yannis Vardakastanis, opened the EPPD.

President of the European Parliament, Antonio Tajani, stated: “Our commitment to improve the lives of persons with disabilities is founded in our values as Europeans, including our attachment to freedom, equality and inclusion of all individuals in society. These values have to be translated into concrete actions, to enable every person to live an independent life, and to make sure that our society empowers everyone.”

EDF President, Yannis Vardakastanis, stated: “Today we show a European Parliament close to its citizens. The EPPD is another milestone in the dialogue between EU elected representatives and citizens with disabilities. Throughout all EDF existence, the European Parliament has always been a strong and vocal defender of the human rights of persons with disabilities. Over the last two legislatures, the European Parliament promoted and protected the rights of persons with disabilities during legislation negotiations on the right to equal access to the internet, to transport or to independent living, as well as on the structural funds – in line with the provisions of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).”

The EPPD gave European citizens with disabilities, both leaders and grass-root activists a unique opportunity to talk with Members of the European Parliament (MEPs) and high level representatives of other EU institutions about their human
rights. This year the topics under discussion were: the right to vote and participate in political and public life, the European Disability Strategy 2020-2030 and the European Union (EU) being a global leader on inclusive Sustainable Development.

During the EPPD, a manifesto on European elections 2019, a resolution on the next European Disability Strategy and an emergency resolution on the European Accessibility Act were adopted by the delegates. During the afternoon session when delegates discussed the Sustainable Development Goals and the importance of taking people with disabilities on board in their implementation Chris Roberts Vice Chair of the EWGPWD, was one of the representatives from different disability organisations to give a speech. A full report of the event can be read here.

You can read more about the participation of Alzheimer European and of the EWGPWD in the “Alzheimer Europe” section of this newsletter.

7 December: EU Council adopts position on Accessibility Act

On 7 December at its meeting the Council agreed on a position on the European Accessibility Act, a proposal for legislation aiming to make several products and services in Europe accessible to all people. Now the negotiations among the three EU institutions, European Commission, European Parliament and Council, to agree on a final text can start. The European Disability Forum (EDF) of which Alzheimer Europe is a member have said that the text agreed by the Council does not meet the demands of the disability movement and excludes some important elements.


11 December: Important milestone for timely diagnosis gets support from European Union

On 11 December, the European Commissions’ science and knowledge service “Joint Research Centre” (JRC) released a set of certified reference materials to support timely diagnosis of Alzheimer’s disease (AD).

Certified reference materials (CRM) provide a reference point for analytical laboratories around the world to deliver accurate and comparable results. The laboratories use CRMs to calibrate their instruments, evaluate test procedures and for quality control purposes.

In this case, the new CRMs are used to calibrate diagnostic tools for amyloid-β 1-42. Amyloid-β can be found in the cerebrospinal fluid and is a biomarker for AD. So far, clinical studies have found evidence of a potential value of biomarkers (such as amyloid-β 1-42, tau and phospho-tau) for an early diagnosis of AD. Biomarkers are organic features used to diagnose or potentially predict diseases such as AD.

Vytenis Andriukaitis, Commissioner for Health and Food Safety, said: "Alzheimer’s disease, the most common form of dementia, remains largely underdiagnosed. While certain gene variants increase the risk for Alzheimer’s disease, not all people having the gene will develop the disease. Therefore, reliable markers are necessary not only for early diagnosis but also for drug development and monitoring treatments."

The set of certified reference materials ERM-DA480/IFCC, ERM-DA481/IFCC and ERM-DA482/IFCC, can be obtained through the JRC catalogue.

11-12 December: Human Brain Project holds a seminar on data governance and informed consent

On 11-12 December, the Human Brain Project (HBP) organised a seminar on data governance and informed consent in Paris, France. This seminar was attended by 34 participants including HBP scientists, HBP data managers, experts in bioethics, patient representatives and external stakeholders.

Karen Riisgaard (pictured) introduced the seminar where participants initiated a dialogue on how to improve data governance and informed consent in big data research projects like HBP. The seminar addressed this challenge through various presentations and plenary discussions focused on ethics governance in biobanking, perspectives on the general data protection regulation and empowerment of data subjects in big data research.

Much of the meeting was taken up with discussions about concerns on open access, data protection, engagement, anonymization, new GDPR and informed consent. Another interesting area highlighted was on how to create trust. Some examples were provided such as newsletter and lay abstracts, roots in local communities and patient friendliness. Project Officer Cindy Birck presented the Alzheimer Europe Clinical Trials Watch as an example of dementia-friendly information on clinical trials. Participants ended the seminar by identifying the new opportunities and the short/long term challenges for the HBP project.

13 December: European Commission adopts the Health Programme’s Work Programme for 2018

The Work Programme for 2018 will focus resources on European Reference Networks for rare diseases, health promotion and mitigating cross-border health threats. The overall budget for 2018 is just over €62 million, with 64% being allocated to grants, 24% to procurement and 12% to other actions including prizes.

Vytenis Andriukaitis, Commissioner for Health and Food Safety, said "I welcome the adoption of the 2018 work
programme of the Health Programme 2014-2020. Our budget is indeed relatively modest but I aim to support actions that deliver undisputed EU added value – such as connecting expertise on rare diseases and preparing a robust response in the event of a serious cross-border health threat. This can make a real difference to European citizens’ health and wellbeing.”

All grants for projects will be implemented through a call for proposals, organised and managed by the Consumer, Health, Agriculture and Food Executive Agency (CHAFEA) which will be launched in the first half of 2018.

For more information on the Health Programme, and to read the 2018 Work Programme in full:
https://ec.europa.eu/health/programme/adoption_workplan_2018_en

POLICY WATCH

1 November: Alzheimer Society of Ireland calls on Minister of Health for dedicated budget for people with dementia

Over 2,000 supporters of The Alzheimer Society of Ireland (ASI) have signed a letter calling on the Minister for Health to ensure that a portion of the €37 million announced in Budget 2018 for home care is ring-fenced for people with dementia.

Since 2016 over 28,000 people have also signed our petitions calling for more community supports for people with dementia, showing that this is a major constituency issue.

The All-Party Oireachtas Group on Dementia, convened by Deputy Mary Butler and Senator Colette Kelleher, continue to provide vital leadership on this issue. Members of the group launched their first Budget Proposals last month and made this submission to the Department of Health on the creation of a statutory home care scheme.

6 December: Italy initiates new project to identify AD risk

On 6 December, Italy launched a new project to identify people with the highest risk to develop Alzheimer’s disease (AD) in the hopes of treating them early.

Italy has the oldest population in Europe. The government has committed 3.5 million euros for the 54-week project aiming to identify the 50% of Italians with the highest risk of developing AD. The screening project entitled “Interceptor” will enrolled 400 people with mild cognitive impairment aged between 50 and 85.

“AD is a global problem that needs to be, if not solved, at least managed with maximum urgency. One million people in Italy live with dementia” said Italian Health Minister Beatrice Lorenzin.

According to the European Dementia Monitor, launched by Alzheimer Europe in June 2017, Italy was the country that was the most committed to and active in European dementia research collaborations.


7 December: The World Health Organisation launches the Global Dementia Observatory

As the global population ages, the number of people living with dementia is expected to triple from 50 million to 152 million by 2050. The estimated annual global cost of dementia is US$ 818 billion, equivalent to more than 1% of global gross domestic product. The total cost includes direct medical costs, social care and informal care (loss of income of carers). By 2030, the cost is expected to have more than doubled, to US$ 2 trillion, a cost that could undermine social and economic development and overwhelm health and social services, including long-term care systems.

The Global Dementia Observatory, a web-based platform launched by WHO on 7 December, will track progress on the provision of services for people with dementia and for those who care for them, both within countries and globally. It will monitor the presence of national policy and plans, risk reduction measures and infrastructure for providing care and treatment. Information on surveillance systems and disease burden data is also included.

To date, WHO has collected data from 21 countries of all income levels. By the end of 2018, it is expected that 50 countries will be contributing data. Initial results indicate that a high proportion of countries submitting data are already taking action in areas such as planning, dementia awareness and dementia-friendliness (such as facilitating participation in community activities and tackling the stigmatization of people living with dementia) and provision of support and training for carers, who are very often family members.

The Observatory will provide a knowledge bank where health and social care authorities, medical professionals, researchers and civil society organizations will be able to find country and regional dementia profiles, global reports, policy guidance, guidelines and toolkits on dementia prevention and care.

13-14 December: Dementia experts meet in Lausanne to discuss the dementia readiness of health systems

The Lausanne Workshops bring together international stakeholders to discuss innovative strategies in Alzheimer’s public policy, research, regulation and access. The first in a series was held in 2014 as a response to the challenge articulated at the G8 Dementia Summit which called for an effective cure or treatment of Alzheimer’s disease by 2025. The 2017 workshop was organised under the auspices of the Organisation for Exconomic Co-operation and Development (OECD) and was supported by the Swiss Federal Office of Public Health, the Global CEO Initiative on Alzheimer’s disease (CEOi) and Alzheimer’s Disease International. The theme of the workshop was: “Building the ecosystem for Alzheimer’s innovation: Defining public policy, research, regulatory and access solutions”.

During the two day meeting, experts
- discussed the development of public policies in the field and welcomed the recent adoption of the WHO Global Action Plan,
- reviewed the progress and setbacks in the search for better treatments and heard that over 90 drugs are currently in late-phase development,
- stressed the importance of integrating patient and caregiver perspectives into drug development decisions and listened to the moving testimony of Geri and Jim Taylor, a person living with Alzheimer’s disease and her husband,
- discussed how the regulatory system of the future should evolve and how new emerging guidelines are dealing with the development of new targets, treatments and technologies,
- explored the health system readiness to diagnose people with Alzheimer’s disease in earlier stages and identified potential roadblocks such as shortages in medical experts and lack of education and awareness,
- listened to the views of payers and health technology assessment experts on new value frameworks for the appraisal and pricing decisions of future Alzheimer’s treatments.

The meeting also welcomed and supported the Global CEOi Biomarker Initiative and the consensus developed by the Alzheimer Europe was represented at the meeting by its Executive Director, Jean Georges.

14 December: World Dementia Council announces new leadership and membership

The World Dementia Council (WDC) has elected Harry Johns and Jeremy Hughes as the next Chair and Vice-Chair. They will succeed respectively, Yves Joanette and Raj Long, who have announced that they will step down in Spring 2018. Harry Johns is the President and CEO of the Alzheimer’s Association, USA and Jeremy Hughes is CEO of Alzheimer’s Society UK. At the same time, Alzheimer’s Disease International will join as a new Associate Member. This category of member nominates a representative to the Council. ADI’s representative will be its CEO, Paola Barbarino.


21 December: Norway has a new national guideline on dementia

The Norwegian Directorate of Health has published a national guideline on dementia to ensure good diagnostics and treatment, and the Norwegian Health Association has been involved in the process of structuring these guidelines.

The aim of the new guideline is to ensure that more people receive the correct diagnosis, as well as better care.

This is a national standard for how health and care services to people with dementia and their carers should be given, says professor emeritus Knut Engedal (pictured), who was involved in the work, and who is also the leader of the Norwegian Health Association’s Council on Dementia.

MEMBERS’ NEWS

29 November: Alzheimer’s Society celebrates the best of the UK’s dementia-friendly work in 2017

Every day Alzheimer’s Society hears examples of people with dementia, carers, volunteers, professionals, fundraisers and others in the wider community, who have made a real difference to the lives of people with dementia. The Dementia Friendly Awards curates the best and most inspiring stories and offers them the recognition they truly deserve. Each year award ceremonies are held in England and Wales as well as Northern Ireland.

The winners of the English and Welsh fourth Alzheimer’s Society Dementia Friendly Awards 2017, sponsored by British Gas, were announced at the awards ceremony on Wednesday 29 November at etc. venues County Hall, London. Award categories included Dementia Friendly Community, Inspiring Individual, Journalist, Young Persons Contribution, Dementia Friends Champion, Dementia Friendly Organisation and Fundraiser of the Year. The awards were hosted by Angela Rippon, TV presenter and Alzheimer’s Society Ambassador.
and presenters included Jeremy Hunt, Secretary of State for Health and actors Lesley Sharp and Richard McCourt. The number of nominations received for this year’s Dementia Friendly Awards was truly phenomenal, reaching 468 in total. Nominations were judged by a panel of people affected by dementia and industry experts who worked hard to choose the finalist’s inspirational and exceptional stories out of the many other fantastic nominations.

Wendy Mitchell, who is living with dementia and winner of the Inspiring Individual 2017 award, said: “This is very humbling and it was quite a shock as so many people like me speak out about their experiences of living with dementia and I am one of many. This will help me raise awareness about dementia in so many ways and will hopefully change the future for my daughters.”

Read more about our award winners at the Alzheimer’s Society blog: blog.alzheimers.org.uk/inside-the-society/2017-dementia-friendly-awards-winners/

30 November: Alzheimer Society Ireland raises awareness at Fianna Fáil and Sinn Féin Ard-Fheiseanna

The Alzheimer Society Ireland recently had stands at the Fianna Fáil and Sinn Féin Ard-Fheiseanna for the first time this year. It was a great opportunity to meet political representatives and members from around the country to discuss the need for more community supports for people living with dementia and raise political awareness. Alzheimer Society Ireland welcome the fact that dementia was raised as an important issue at both Ard-Fheiseanna, with calls for more funding for dementia-specific services and for the full implementation of the National Dementia Strategy.

1 December: Alzheimer Netherlands reports on its recent TV show

This autumn, Alzheimer Nederland has launched a campaign entitled “Stop dementia”. On 21 October, as a highlight of the campaign, the association held a prime time TV show under the banner “Unforgettable memories”. Seven families shared personal stories and memories. The audience had the opportunity to learn more about the impact of living with dementia as well as on the everyday life of people with dementia.

Sharon Bilars talked about her husband Wilco who is living with frontotemporal dementia. In a short film, the audience saw them on a duo-bike climbing the Dutch hills for their weekly tea with apple pie. The talented OG3ne sisters group performed a special version of the song ‘Always’ (Bon Jovi) especially for Sharon and her children as it is a song that means so much for this family.

In short interviews, professors from Dutch Alzheimer’s disease centres presented the progress on brain’s research. A live call centre, held by the staff of Alzheimer Nederland and by prof. Philip Scheltens and prof. John van Swieten, registered over 8,500 new donors for Alzheimer Nederland.

2 December: People with memory diseases and carers gather together at seminar in Finland

Good mood, stories and music formed the main essence of this year’s seminar for people with memory related diseases and their carers in Finland. This annual seminar is one of the main yearly events of the Alzheimer Society of Finland and was held this year in December 2nd in Kokkola, Ostrobothnia. The seminar was organized in co-operation with the Memory Association of the Central Ostrobothnia and the Dementia Association of Finland.

For the Alzheimer Society of Finland and its 44 member associations it is important to strengthen the equal participation of the people with memory diseases and their carers, for example by organizing with them events with active participation and networking. These seminars are one way to encourage more people with memory diseases and their carers to take part in the activities of the memory associations and thus influence their own rights as people with memory diseases or carers.

As Finland celebrates its 100th year of independence this year, the theme of the seminar was: “A memory trip to past, present and future”. Within this theme many life stories of people with memory diseases were shared, together with a brief history of the Alzheimer Society of Finland. The stories were accompanied with music performances and an overview of the participants’ thoughts on good mood. The seminar finished with an open dance floor accompanied with the rhythms of some traditional Finnish accordion music. The dance was requested in the seminar feedback last year. Click here to enjoy the dancing spirit on Instagram.
8 December: Alzheimer Croatia holds 3rd edition of “EdukAl” conference and launches Dementia Friends Initiative

On 8 December 2017, Alzheimer Croatia held its annual Educational Conference on Alzheimer’s Disease, EdukAl 2017 and the day later the cross-border Event as a part of EU project Demenca aCROsSLO between Croatia and Slovenia. The topic of this year’s conference was: “With dementia we can have better life longer!” More than two hundred participants discussed issues of public health and social policies with dementia, problems of early detection of dementia, and ways to improve the quality of life of people with dementia and their families, who are caregivers in their homes in 90 percent of cases.

During the opening ceremony of the conference, the Dementia Friends Initiative was launched, giving the EdukAl’s participants the opportunity to be the first to join.

The second day of conference was dedicated to a cross-border event entitled “Demenca aCROsSLO”. This European project aims to improve the quality of life of people with dementia in the cross-border area of the Croatian and Slovenian Istria, in which Alzheimer Croatia has a significant role.

The patrons of the EdukAl conference were the Ministry of Health and the Ministry of Demography, Family, Youth and Social Policy of the Republic of Croatia and the City of Zagreb. Further, it was supported by Alzheimer’s Disease International, Alzheimer Europe and the Mediterranean Alzheimer’s Alliance.

8-10 December: Bridging the Generation gap - 1st Festival of game development for people with Dementia

For the first time in Greece experienced game-designers along with psychologists, neurologists, occupational therapists, nurses, professionals carers and relatives, students and older people gathered together to collaborate in making innovative games for people with dementia. The Bridge Game Jam took place in Chalkida, from the 8-10 December 2017, and was the first Game Design Festival Dedicated to Dementia organized by the Greek Association of Alzheimer’s Disease and Related Disorders of Chalkida, the Challedu-play learn evolve under the hospices of the Administrative office of Central Greece prefecture, Regional Administration of Euboea.

During the festival about 150 geriatric patients in various stages of dementia together with young people were invited to talk, play, entertain and share experiences and memories through game designing. The game leaders helped the teams to design 10 innovative games. The 3 day experience was run in a warm collaborative atmosphere where the generations mingled together through playing. The evaluations at the end of the event were rewarding and stressed the need to follow-up the event and expand the idea of game designing specifically for dementia.

Bridge Game Jam was opened with welcoming speeches from the organizers. Mr Fanis Spanos, from the Regional Administration of Euboea, highlighted the importance of the organization of such events that aim to help the third generation and involve the active participation of youth. Evangelia Angelidou, as president of Chalkida Alzheimer, presented the work of the organization and the importance of social interaction for the people with Dementia. Asimina Brouzou from Challedu-play learn evolve presented the organization which uses games as a tool for education and engagement. Invited speaker neuropsychologist Dr. Marieta Remoundou presented the cognitive domains that are affected at the various stages of dementia and the underlined abilities that need to be considered during game designing. The opening concluded with the speech of game-designer Dr. Ioannis Brouzos who presented several examples of games and their mechanisms and elaborated on how they can be used to support several functions of the patients with dementia and delay the effects of the disease.

On Saturday, the all-day event, began with dividing people into mixed groups and playing of several old and new board and digital games. This intergroup achieved a house warming atmosphere that facilitated the good communication of the participants with no age barriers. The afternoon was dedicated to the design and implementation of novel games. Participants with the lead of experienced game designers worked on 10 innovative board and spatial games. The day was long but successful.

The closing ceremony on Sunday was an ultimate playful experience. The games were tested and the teams got very important feedback for their creations.

The Bridge Game Jam Festival concluded with the presentation of the games from the team leaders and their teams. Older participants took the floor to share their enthusiasm and experience of it. The organizers promised that many Bridge Game Jams will be organized in the future and this first time was a clear proof that this is necessary.
8-10 December: Mental health is focus of 18th Annual Conference of the Panhellenic Nurse Labour Union

From 8-10 December 2017 mental health was the focus of the 18th Annual Conference of the Panhellenic Nurse Labour Union (ΠΑΣΥΝΟ-ΕΣΥ). The organisers also included a session emphasizing the need for special training for health professional and caregivers to the elderly. Anticipating the participation of undergraduates and young professionals, Dr Ioanna Papathanasiou, Assistant Professor of Mental Health, Department of Nursing, TEI of Thessaly, invited EENAA (Larissa Association of Alzheimer’s Disease and Related Disorders) to formulate an independent thematic session. EENAA led a session on the “Promotion and Management of Health in Dementia”.

EENAA is a cornerstone of the local community in Central Greece, promoting patient-centred care. It has made steady efforts to increase public awareness, and motivate and involve various professionals to contribute to the field. Neurologist Ioannis Pagitsas, vice-president of the Association, introduced the basic diagnostic tools and provided updates on the epidemiology of the disease. Neuroscientist Artemissia-Phoebe Nifli, MSc, PhD, Principal Researcher at TRC elaborated on the behavioural and psychological findings, how and when they are manifested in dementia patients, and their contribution to morbidity and probable cases. Because of the impact of BPSD on cognitive deterioration and quality of life, validated tools would assist in differential diagnosis and course of treatment.

Non-pharmaceutical interventions against chronic stress were described by psychologist Kyrkaki Giota, MSc, PhD. Finally, Dr Vasileios Vlachos, Assistant Professor of the Department of Computer Science and Engineering, TEI of Thessaly, addressed security and safety issues in health care. Besides the financial cost of malware infections, and the risk of data breach, he showed patient life being in immediate risk upon attempts against portable or implantable devices, incidences that are beyond the abilities of health professionals.

EENAA’s thematic session initiated a discussion about the availability and versatility of diagnostic tools in dementia, and the related experience of health professionals, particularly nurses. Furthermore, the session was successful in proving how experts among local non-profit organizations, industry and academia, may contribute to coordinated efforts, such as the Global Dementia Observatory, and assist health care professionals in providing high quality patient care.

13 December: Foundation Alzheimer’s Bulgaria publishes a manual for caregivers of people with dementia

Foundation Alzheimer’s Bulgaria has published a ‘Manual for caregivers of patients with dementia’ this is the first time this type of publication has ever been published in Bulgaria. It reaches out to all those who look after relatives diagnosed with dementia in their families and homes. A campaign for early diagnosis of different types of dementia was also launched in November. It started from the small village Gorna Mitropoliya in one of the poorest and most depopulated regions with an ageing population in Bulgaria. In the pensioners club of the village Alzheimer Bulgaria talked about various dementia types, we administered tests for self-assessment and provided information to the elderly about the nearest places they can seek help from, and about the available ways of contacting neuropsychologists and neurologists for consultations.

The full report with the complete text in Bulgarian can be downloaded here:

https://alzheimer-bg.org/pechatni-izdanija/knigi/

14 December: Zagreb becomes first Dementia Friendly City in Croatia

On 14 December 2017, Zagreb (capital city of Croatia) signed an agreement on becoming a Dementia Friendly Community with Alzheimer Croatia. Among others plans, the top ones will be action on early detection of neurodegenerative diseases in primary health care, development of new social policies which will focus on cognitive disabilities and implementation of better home care services and support for family caregivers.

The city of Zagreb is becoming our first Dementia Friendly Community, and with help of Alzheimer Croatia, which we support for years, we are going to further develop our project “Zagreb Healthy City” - emphasised Deputy Mayor, Olivera Majić.

It is great that the city of Zagreb, with one fourth of all Croatian inhabitants and all mayor health services, is the first start its transformation into a Dementia Friendly Community. This will encourage other Croatian cities, institutions and businesses to do the same - stressed Tomislav Huić, vice president of Alzheimer Croatia and director of Dementia Friends Initiative in Croatia.
15 December: MemoryMIKE – a new tool developed for assessing and monitoring quality of life – is launched in Finland

MemoryMIKE is an instrument for assessing and monitoring the Subjective Quality of Life of a Person with a Memory Disorder (referred to as MIKE, its Finnish acronym, from now on). It was developed by the Memory Association of Oulu Region and the Memory Association of South Ostrobothnia, which are member organisations of the Alzheimer Society of Finland, and the Finnish Association for the Welfare of Older People. Health professionals and people with memory disorders participated in the development of MIKE. The instrument and the associated forms, as well as further information about the method, are available here. More about the Active Age programme, within which MIKE was developed, can be read here. In Finnish #MemoryMIKE is called #MuistiMIKE.

18-19 December: Alzheimer Slovenia reports on its involvement in new AD-AUTONOMY project

On 18 and 19 December 2017, Spominčica - Alzheimer Slovenia attended the kick-off meeting of the AD-AUTONOMY, Erasmus+ KA2 project. The meeting was held by AFA Castellón in Castellón, Spain. The project, which started in October 2017, will last 24 months, ending in September 2019. At the meeting, the project and the partners were introduced. Spominčica and other partners presented their previous activities. Spominčica will be responsible for proposing the structure and procedures of co-creation sessions and methodology in the project.

The main objective of AD-AUTONOMY is to improve the quality of life of persons with dementia and their carers, through an innovative training programme. The programme aims to raise awareness and to emphasise the importance of maintaining autonomy, to increase the autonomy of persons with dementia where decision-making and independent living are concerned, to promote autonomy through training, to support the process of empowerment through introducing technology and techniques for emotional management, to include professionals in the process, and to develop training methodology with tools.

Partners in the project are AFA Castellón (Spain), Spominčica – Alzheimer Slovenia (Slovenia) and Alzheimer Dernegi (Turkey), all of whom will be directly supporting people with dementia, their relatives and professionals; and Bournemouth University (United Kingdom), Universitat Politècnica de València (Spain) and Aristotle University of Thessaloniki (Greece), all of whom will be responsible for developing the ICT and assistive technologies for increasing quality of life.

AD-AUTONOMY represents a unique and innovative training programme, which will be based on direct involvement and training of persons with AD and involvement of families and professionals. The project will be focused on experiential practical activities in everyday environments.

21 December: Norwegian dementia friendly workshop brings together over 30 municipalities

Over 80 municipalities have joined the Norwegian campaign for a more dementia friendly society. In signing the agreement they promise to teach people in their communities about dementia and how to give people with the diagnosis better customer service. As a part of the campaign, representatives from each municipality meet once a year for a workshop, to evaluate and learn from each other. On 20 October, over 30 municipalities gathered in Oslo to join forces and learn from each other.

The workshop offers much valued feedback from the municipalities to the Norwegian Health Association, as well as motivation to keep up the good work. The participants reported that they were proud to be a part of the work for a more dementia friendly society.

As part of this work, dementia awareness sessions have been held for a range of different groups, including taxi drivers, shop assistants, employees of libraries and pharmacies, as well as ecclesiastical staff and school students. Based on the feedback, approximately 3,500 individuals have taken part in these sessions.

SCIENCE WATCH

16 November: Researchers suggest a link between astrocytes and AD

In a study published in the journal Stem Cell reports on 16 November, researchers from the University of Eastern Finland reported that astrocytes could play an important role in the pathogenesis of Alzheimer’s disease (AD).

Astrocytes, the most numerous cell type within the brain, are considered to provide support and guidance to neurons. In the published study, researchers generated functional astrocytes from induced pluripotent stem cells derived from AD people with a specific mutation observed in familial early-onset type AD (PSEN1 ΔE9). The findings suggested that PSEN1 ΔE9 mutant astrocytes manifested many hallmarks of AD.
pathology. They contributed to β-Amyloid pathology by increased release of beta-amylloid compared to astrocytes from people without AD. In addition, scientists described that PSEN1 ΔE9 mutant astrocytes altered their energy metabolism, the cytokine secretion promoting thus brain inflammation and the calcium signalling activity of healthy neurons.

http://www.cell.com/stem-cell-reports/fulltext/S2213-6711(17)30471-X

28 November: TauRx Therapeutics publishes data of LMTM for AD

In a study published in the journal of Alzheimer’s Disease on 28 November, the pharmaceutical company TauRx Therapeutics, which develops treatments and diagnostics for Alzheimer’s disease (AD), reported the full results from its second Phase 3 clinical trial of LMTM, a Tau aggregation inhibitor being developed as an AD treatment. The trial was a double-blind and randomized trial designed to evaluate the efficacy and safety of LMTM in people with mild AD. 800 participants with mild AD from US, Canada, Australia and Europe received 100 mg or 4 mg (low dose selected as a control dose) twice a day over an 18-month treatment period. Participants were divided in different groups, receiving the experimental drug in combination with drugs approved for the symptomatic AD (add-on therapy) or receiving only the experimental drug (monotherapy).

In the non-randomized cohort comparisons, results revealed that both cognitive (ADAS-cog) and functional (ADCS-ADL) coprimary outcomes were significant for 4 and 100 mg twice a day as monotherapy compared with participants receiving the experimental drug twice a day as add-on therapy. However, no differences were observed between both doses as monotherapy. Additional findings from brain scans revealed a reduction of brain atrophy after 9 months of treatment in participants receiving LMTM as monotherapy.

The data were consistent with earlier studies suggesting that LMTM could be effective as monotherapy. A further randomised controlled clinical trial is planned to evaluate efficacy and safety of LMTM in people with mild AD not taking current treatments compared with placebo.

https://content.iospress.com/articles/journal-of-alzheimers-disease/jad170560

29 November: Gene-variant may be new target in Alzheimer’s disease (AD)

On 29 November, a research team led by scientists from the Brigham Young University published their results in the journal Genome Medicine. The team is highly interested in genetic variants that may shed light into why some people develop Alzheimer’s disease (AD) although they are at a higher risk and others don’t.

So far, researchers have gathered a lot of evidence that shows a clear association between the risk to develop dementia in people that carry at least one APOE ε4 allele in their genes. In order to know more about the genes that may render some individuals more resilient than others, they looked at data of people that were at least 75 years old, without apparent cognitive symptoms and carried at least one APOE ε4 allele.

Using information from 20,000,000 people that are part of the large Utah Population Database, the scientists identified 232 so-defined AD resilient individuals.

As a next step, the team looked for common DNA in this group, which had not been present in people that died of AD. Through whole genome sequencing and a linkage analysis methodology, they discovered a variant these shared in the RAB10 gene.

As a last step, the researchers made the RAB10 gene inoperative and found that this resulted in a decrease of the Aβ42 as well as Aβ42/Aβ40 ratio in mouse neuroblastoma cells (both Aβ42 and Aβ40 are crucially involved in AD as main component of the amyloid plaques found in the brains or people with AD) during an experiment. The team concludes that RAB10 could be a promising therapeutic target for AD prevention.

29 November: Is there a link between marital status the risk of dementia?

On 29 November scientists from University College London have published a systematic review and meta-analysis they conducted in order to assess the possible link between marital status and the risk of developing dementia. The paper has been published in the Journal of Neurology Neurosurgery & Psychiatry.

The team included 15 studies with altogether over 800,000 participants from which one study from Sweden contributed the biggest amount (92%). The analysis of the publications provided insights that in people the risk to develop dementia was at the highest in people that were single for their whole life (42%) and still higher in widowed but not divorced people (20%) compared to those that were married.

The study’s lead author Dr Andrew Sommerlad (UCL Psychiatry) commented on the results stating that; “‘Married people tend to have healthier lifestyles and are more socially engaged, which may explain why they’re less likely to develop dementia’.

In the context of this rather unbalanced availability of data from different countries, it is important to consider that data from a specific population may be able to bias this link and further studies that provide comparisons of different countries using the same methods and taking into account further lifestyle factors are needed to additionally elucidate the possible link between marital status and the risk to develop dementia.
5 December: UCI MIND and WAM launch new women-focused AD research initiative

On 5 December, the Women’s Alzheimer’s Movement (WAM) and the University of California at Irvine’s Institute for Memory Impairments and Neurological Disorders (UCI MIND) announced together the launch of a new research initiative aiming to make funding available to UCI researchers for scientific proposals investigating the role of sex and gender in Alzheimer’s disease (AD).

"Two out of three Americans living with Alzheimer’s disease today are women. By 2050, 16 million people in the U.S. and 135 million worldwide will have fallen victim to this disease, and millions more family members and friends will suffer alongside those diagnosed, mostly women” said Maria Shriver, founder of the WAM.

http://thewomensalzheimersmovement.org/uci-mind-womens-alzheimers-movement/

6 December: Preventing excessive mitochondrial damage could reduce amyloid accumulation in AD

In a study published in the journal Nature on 6 December, Swiss researchers from the École Polytechnique Fédérale de Lausanne, reported that healthy mitochondria could reduce the formation of amyloid plaques, observed in Alzheimer’s disease (AD).

Using both bioinformatics and animal (worms and mice) models, scientists found that prevent mitochondria from brain damage could reduce amyloid plaques formation and improve significantly the brain function. The 2 mechanisms identified to keep mitochondria healthy included a cellular stress response protecting mitochondria from stress stimuli and a specific process to degrade defective mitochondria.

http://www.nature.com/articles/nature25143

6 December: US researchers forecast the prevalence of preclinical AD and MCI

On 6 December, US researchers from the University of California, Los Angeles, published in the journal of Alzheimer’s & Dementia the first estimation of Americans living with preclinical Alzheimer’s disease (AD) or mild cognitive impairment (MCI).

46.7 million people are living with AD in the US. Most of them have sign of preclinical AD but do not have clinical disease. Using a new bioinformatics model, scientists reported that 6.08 million Americans already had clinical AD or MCI due to AD in 2017. According to the study, this number will more than double to fifteen million by 2060.

The study showed that a large number of people are living with biomarkers of preclinical AD and highlighted thus the need to develop preventive measures.

http://www.alzheimersanddementia.com/article/S1552-5260(17)33813-X/fulltext

7 December: Researchers report a new retinal amyloid imaging to detect AD pathology

A recent study published on August 2017 in the journal of Clinical Investigation Insight reported the detection of amyloid plaques deposits in the retina of people with Alzheimer’s disease (AD).

In an article published on 7 December in the journal Neurology today, US researchers from University of Minnesota described a new technology to noninvasively detect amyloid plaques in the retina of AD people. Scientists found a significant increase of amyloid plaques deposits in the retinas of people with AD compared to healthy controls. They also reported a strong correlation of amyloid pathology in the retina and the brain. Together with the company Neurovision, researchers performed a pilot trial to evaluate curcumin as a fluorescent staining to detect amyloid plaques in living humans. Curcumin, a substance derived from plants, has the ability to bind aggregated amyloid-beta protein, the principal component of amyloid plaques. They found that curcumin staining revealed higher levels of amyloid deposits in the retina of people with AD than in controls.

http://journals.lww.com/neurotodayonline/Fulltext/2017/12070/In_the_Pipeline_Amyloid_Plaque_Detection_with_Curcumin.htm

7 December: Study suggests that education could reduce the risk of AD

In a study published in the British Medical Journal on 7 December, Swedish researchers from the Karolinska Institutet reported that higher education is linked to lower risk of Alzheimer’s disease (AD).

The aim of the study was to determine risk factors associated with AD. Using data from studies already published, scientists analysed 24 risk factors including socioeconomic, lifestyle and cardiometabolic factors from 2 groups: 17,008 people who had AD and 37,154 controls without the disease. They found that higher education was significantly associated with a reduced AD risk. In fact, they estimated that each additional year of education was associated with a further lowering risk. However, none of the 23 other risk factors predicted by genetic variants were significantly associated with AD.

http://www.bmj.com/content/359/bmj.j3375
11 December: Study suggests that urea is a cause of dementia

In the study published on 11 December in the journal Proceedings of the National Academy of Sciences, researchers suggested that brain urea could be a cause of dementia. They used both donated human brains and genetically modified sheep brains to show that Huntington’s disease, one of the seven main types of dementia, is linked to brain urea levels. Findings reported that high levels of urea including increased levels of urea transporter, other osmotic regulators and associated metabolites led to brain damage.

"Urea is a natural chemical produced by the body that is normally cleared away in our urine, but this study suggests a build-up of urea in the brain could be involved in the development of Huntington’s disease. This could be because the use of energy is compromised in the brains of people with Huntington’s and urea is produced as the damaged brain tries to find alternative energy sources", said Dr Doug Brown, Director of Research and Development, Alzheimer’s Society.

http://www.pnas.org/content/early/2017/12/05/1711243115.abstract?sid=c67b7c4e-d72c-4cd2-b0b9-18b66513bba7

15 December: Scientists describe the genetic profile of DLB

On 15 December, the journal Lancet Neurology published online a genome-wide association study conducted by University College London aiming to identify genetic risk factors for dementia with Lewy bodies (DLB). The study reported that DLB, a form of dementia that shares characteristics with both Alzheimer's (AD) and Parkinson's (PD) diseases, has a unique genetic profile, distinct from the 2 other diseases.

In the published study, scientists collected samples from 1,743 European participants living with DLB and 4,454 controls. They confirmed previous studies highlighting that both APOE and GBA genes, also implicated in AD and PD, were associated with DLB. Although SNCA is known to be associated with PD, researchers found that a different part of this gene was linked to DLB. Interestingly, they also found that few genes associated with AD and PD were not associated with DLB.

“Despite DLB being one of the most common forms of dementia in older people, until now there simply hasn't been enough information on its causes, so the finding that up to 36% of cases might be genetically inherited is a real revelation,” said Dr Doug Brown, research director at the Alzheimer’s Society.


LIVING WITH DEMENTIA

Nina Balackova, member of the EWGPWD, reports on her involvement over the last months

I have been quite busy over the last months. I had the opportunity to meet the director of the Bulgarian Alzheimer Society in Sozopol and was able to provide some feedback to her about the work that I am doing at national and European level. Also, I have attended recently an international conference on dementia in Bratislava. I was very pleased to be invited as a speaker to this conference. My speech was about what it is like to live with dementia and the work I am carrying out as member of the EWGPWD. I found the conference very informative and I particularly enjoyed Prof. Alexander Kurz’s speech about non-pharmacological interventions for people with dementia. During the second day I attended a very inspiring workshop about brain training and stimulation. My husband, who came with me to the conference, attended a workshop about support for carers. I am grateful for this invitation. It is very useful and interesting to be able to participate in this type of event.

Helen Rochford-Brennan Chair of the EWGPWD promotes better care for people with dementia

I was recently invited by the National Dementia Office and Director of Nursing and Midwifery to take part in a training session of The Virtual Dementia Tour (VDT).The VDT is an interactive learning experience that takes place in a mobile simulated training unit. It aims at supporting carers of people with dementia to have greater understanding and empathy in their caring role of what it is like to live with a diagnosis. I found the experience very interesting especially in how it affected those taking part in the training. For a person with dementia it takes a lot of courage to do this training and it certainly is not for the faint hearted. I could also see first-hand that there is still a lack of training across the health service which I am happy to learn is now being addressed.
I also have attended a national conference organised by the Social Work Special Interest Group in Ageing (SIGA) in Ireland. The conference was entitled “Promoting Excellence in Dementia Care” and was organised to provide multidisciplinary professional development for those who sought to promote excellence when supporting people living with dementia and their families. I was honoured to be invited to provide the first keynote address. Part of the keynote was based on human rights. I also spoke about my own personal journey and the importance of diagnosis and post-diagnostic support. The latter was very important for the audience as social workers play a key role in providing information and coordinating supports for the person affected and their families at all stages of dementia. I also spoke about my personal experience of receiving a diagnosis, the emotional impact of diagnosis on myself and my family, my experience accepting the diagnosis, the strategies I am using to live well and my current role acting as an advocate for others. I was told by the organisers that the feedback from the audience was very positive and reflected the value the audience placed on hearing the lived experience of a person living with dementia.

**Good news from Idalina Aguiar about a new centre for people with dementia in Madeira**

I would like to share with you some very exciting news from Madeira (Portugal). In November, the first adult day care centre in Madeira for people with dementia “Lugar de Memórias” was inaugurated. This centre has been opened thanks to the collaboration between different organisations including the Alzheimer Portugal’s Association in Madeira, the Funchal Community Development Association (Garouta do Calhau) and Madeira Social Security. The centre counts with several rooms which will provide therapeutic activities to people with dementia, as for example a Snoezelen room, which I have already tested! The centre is nicely equipped and its opening is very timely as this is the first adult centre for people with dementia in our community. 15 people with dementia will be able to participate in the activities of the centre. I was the first person to use this centre!

**Petri Lampinen talks about his experience of joining the EWGPWD in September**

For about a year I followed the activities of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD). I was delighted that the Alzheimer Society of Finland agreed to nominate me and I was able to join the group in Berlin as a member from Finland. This meeting of the group coincided with Alzheimer Europe’s annual conference in Berlin. I was warmly welcomed by all members of the group and I felt immediately a sense of belonging. I enjoyed participating in the conference together with my wife, Nina. The days at the conference were busy and rich with experiences. The best part, however, was forging new ties. I was also able to share my idea for designing a digital whiteboard. The working group is like a big family and I am looking forward to all the things that we can achieve together. Curiosity, courage and positive thinking keep me going. This is a good starting point on our journey towards our common goals.

**NEW PUBLICATIONS & RESOURCES**

**28 November: Eurofound publishes new report “Care homes for older Europeans: Public, private and not-for-profit providers”**

Eurofound’s new report, “Care homes for older Europeans: Public, private and not-for-profit providers” is the most comprehensive exercise to date to gather all available data across Member States. The report provides a picture of the quality, accessibility and efficiency of services. It examines services in the public and private sectors, how they differ in the services they provide in terms of the quality, accessibility and efficiency of services. With people living longer, the need for affordable care of high quality to support Europe’s population has increased as well as the challenge to maintain public funding and spending for long-term care.

The full report can be read here.

**JOB OPPORTUNITIES**

**1 December: Janssen seeks a clinical leader in neurodegeneration**

Janssen Pharmaceutica N.V is looking for a Clinical Leader Experimental Medicine/Neurodegeneration. The position is based in Belgium-Antwerp-Beerse. Janssen’s vision is to transform patients’ lives by discovering and developing innovative solutions to address the most important medical needs of our time. By delivering differentiated new treatments consistently and cost-effectively, they will also accelerate the growth of Johnson & Johnson’s pharmaceutical business.

Applicants should have a MD or equivalent with relevant experience with completed postgraduate training in neurology and/or psychiatry. An expert knowledge of and experience in...
neurodegenerative disorders is desirable. The ideal candidate will have a good understanding of the drug development and clinical trial process in the pharmaceutical industry, based on experience derived from prior employment in pharmaceutical/biotech company or CRO. Find out more about the position and about the application and recruitment process here.

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 Rosário 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 Lukič Zlobec (Slovenia).

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>15 January</td>
<td>ROADMAP Systematic literature review data synthesis meeting (Edinburgh, Scotland)</td>
<td>Chris</td>
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<td>15-16 January</td>
<td>PRODEMOS Kick-off meeting (Amsterdam, The Netherlands)</td>
<td>Cindy, Jean</td>
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<td>16 January</td>
<td>BD4BO WP3 face to face discussion (Brussels, Belgium)</td>
<td>Chris</td>
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<td>24 January</td>
<td>#EU4Health meeting (Brussels Belgium)</td>
<td>Vanessa</td>
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<td>25-26 January</td>
<td>DISTALZ Scientific Advisory Board meeting (Lille, France)</td>
<td>Jean</td>
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<td>30 January</td>
<td>MSD, Roundtable (Brussels Belgium)</td>
<td>Vanessa</td>
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<td>30-31 January</td>
<td>PredictND meeting (Saariselkä, Finland)</td>
<td>Dianne</td>
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<tr>
<td>31 January</td>
<td>INDUCT Winter School (Witten, Germany)</td>
<td>Ana</td>
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CONFERENCES 2018

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>15-16 February</td>
<td>8th International Conference on Pharmacoeconomics of Alzheimer’s Disease (IPECAD), <a href="http://www.ipecad.org">www.ipecad.org</a></td>
<td>Paris, France</td>
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<td>22-23 February</td>
<td>11th International Conference on Vascular Dementia, <a href="http://vasculardementia.conferenceseries.com">http://vasculardementia.conferenceseries.com</a></td>
<td>Paris, France</td>
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<td>1-3 March</td>
<td>Nutrition and maintaining functions with aging (IANA 2018)</td>
<td>Miami, Florida, USA</td>
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<td>15-18 March</td>
<td>AAT-AD/PDTM Focus Meeting on Advances in Alzheimer’s and Parkinson’s Therapies</td>
<td>Torino, Italy</td>
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<td>22-25 March</td>
<td>12th World Congress on Controversies in Neurology (CONy)</td>
<td>Warsaw, Poland</td>
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<td>2-4 May</td>
<td>24th Nordic Congress of Gerontology (24NKG), <a href="http://www.24kg.no">www.24kg.no</a></td>
<td>Oslo, Norway</td>
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<td>7-8 June</td>
<td>HammondCare International Dementia Conference - Mission Impossible? Truth and Lies in the Age of Choice, <a href="http://www.dementiaconference.com">www.dementiaconference.com</a></td>
<td>Sydney, Australia</td>
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<tr>
<td>7-8 June</td>
<td>BestCare4Dem - Sharing effective community-based support in dementia, <a href="https://www.meetingdern.eu">https://www.meetingdern.eu</a></td>
<td>Amsterdam, Netherlands</td>
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<td>3-6 October</td>
<td>Croatian Congress on Alzheimer’s Disease with International participation, CROCAD-18</td>
<td>Novigrad, Croatia</td>
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<td>29-31 October</td>
<td>28th Alzheimer Europe Conference “Making dementia a European priority”</td>
<td>Barcelona, Spain</td>
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<tr>
<td>22-25 October</td>
<td>29th Alzheimer Europe Conference “ Making valuable connections”</td>
<td>The Hague, Netherlands</td>
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AE CALENDAR
This conference presents an overview of the latest insights in the field of effective care and support for home-dwelling people with dementia and their informal carer(s).

There are many new types of interventions and services that aim to offer practical support to people with dementia and their informal carers and to make their life more comfortable and pleasant. For example, meaningful activities organized by welfare organizations and cultural facilities (such as museums), innovative technologies and initiatives for a more dementia-friendly society. But which of these work best in actual practice? Which are effective and should be made widely available for the target group?

At the conference a special place is reserved for new day care facilities, such as meeting centres. Many of these centres function as knowledge centres in the community. Adapting new effective types of support enables them to serve a broader target group, also outside the centres, and lessen stress, the variety of needs experienced by people with dementia and their relatives.

International conference

During the conference various internationally recognised experts will present their views on post-diagnostic dementia care.

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Inspiring parallel sessions will focus on providing the latest information about best practice, scientific research, successful implementation of innovations and policy, and on the international exchange of best practice. In addition to lectures there will be interactive sessions, an information market, film presentations, live performances and possibilities for networking.

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The conference is intended for care providers, scientists and policy makers in the field of dementia care as well as for people with dementia and their informal carers.