I am delighted to report that May has been a very positive month for Alzheimer Europe and for collaboration at both European and global levels. A joint statement has been signed by the trio of EU Presidencies 2016-2017 (Netherlands, Slovakia and Malta) calling on the Commission and Member States to increase co-operation on dementia. The signing took place in Malta, during a meeting of the Government expert group on dementia, which I was delighted to attend. Later in the month, the 70th World Health Assembly (WHA 70) of the WHO unanimously adopted the “Global Plan of Action on the Public Health Response to Dementia 2017-2025”. At a time when the number of countries in Europe developing national dementia strategies continues to grow, it is encouraging to see this call for greater global collaboration. We were also pleased to note that representatives of WHO Member States and civil society joined a dementia side event, to discuss opportunities from this new global plan.

The projects in which we are involved had a busy month too, with project meetings taking place in the four corners of Europe, including a General Assembly for the EPAD project, under the banner “From Delivery to Data”, in Stockholm. The meeting was officially inaugurated by HRH Queen Silvia of Sweden and the story was picked up by the Swedish media. Such a high-profile guest helps, of course, to bring much-needed attention to the project and to the wider dementia cause.

In AE news, I am pleased to announce that our position paper on involving people with dementia in research through PPI (patient and public involvement) was published in the journal Aging & Mental Health this month. The paper highlights some of the challenges and potential risks and benefits associated with meaningful involvement in research. The paper was drafted in collaboration with members of INTERDEM and the European Working Group of People with Dementia (EWGPWD).

The EWGPWD provides crucial input to much of the work we do and we were delighted to welcome all ten members of the group to Luxembourg for their first full meeting of the year. They discussed, amongst other things, the upcoming 27th AE Conference and consulted on two of our EU projects – MinD and INDUCT. We are very grateful to all the members of the group for their involvement in our conference and very much look forward to their participation in plenary sessions.

Finally, all 387 abstracts (a record number!) for our conference have now been reviewed, with 132 oral presentations and 206 poster presentations selected. I would like to remind you that Early Bird rates on 30 June and all presenters must register by this date to secure their spot.

Jean Georges
Executive Director
ALZHEIMER EUROPE
26 April: Ethics working group explores issues surrounding disability and dementia

The kick-off meeting of the Alzheimer Europe (AE) ethics working group took place in Amsterdam on 26 April 2017. This was the first meeting of the working group, which will explore ethical issues linked to the recognition of dementia as a disability. The group will meet again later in the year and will be working for the next six months on the preparation of a discussion paper, which will also contain AE’s position on this important issue.

The group is chaired by Director for Projects Dianne Gove. Members of the group include Helga Rohra and Helen Rochford Brennan from the European Working Group of People with Dementia (EWGPWD), as well as Toby Williamson, Grainne McGettrick, Sébastien Libert, Simo Vehmas, Andrea Capstick, Fabrice Gzil and June Andrews.

The meeting was successful in that consensus was reached on the model of disability to adopt (moving beyond the social model of disability), on the type of document to produce (a discussion paper incorporating a formal position), the main topics to cover, the organisation of the sections and the methodology for the inclusion of the full EWGPWD.

Sébastien Libert, who is a PhD student with a background in anthropology and sociology, is contributing to the ethics work as part of a secondment with AE, linked to the INDUCT project. He gave a presentation at the meeting and co-moderated (with Dianne) a consultation with the members of the EWGPWD on 14 May. The discussion/position paper will be launched at a lunch debate at the European Parliament in Brussels at the beginning of December.

4 May: AE joins fundamental rights platform
Alzheimer Europe (AE) is delighted to announce that it is now a member of the Fundamental Rights Platform (FRP) which is part of the Fundamental Rights Agency (FRA) of the European Union.

The FRP is FRA’s channel for cooperation and information exchange with civil society organisations active in the field of fundamental rights at the national, grassroots, European or international level. AE will now be consulted alongside other civil society organisations.


14-15 May: EWGPWD meets in Luxembourg

On 14 and 15 May 2017, the European Working Group of People with Dementia (EWGPWD) met in Luxembourg. All ten members of the group were present at the meeting.

During the first day of the meeting, they were provided with feedback on the activities and work in which the group had been involved since its last meeting and also about some of the ongoing Alzheimer Europe (AE) projects in which the group is involved. The group also had the opportunity to discuss the upcoming AE conference from 2-4 October 2017 in Berlin. Their involvement includes the group contribution to the selection of abstracts, participation in plenary sessions and the preparation of the EWGPWD symposium and stand.

In the afternoon, the group took part in a focused discussion about the ethical implications of recognising dementia as a disability, as the whole group will be working alongside experts in ethics, dementia and disability in order to produce this year’s AE ethics report. The members of the group reflected on the potential impact of being perceived as having a disability, the connotations surrounding the terms “disability” and “disabled” in different languages and the different models of disability. They also identified a number of key areas of daily life they would like to address in this year’s work. A PhD student from the INDUCT project (Sébastien Libert) participated in the meeting and co-moderated the discussions on ethics and disability, as part of his secondment with AE.

During the second day of work, the group participated in a consultation led by health experts and designers from the MinD project. MinD, a project funded by the European Commission, is working to develop new designs to enable people living with dementia to be more confident and empowered. The project uses the concept of mindful design and is especially interested in helping to promote social interaction and in understanding how the environment influences social engagement. The event was an opportunity for the EWGPWD to hear and provide feedback about the preliminary findings of the research conducted with people with dementia and carers in three European countries. In the afternoon, members of the group, their carers/supporters and the MinD researchers discussed how the findings could be used in the development of new designs for dementia.
17 May: AE publishes its position on involving people with dementia in research

On 17 May, the position of Alzheimer Europe (AE) on involving people with dementia in research through PPI (patient and public involvement) was published in the journal Aging & Mental Health.

This paper highlights some of the challenges and potential risks and benefits associated with meaningful involvement. The paper was drafted by AE in collaboration with members of INTERDEM and the European Working Group of People with Dementia (EWGPWD). It has been formally adopted by the AE Board and endorsed by the Board of INTERDEM and by the JPND working group ‘Dementia Outcome Measures - Charting New Territory’.

AE is keen to promote the involvement of people with dementia in research, not only as participants but also in the context of PPI, by generating ideas for research, advising researchers, being involved in consultations and being directly involved in research activities. This position paper is in keeping with this objective. Topics covered include, amongst others, planning involvement, establishing roles and responsibilities, training and support, managing information and input from PPI, recognising the contribution of people with dementia involved in research in this way, promoting and protecting the rights and well-being of people with dementia, training and support, and promoting an inclusive approach and the necessary infrastructure for PPI in dementia research.


31 May: Our online Diagnosis of dementia carers’ survey is still open in the Czech Republic

Our Diagnosis of dementia carers’ survey is being conducted across five European countries: the Czech Republic, Finland, Italy, the Netherlands and Scotland (UK). Feedback is being sought from 1,000 informal carers (e.g. family members or friends) in total (200 per country).

The online survey has been finalised in Finland, Italy, the Netherlands and Scotland but is still live in the Czech Republic, so if you are caring for a relative or friend with dementia in the Czech Republic, we invite you to participate in the survey:

https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-czech

31 May: Alzheimer Europe finalises abstract selection for 27AEC

Alzheimer Europe would like to thank everyone who submitted abstracts for its 27th Annual Conference (27AEC) in Berlin from 2 to 4 October 2017. The Scientific Committee has reviewed a record 387 submitted abstracts and has approved 132 oral presentations and an additional 206 poster presentations.

Notifications are currently being sent out to all applicants. Selected presenters for poster and oral presentations must register by 30 June, when Early Bird registration closes.

To find out more about some of the keynote speakers at the conference, please see the “spotlight” articles hereunder. This month features Chris Roberts, Knut Engedal, Horst Bickel and Helen Rochford-Brennan.

You can also follow our list of keynote speakers on Twitter: https://twitter.com/AlzheimerEurope/lists/27aec-speakers/members

27AEC - MEET THE SPEAKERS

Chris Roberts

Chris Roberts is 55 years old and is from Wales. He was diagnosed with mixed dementia (Alzheimer’s type and vascular dementia) in early 2012 but has not let this diagnosis get in the way of leading a full life.

He spends most of his time promoting and providing education to others about dementia. He regularly gives talks on what it’s like to live with dementia and contributes to various social media platforms. He believes in dementia rights, inclusion, co-production and the promotion of better services for everyone living with dementia.

Chris joined the European Working Group of People with Dementia (EWGPWD) and was elected as Vice Chair in 2016. He also represents people with dementia in the following roles: Ambassador for the UK Alzheimer’s Society; Dementia Friends Champion; Join Dementia Research Champion; Affiliate member of Dementia Action Alliance UK; Honorary Lecturer, Bangor University, Wales; Member of DEEP Policy Think Tank Group; BCUHB SBRI and Dementia Strategy Ambassador; and Member of the NICE Dementia Clinical Guideline Review Committee.

Mr Roberts is one of the speakers in Plenary 1, on 3 October.

Knut Engedal

Knut Engedal is professor emeritus of geriatric psychiatry at the University of Oslo, Norway and was the former director for research at the Norwegian Advisory Unit for Aging and Health, a centre for research, education and service development in the fields of geriatric psychiatry, dementia, ageing and functional and intellectual disabilities. His main interest in research is on dementia and depression in late life.
In addition to scientific papers he has published several textbooks about dementia and geriatric psychiatry. At the time being, he is chairing a regional ethics committee for medical research, chairing the Standing Committee for dementia in the Norwegian Health Association and chairing an advisory group for the development of national guidelines for dementia assessment, treatment and care in Norway.

Prof. Engedal is one of the speakers in Plenary 2, on 3 October.

Horst Bickel
Horst Bickel is a psychologist and epidemiologist. After being active in epidemiological research at the University of Heidelberg and at the Central Institute for Mental Health in Mannheim, he has been head of the Psychiatric Epidemiology section of the Department of Psychiatry at the Technical University of Munich, Klinikum rechts der Isar, since 1997.

The topics of his recent research projects include: effects of multimodal GP interventions against stroke and dementia; risk of dementia in the last year of life; dementia in the general hospital; association between education and cognitive decline in old age; suitability of short cognitive test procedures for use in different fields of medical care; long-term effects of delirium on cognitive decline and the onset of dementia; risk factors for dementia and gene-environment interactions in the development of dementing disorders; loss of autonomy in old age and determinants of loss. He is a founding member of Deutsche Alzheimer Gesellschaft.

Dr Bickel is one of the speakers in Plenary 3, on 4 October.

Helen Rochford-Brennan
Helen Rochford-Brennan is from Tubbercurry in County Sligo, Ireland. She spent many years working in the tourism and disability sectors and has also devoted tireless years to community activism, working at board level in several organisations. In July 2012, she was diagnosed with early onset Alzheimer’s disease. She was Chair of the Irish Dementia Working Group until recently, which is resourced by The Alzheimer Society of Ireland. She has used her time with the Irish Dementia Working Group to raise awareness of dementia and raise the profile of human rights for people with dementia.

Ms Rochford Brennan joined the European Working Group of People with Dementia (EWGPWD) in October 2014 and served as a Vice-Chairperson for two years. On 30 October 2016, she was elected as Chairperson for a two-year term.

Ms Rochford Brennan is one of the speakers in Plenary 4, on 4 October.

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EU PROJECTS
20-22 April: EPAD presented at the 2nd Annual GBHI conference

From 20 to 22 April, the 2nd Annual Global Brain Health Institute (GBHI) conference took place in Barcelona, Spain. During session 8 (of 10 sessions), José Luis Molinuevo, Clinical Director of the BarcelonaBeta Brain Research Center, gave a talk on new approaches to prevent Alzheimer’s disease (AD). After having explained the rationale behind the disease, he gave some examples of studies focused on primary as well as secondary prevention of AD. The EPAD project, whose objective is to develop a platform to test treatments for the secondary prevention of Alzheimer’s dementia was presented by Dr Molinuevo. In addition to giving an overview of the project and its aims, he explained the EPAD register, EPAD proof of concept (PoC) trial and EPAD adaptive trial. To access to the detailed GBHI programme, please download it here.

http://ep-ad.org/2017/04/20/epad-presented-at-the-gbhi-conference/

24 April: ROADMAP project to hold a panel session at HTAi 2017

A ROADMAP abstract has been accepted for the next Health Technology Assessment international (HTAi) annual meeting in Rome, 19- 21 June. During a panel session, five speakers from the ROADMAP Consortium will discuss a wide range of perspectives on "The state of Alzheimer’s disease in Europe - innovation, value and challenges for HTA". Martin Knapp of the London School of Economics and Political Science, both speaker and moderator of the session, will introduce the implications of upcoming new therapies and diagnostics on the Alzheimer’s disease (AD) treatment horizon over the next five years. Alzheimer Europe Executive Director Jean Georges will follow up with the perspectives of patients and caregivers regarding the impact of AD. Ron Handels from Maastricht University, will give an overview of health economic considerations for new interventions in AD. Jacoline Bouvy of the National Institute for Health and Care Excellence will provide the payers’ perspectives for potential disease-modifying therapies in AD. Finally, Catherine Reed, EFPIA – Eli Lilly and Company Ltd will present the goals of the project and the real world evidence (RWE) challenges for new AD treatments.
The presentations will be followed by a 30-minute structured panel discussion in which the audience is invited to ask questions.

**25 April: AETIONOMY/PRICESESADS holds 2nd Joint Legal and Ethics Meeting in Berlin**

On 25 April 2017, the second joint legal and ethics meetings of the AETIONOMY and PRECISESADS projects was held in Berlin. Alzheimer Europe (AE) was represented at the meeting by Director for Projects Dianne Gove and Project Officers Cindy Birk and Christophe Bintener. Participants from both projects discussed developments over the last 18 months, with particular attention to the issues surrounding the transfer of data between the United States and Europe.

Marc Stauch, from the Leibniz University of Hannover, gave an overview of relevant issues related to data and bio-sample sharing in research projects under the new General Data Protection Regulation, which will take effect in May 2018. Irene Schlünder presented the Biobanking and BioMolecular resources Research Infrastructure (BBMRI) Code of Conduct Initiative, which she proposed as a follow-up to the 2014 IMI Draft Data Re-use Code.

Cindy and Dianne gave a joint presentation about the EPAD project. Cindy provided an overview of the project and showed a video clip (developed by EPAD, with input from AE). Dianne then described some of the key ethical issues, which had been discussed by the ethics work package of EPAD. An interesting discussion ensued about the tiered model of withdrawal, which provides participants with a choice about how data that has already been collected from a particular participant is managed, and the extent to which it is feasible to propose the complete withdrawal of such data from a study.

It was a very productive meeting with interesting debates about data protection and management, and the engagement and involvement of participants in the research process.

**2 May: First AMYPAD project newsletter is out!**

AMYPAD has released its first newsletter!

The "Amyloid imaging to prevent Alzheimer’s disease" project aims to improve the diagnostic workup of patients suspected to have Alzheimer’s disease and their management. The partners aim to improve knowledge of the natural history of AD in a pre-symptomatic stage, in order to better select patients for trials.


**8-9 May: PACE consortium meets in Italy**

On 8 and 9 May, in Treviso, Italy, the EU-funded project PACE - Comparing Palliative Care in Care Homes Across Europe - held a General Assembly and a Consortium Meeting, including two Impact and Dissemination meetings.

During the second day of the meeting, AGE platform and Alzheimer Europe (AE), conducted a workshop on planning the work towards the project Policy Recommendations. In the workshop, partners of the consortium discussed the main aims and scope of the recommendations, the methodology and timeframe that will be used, and what PACE researchers can contribute to the development of these recommendations.

Delegates also heard about the recent conference on palliative care in Poland organised by the Polish PACE partner, and how the event had contributed to raising awareness of palliative care in the country.

Director for Projects Dianne Gove and Project Officer Ana Diaz attended the meeting on behalf of AE.

You can subscribe to the PACE newsletter to keep up to date with progress, and can find more information about the project also, on the project website: [http://www.eupace.eu/](http://www.eupace.eu/)

The PACE project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no 603111.

**8-19 May: AE and University of Luxembourg co-host MinD project exchange visit**

From 8 to 19 May, 12 researchers from the MinD project took part in a secondment in Luxembourg co-hosted by the University of Luxembourg and Alzheimer Europe (AE). During their time in Luxembourg, project partners worked to bring together the results of the data collection
from year 1 of the MinD project and to discuss the results to identify and define relevant points for the design interventions from the data to take forward and respond to in the design secondments. The researchers also had the opportunity to meet the European Working Group of People with Dementia (EWGPWD) and to consult its members about a number of relevant issues for the project.

MinD, is an EU-funded project. Using the concept of mindful design, it aims to find new innovative design solutions to enable self-empowerment and confidence building of people living with dementia.

AE Projects Officers Ana Diaz, Cindy Birck and Christophe Bintener all took part in meetings with the MinD project during the secondment.

https://designingfordementia.eu/mind-secondment-in-luxembourg

9 May: PredictND consortium members publish paper in Frontiers in Aging Neuroscience journal

Two members of the PredictND Consortium, Hanneke Rhodius-Meester and Wiesje Van der Flier are pleased to announce the publication of their paper “MRI visual ratings of brain atrophy and white matter hyperintensities across the spectrum of cognitive decline are differently affected by age and diagnosis” in the journal Frontiers in Aging Neuroscience. The paper, which has seven authors in total, was published on 9 May and is available online: https://goo.gl/MEemZC

This project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no 611005.

9-10 May: SyDAD annual meeting held in Bonn

The SyDAD (Synaptic Dysfunction in Alzheimer Disease) annual meeting was hosted by DZNE (Deutsches Zentrum für Neurodegenerative Erkrankungen) on 9 and 10 May in Bonn, Germany. This meeting was attended by 45 participants and gathered together Early Stage Researchers (ESRs), supervisors and partner organisations to discuss research projects, the methods for assessment of synaptic function, innovation opportunities and the project’s training programme.

SyDAD is a European training network, sponsored by Marie Skłodowska Curie Actions that supports 15 ESRs. All of them reported their respective work and main achievements and a mid-term review meeting with the Research Executive Agency of the European Commission (EU) was held.

Alzheimer Europe (AE) is a partner organisation in this project supporting the dissemination activities. Cindy Birck, AE Project Officer attended the meeting. She gave a presentation about the main activities of AE and an interesting discussion ensued on the public dissemination.

15 May: ROADMAP project Work Package 3 submits its first deliverable to IMI

The “Real world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform” (ROADMAP) project’s Work Package 3 (WP3) “Identification, mapping and integration or RWE” has submitted its first report, called “D3.1 Initial Overview of potential data sources with Real World Evidence (RWE) data in Europe” to the Innovative Medicines Initiative (IMI). This is not the first project deliverable, but is the first deliverable for WP3 and constitutes an important milestone for the project.

The aim of ROADMAP is to deliver a series of data integration methods and tools for patient outcomes, developed and tested through pilot projects, which are scalable and transferable, and which will provide the foundation for a future Europe-wide RWE platform on Alzheimer’s disease (AD).

In this realm, WP 3 will address the challenges related to finding, extracting, harmonising, integrating and analysing data from RWE sources relevant to AD. The report contains information on the identification and characterisation of the data sources. This is crucial in order to create a landscape of available real world health care data. It is the first step to provide an understanding of currently available data for the relevant outcomes and outline potential gaps in currently available information about Alzheimer’s disease at various stages.

Since the landscape of data should be sustainable information that is available for the current ROADMAP objectives as well as future research on the various stages of Alzheimer’s disease it should be documented in an accessible data source catalogue with curation and search features. For that purpose, the existing EMIF AD and EMIF EHR catalogues were selected as the preferred repositories, (https://emif-catalogue.eu/) but at the same time taking into account the different fingerprinting needs for cohort type and EHR/national register type data.

http://roadmap-alzheimer.org/downloads/deliverables/

15-17 May: EPAD consortium gets a royal welcome at its 2017 General Assembly

This year’s European Prevention of Alzheimer’s Dementia (EPAD) General Assembly meeting (GA) was held at the World Trade Center in Stockholm, Sweden from 15 to 17 May, under the banner “From Delivery to Data”. It was hosted by the Karolinska Institutet and jointly sponsored by Boehringer Ingelheim and
Lundbeck. EPAD is co-ordinated by Craig Ritchie, Professor of the Psychiatry of Ageing at the University of Edinburgh and Dr Serge Van der Geyten, Director for Neuroscience External Affairs at Janssen Pharmaceutica.

The stated aims of this year’s GA were to:

- Create an environment for the sustained success of the project
- Expand and “future proof” the Longitudinal Cohort Study (LCS)
- Build the Proof-of-Concept (PoC) Platform.

On 15 May, meeting host and EPAD WP4-leader Prof. Miia Kivipelto, Karolinska Institutet and Prof. Ritchie gave a general overview of the project and introduced the agenda for the coming days. Each WP then had the opportunity to present its remit and progress so far. You can read more about each of the WPs here: http://ep-ad.org/project-structure/

On 16 May, the General Assembly gathered for its official inauguration by HRH Queen Silvia of Sweden, who welcomed delegates to Stockholm and the first session of the day on “the future of AD research”. Queen Silvia has long been involved in advocacy work for people with dementia, people at end of life and for many children’s charities also. HRH remained in the audience for most of the morning programme and the Swedish newspapers picked up the story of her involvement in the meeting the next morning (pictured). See http://www.silviahemmet.se/en/ for more info regarding the Queen’s dementia advocacy work. Following Her Majesty, Karolinska Institutet CEO Prof. Melvin Samson also welcomed delegates, as did Dr Van der Geyten. Dr Van der Geyten also took the opportunity to welcome Edinburgh-based research participant Eileen, a member of the newly formed EPAD Research Participant Panel, who is the first member of this Panel to attend an EPAD consortium meeting.

The programme for this second day focussed on the status of the EPAD LCS; creating an environment for sustained success; the “EPAD enhancement programme”; and the “EPAD Academy”. There was also a presentation on EPAD’s collaboration with its sister project, AMYPAD, by Dr Gill Farrar, GE Healthcare. The AMYPAD project was detailed in Alzheimer Europe (AE)’s most recent Dementia in Europe magazine (issue 24) and also recently launched its own project website, http://amyypad.eu/.

Over the lunch break, WP8 Ethical, Legal and Social Implications held a Satellite Symposium on “Conceptualising Alzheimer’s Disease, hosted by Krista Tromp from VUmc Amsterdam. Dr Luc Truyen of Janssen delivered the research perspective, AE Director for Projects Dr Dianne Gove presented AE’s position, and finally Dr Edo Richard of Radboud UMC spoke from the physician’s perspective. There was a lively discussion about emerging ethical issues within EPAD during this session, which continued into the WP8 breakout session at the end of the day. There were dedicated breakout sessions for many of the WPs at this time and AE Project Officer Dr Cindy Birck attended the WP4 EPAD Cohort and EPAD Trials session, while Dr Gove and AE Communications Officer Kate Boor Ellis attended the WP8 session.

On the third and final day, the emphasis was squarely on the PoC Study Platform – progress so far and looking to the future. Presentations were delivered on the PoC Master Protocol, multi-arm simulations and recent data on CSF cut offs. Next steps were discussed, and the meeting closed with the 150+ delegates being invited to the 2018 GA, which will take place in Amsterdam.

To see tweets from this year’s GA, see #EPADGA2017 and #EPADGA17

To keep up to date with EPAD’s progress follow @IMI_EPAD on Twitter, visit https://www.facebook.com/IMIEPAD/ and visit the website http://ep-ad.org/.

EPAD also now has its own YouTube Channel:
https://www.youtube.com/channel/UCUDfoj0UvWCC0B9BFdvTvTA

16 May: INDUCT project invites people in the UK to take part in its research study

The INDUCT project invites people in the UK, with and without dementia, to take part in a major international research study to explore how Everyday Technologies, from the simple kettle to self-service check-outs and ATMs, impact daily life.

The study offers people aged 55+ the opportunity to get involved with dementia research until December 2017. It was officially launched on 16 May 2017, coinciding with “Dementia Awareness Week”.

The studies are planned to give people the chance to tell their stories about how they use technology in their day-to-day lives, both at home and out-and-about. Successes, niggles and frustrations - this is research about ordinary life.

By finding out more directly from UK communities, more can be understood about how to make places dementia friendly. Recent studies published by Anna Brorsson and colleagues are showing that this is possible. Stories of people living with dementia are helping to revolutionise grocery shops in Sweden and making the experience easier for everyone.

Occupational therapist researchers, Sarah Wallcook from Cumbria and Sophie Gaber from London, are delivering this study with the Karolinska Institutet in Stockholm.

For further information and for contact details, see: http://www.dementiainduct.eu/doing-it-for-dementia/

Pictured: Sarah Wallcook’s mother, Jane - “success with the cash machine”.

31 May: PACE featured in Science Impact Ltd magazine

In May 2017, an article about the (targeted) impact of the PACE project appeared in the international magazine of Science
Impact Ltd, an edition titled ‘multidisciplinary health research’. The magazine is printed in English (https://impact.pub/) and contains articles on changing the attitudes to palliative care for older people, patient-centred cancer care, but also on biases in clinical trials, rare diseases and wellbeing.

Project coordinator Lieve Van den Block (VUB) and partner leads Bregie Onwuteaka-Philipsen (VUMC) and Anne-Sophie Parent (Age Platform Europe) were interviewed to discuss the challenges (“It is as much about changing the culture of the care homes, as it is the attitudes of individuals within them”) of the project thus far and to voice their opinion on the scientific and practical impact (“The team hopes to gain an understanding of which countries, systems, and practices might be related to higher quality of dying”) of the project.

The article can be read here: http://www.eupace.eu/pressfile/pace-featured-science-impact-ltd-magazine

A number of the projects in which Alzheimer Europe is a project partner receive funding from the Innovative Medicines Initiative (IMI) 2 Joint Undertaking. The Joint Undertaking receives support from the European Union's Horizon2020 research and innovation programme and EFPIA.

The projects mentioned in this newsletter, with funding are:

- AETIONOMY – grant agreement 115568
- AMYPAD- grant agreement 115952
- EPAD - grant agreement 115736
- ROADMAP - grant agreement 116020

Alzheimer Europe Networking

On 2 May (Brussels, Belgium), Jean attended the Infoday on the call for proposals for operating grants 2017.

On 3 May (Luxembourg, Luxembourg), Jean met with Info-Zenter Demenz at the AE office.

On 3 May, Dianne participated in a telephone conference for the Global Alliance for Genomics and Health (GA4GH) - Ageing and Dementia Task Team and in the ROADMAP ethics work package telephone conference.

On 3-4 May (London, United Kingdom), Chris and Cindy attended the DPUK conference.

On 4 May, Jean participated in the telephone Steering Committee of the AETIONOMY project.

On 8-9 May (Treviso, Italy) Dianne and Ana attended the PACE consortium meeting.

On 8-19 May (Esch, Luxembourg) Ana, Chris and Cindy participated in various meetings of the exchange visit of the MinD project.

On 9-10 May (Bonn, Germany), Cindy attended the SyDAD annual meeting.

On 9-10 May (London, United Kingdom), Jean attended the Alzheimer’s Prevention European Registries Workshop organised by the US Alzheimer’s Association.

On 12 May (Amsterdam, Netherlands), Chris attended the ROADMAP f2f Research Questions workshop.

On 14-15 May (Luxembourg, Luxembourg) Dianne, Ana, Chris and Cindy, participated in the meeting of the EWGPWD.

On 15-16 May (Malta), Jean attended the meeting of the Government expert group on dementia with Helen Rochford Brennan.

From 15 to 17 May (Stockholm, Sweden), Dianne, Kate and Cindy attended the EPAD project General Assembly meeting.

On 19 May (London, United Kingdom), Jean attended the PRIME Workshop of the European Medicines Agency (EMA).

On 22 May (Geneva, Switzerland), Stefanie Becker attended the Lunch Meeting in the context of the 70th General Assembly of the WHO, organised and invited by the CEO Initiative.

On 25 May (Geneva, Switzerland), Stefanie Becker attended the Side-event on the Global Action Plan on Dementia in the context of the 70th General Assembly of the WHO, organised by the Swiss Federal Office of Health.

On 23 May, Dianne took part in the first expert panel telephone conference for the (self-) toileting and containment strategy project, organised by KPMG in collaboration with SCA Hygiene.

On 29 May, Cindy attended the EUPATI Webinar “Guidance on Patient Involvement in Ethical Review of Clinical Trials”.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 127, 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 Brempt (S&D); Hilde Vautmans (EPP).
**Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).
**Cyprus:** Costas Mavrides (S&D); Eleoni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Philipsen (VUMC) and Anne Sophie Parent (Age Platform Europe).
**Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Mapietra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); François Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Kostas Chrysogonas (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Zenter Demenz at the AE office.
**Ireland:** Mary Lou McDonald (S&D); **Italy:** Biljana Borzan (S&D); **Latvia:** Daniel Oskeršte (EPP); **Lithuania:** Ingrida Gudaitė (ALDE); **Luxembourg:** Pierre Ky (EPP); **Malta:** Mila Mifsud (S&D); **Netherlands:** Angelique Visser (S&D). **Norway:** Marit Ulvsbo (ALDE); **Poland:** Anna Bachleda (EPP); **Portugal:** Maria Paula Galvão (EPP); **Romania:** Liviu Dragnea (PES); **Sweden:** Tim Gouda (S&D); **Switzerland:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); François Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **UK:** Nicola Blackwood (S&D); Charles Walker (NI); Caroline Lucas (Greens/EFA).
Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraki (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg-Vixonidi (EP). **Hungary:** Ádám Kósa (EP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marían Harkin (ALDE); Brian Hayes (EP); Seán Kelly (EP); Mairead McGuinness (EP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Stefano Maullu (EP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). **Lithuania:** Vilija Blinkyaviciute (S&D). **Luxembourg:** Georges Bach (EP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EP). **Malta:** Therese Comodini Cachia (EP); Roberta Metsola (EP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EP); Jeroen Lenaers (EP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EP); Marek Pluta (EP); Bogdan Wenta (EP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Silviu Busoi, MEP (EP); Marian-Jean Marinescu (EPP); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tanase (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolásik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Jana Žitňanská (ECR). **Slovenia:** Franc Bogovič (EP); Tanja Fajon (S&D); Alojz Peterle (EP); Igor Šoltes (Greens/EFA); Patricija Šulin (EP); Romana Tomc (EP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (ALDE); Soledad Cabezón (S&D); Luis de Grandes Pascual (EP); Rosa Estarás Ferragut (EP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Pablo Zabalduzkie (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claire Perry (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

**EUROPEAN ALZHEIMER’S ALLIANCE**

**22 May: MEP Sofia Ribeiro, member of the European Alzheimer’s Alliance - action on dementia**

 MEP Sofia Ribeiro (Portugal) has been a member of the European Alzheimer’s Alliance since March 2015. She recently attended Alzheimer Europe’s European Parliament lunch debate, “Comparing and benchmarking national responses to the dementia challenge”, in December 2016.

In light of this, Alzheimer Europe (AE) asked Ms Ribeiro: From a policy maker’s perspective, why do you think it is important to bring the challenge of Alzheimer’s disease to the front and centre of the European Parliament, and what could be done to meet this public health challenge?

"The figures of Europeans with Alzheimer’s disease, (AD) in the EU, are alarming. There are about 10 million people with AD (which means 10 million families are also coping with this disease), and it is estimated that this number will increase about 50% in the next 20 years. Europe’s average age is increasing alarmingly, and since dementia, in its multiple forms, is associated with age, that also implies a rise on the social and economic impact of the disease. Those growing figures will have an increasing impact on health and care systems as well as on the need for resources in the fields of formal and informal health care.

Besides continuing investing in prevention and scientific research, it is necessary to ensure more effective and socially more responsible forms of care, including special conditions for family members. Formal and informal care providers are an essential element in responding to the rapidly increasing needs of future delivery systems in Europe. It is important to improve the social protection of family carers, who are often forced to reduce paid working hours to provide unpaid care, thus losing their social security rights. It is also important that non-formal and informal skills and competences acquired in care settings are duly recognized by a sort of European Skills Validation System, like the European Qualification Framework, in order to improve the employability of young people and people who have been removed from the labour market for reasons of care. There is a whole subsystem of family work that must be validated, safeguarding the labour rights of the carer, including the right to training, which should be facilitated.”

**EU DEVELOPMENTS**

27-28 April 2017: Network of European dementia researchers meets in Bucharest

The European Alzheimer’s Disease Consortium, a network of European researchers involved in clinical research met in
Bucharest for a two-day meeting. The group meets twice a year with representatives providing updates on the collaborative research projects they are involved in. The Bucharest meeting provided an opportunity for information on EPAD and EMIF by Pieter Jelle Visser (Netherlands), the Biomarker Roadmap by Giovanni Frisoni (Italy, Switzerland), the INTERREG Danube network by Shima Mehrabian (Bulgaria), ADAPTED by Agustín Ruiz (Spain) and MOPEAD by Mercè Boada (Spain).

Interesting symposia were also held on the issues of genetics and epigentics and on early/very early diagnosis of Alzheimer’s disease and the current revision of the NIA-AA research criteria.

Jean Georges was invited to highlight how organisations like Alzheimer Europe can support research efforts and gave an overview of the role of AE in various EU funded projects.

[http://www.eadc.info/sito/pagine/home.php]

10 May: Researchers discuss Alzheimer’s prevention registries

The US Alzheimer’s Association and the F-Prime Biomedical Research Initiative (FBRI) convened a workshop on 10 May in London which brought together a number of funders, researchers and other stakeholders with an interest in Alzheimer’s prevention.

The aim of the meeting was to get an understanding of the current state of prevention registries, evaluate their effectiveness and identify and learn from existing good practices. A number of research centres involved in the EPAD and AMYPAD projects (Amsterdam, Barcelona, Cologne, Edinburgh, Stockholm and Toulouse) presented their current models and experiences in developing trial-ready cohorts of potential research participants. Discussions centred on how to better support dementia registries and how to collaborate at a European level.

Jean Georges participated in the meeting and presented results of a survey into public perceptions on the value of diagnosis and predictive testing.

13-14 May: European Disability Forum holds its Annual General Assembly

On 13-14 May in Madrid the European Disability Forum (EDF) brought together over 200 participants for its Annual General Assembly (AGA), entitled “20 years later: Building an inclusive disability movement for the future”. The conference was an opportunity to recall the great achievements of the disability movement for the first 20 years later, but also to identify the challenges ahead and how the disability movement should address these challenges.

On Sunday 14 May 2017, the discussion focused on what the European disability movement needs to do to continue fighting successfully for equality and social justice in the future.

EDF President, Yannis Vardakastanis raised the importance of the active involvement of persons with disabilities through their representative organisations in line with the motto of the disability movement: “Nothing about us without us”. He stated:

“There are cases at national level that organisations of persons with disabilities are not supported or not allowed to do their work. The EU and its Member States have the obligation, under the CRPD that they have ratified, to ensure that the organisations of persons with disabilities are involved and consulted. Capacity building and funding should be secured, and barriers should be removed”

The EDF AGA adopted important resolutions on the Accessibility Act and on the Marrakesh Treaty, as well as a report on Forced Sterilisation and a declaration with the vision of the disability movement and a plan for action for the coming years.

The EDF AGA adopted a resolution calling on:

- The European Parliament’s plenary assembly to significantly amend the Internal Market Committee (IMCO) report for a strong, ambitious and meaningful Act in order to respond to the rights and expectations of the 8 million European persons with disabilities;
- The Council of the EU to live up to its obligations to implement the CRPD in the EU and to take appropriate steps for a swift adoption of the proposal while keeping crucial parts of the text such as accessibility of the built environment, transport, and the relation with other Union Acts, as well as consulting persons with disabilities and their representative organisations both at the EU and national levels at all steps of the decision-making process.


Alzheimer Europe became a member of the EDF earlier this year. Read the full EDF AGA report and about the newly elected EDF Board here:

15 May: Trio of EU Presidencies signs joint statement calling for more support and coordination on dementia

The governmental expert group on dementia, convened by the Health Directorate General of the European Commission, met in Malta this week on 15 and 16 May. On the first day of this meeting, a joint statement was signed by the trio of Presidencies of the Council of the EU 2016-2017 - the Netherlands, Slovakia and Malta - calling on the Commission and the Member States to further support and coordinate work on dementia. The three signatories were: Dr Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disabilities and Active Ageing (Malta), Mr Martin van Rijn, State Secretary for Health, Welfare and Sport (Netherlands) and Medical Director Ministry of Health Slovakia, Dr Boris Banovsky, on behalf of Ms Andrea Kalavská, State Secretary for Health (Slovakia).

It calls upon the European Commission to:

- Promote and support the international cooperation in dementia research and improve the coordination of existing European research programmes;
- Promote and support the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia;
- Stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society;

It calls upon EU Member States to:

- Participate in, promote and support the international cooperation in dementia research;
- Work together in the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia;
- Support persons with dementia to have the best possible quality of life, to live a life with dignity and to participate in society, in accordance with their human rights;
- Stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society;
- Support patient advocacy by national and international Alzheimer organisations.

https://goo.gl/mnJ80x

15-16 May 2017: EU governmental experts on dementia discuss rights-based policies for people with dementia

As part of its programme of its Presidency of the European Union, Malta collaborated with DG SANTE of the European Commission to convene the group of governmental experts on dementia to meet in St Julian’s on 15 and 16 May 2017. The meeting was opened by Dr Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disability and Active Ageing who welcomed the participants to Malta and outlined some of the key priorities of the Maltese Dementia Strategy. During the same day, she signed a declaration with her colleagues from the Dutch and Slovak Presidencies calling for greater European collaboration on dementia (see article on page XX).

The welcome was followed by a tour de table of national health ministry representatives from 20 European countries presenting their latest national initiatives in the dementia field. Of these countries, 13 already have a dementia or neurodegenerative diseases strategy in place (Czech Republic, Denmark, Finland, France, Ireland, Italy, Luxembourg, Malta, Netherlands, Norway, Slovenia, Spain and the United Kingdom which was represented by Scotland) whilst an additional 4 countries (Germany, Portugal, Romania and Slovakia) announced that they were working on the development of such a strategy and hoping to announce it in the coming 12 months. Only Bulgaria, Croatia and Cyprus who were participating in the meeting currently had no plans for the development of such a strategy.

The meeting was also an opportunity for the national representatives to be updated about the progress of the Joint Action on Dementia and its focus on timely diagnosis and post-diagnostic support, care coordination, residential care and dementia-friendly communities, as well as about other international efforts by the World Health Organisation and its global action plan on dementia and global dementia observatory and by the OECD and its work on care indicators in dementia.

The second day of the meeting was primarily dedicated to discussing a rights-based approach to dementia. Helen Rochford-Brennan, the chairperson of the European Working Group of People with Dementia talked about her own experience of living with dementia and gave an impassioned call on national representatives to involve people with dementia in the development and monitoring of dementia.
policies. Jean Georges, Executive Director of Alzheimer Europe, presented the findings of the organisation’s 2016 Yearbook and gave an overview and comparison of national policies on legal capacity and decision making systems. Both presentations led to interesting discussions and the group decided to further consider this issue and develop a recommendation outlining some of the principles of importance when discussing the rights of people with dementia.

Sofia Lourenco from DG Employment provided an update on the European Accessibility Act and the European Union’s obligations resulting from the UN Convention on the Rights of Persons with Disabilities and Maja Groff presented the Hague Convention on the International Protection of Adults which provides important rules for the cross-border recognition of powers of attorney.

In addition to Jean Georges, Iva Holmerová, Chairperson, Charles Scerri, Vice-Chairperson and Nino Mimica, Chairperson of Alzheimer Croatia were also in attendance and represented their respective countries at the meeting.

MEMBERS’ NEWS

3 May: Election of new Irish Dementia Working Group Steering Group takes place

On 3 May, the Irish Dementia Working Group (IDWG) was delighted to elect its first Steering Group. Up to now, the Group had been working with a pseudo steering group comprised of three members (Kathy Ryan, Ronan Smith and Helen Rochford Brennan) who, apart from the former Chairperson (Helen), had not been elected or nominated by members of the IDWG. As Helen has recently stepped down as Chair of the IDWG, this was an opportune time to address this, and each of the pseudo steering group were very keen for the election process to be democratic, transparent, accessible and fair.

All members of the IDWG were invited to express their interest in putting their names forward for nomination to the Steering Group. Each member was contacted individually and had the opportunity to discuss the responsibilities attached to the roles, and was given every opportunity to get involved.

The Alzheimer Society of Ireland was delighted that, at the last IDWG meeting, each of the members had the opportunity to vote for their choice of representatives on the Steering Group. We look forward to working with the Steering Group and wish them the very best in their new roles!

Des O’Grady, Kathy Ryan (Vice Chair), Dolores Power, Ronan Smith (Chair), Anne McGeown and Helen Rochford Brennan.

4 May: The Alzheimer Society of Ireland report on Tea Day 2017

The Alzheimer Society of Ireland (ASI) hosted its largest annual fundraising campaign, Alzheimer’s Tea Day, in May. Over EUR 7.5 million has been raised since the very first Alzheimer’s Tea Day in 1994.

Every year, thousands of people host tea parties in their homes, offices and schools. The ASI was delighted to have two very special ambassadors, Daithi O’Se and Miss Ireland Niamh Kennedy, behind the campaign.

Irish broadcaster TV3’s “Ireland AM” staged a live broadcast from the ASI’s Heskin Court Day Care Centre in Dublin, to kick-start Tea Day 2017 on 4 May.

The ASI held a live tea cosy auction on “Ireland AM”, which raised EUR 1,070. The seven tea cosies that were auctioned off were Mr T (EUR 150); Captain Jack Sparrow (EUR 120); Mrs Agnes Brown (EUR 200); Ed Sheeran (EUR 130); Belle (EUR 100); Bosco (EUR 120) and President Higgins (EUR 250).

A number of guests appeared on the show to talk about dementia including Miss Ireland Niamh Kennedy and her mother Catherine; actor Rory Cowan; ASI helpline volunteer Gerard Mulligan; and Irish Dementia Working Group member Ronan Smith.

In addition to this, there were numerous Tea Day events staged throughout the country, including one hosted by members of the Irish Parliament in Leinster House; by ASI sponsors Medtronic in Dublin city centre; and by ASI corporate partners Munster Rugby in the University of Limerick.

There were also many regional and local events throughout the country.

9 May: Alzheimer Bulgaria reports on its participation at a recent Eurocarers meeting

Alzheimer Bulgaria joined a recent meeting in Brussels, between members of the Eurocarers group, of which it is a member. Representatives from different countries (Belgium, UK, Italy, Germany, Greece and Bulgaria) took part in the working group and their mission and main objective was to discuss policies in several priority axes:

- Informal care as an obstacle to employment;
- Mental health and informal care;
- Young carers;
All participants attended a session in the European Parliament to participate in the Interest Group on Carers. The plenary session in Parliament addressed and discussed the main priority points in the following areas: Social, Labour and Health.

The afternoon session was intended for group discussions between participants about what they thought would be important in the day-to-day to help and support carers. The aim is to develop a common political message by the end of the year so that the group’s work on advocacy, at EU and national level, can have the most positive impact.

You can find more information about Eurocarers here: http://www.eurocarers.org/
You can find the full meeting report (in Bulgarian) here: https://alzheimer-bg.org/novini/provedena-sreshha-mezdu-chlenovete-nach-eurocarers-prez-april

9 May: Alzheimer Nederland reports on its recent pre-election campaign

“Voting dementia friendly in the Netherlands”:

At the start of 2017, Alzheimer Nederland began a campaign: “Think... and choose with your heart: vote dementia friendly”, in the run up to the 15 March 2017 national elections in the Netherlands for the House of Representatives.

We examined the manifestos of 13 political parties on issues such as day care, informal care, case management and palliative care.

We informed people via Facebook and Twitter and introduced an “action page” on our website. We approached people to check if their political party had a focus on dementia and had actions on it.

We also encouraged people with dementia to vote. On this theme, there was also a little discussion: “Should people with dementia vote at all? Are they well-informed to make a decision about this?” We shared arguments and gave advice via newspapers and television.

We recommend other countries to also have a discussion about voting rights, especially regarding dementia. After all, in the end we choose with our heart.

15-22 May: Jersey Alzheimer’s Association marks Dementia Awareness Week

Dementia Awareness Week (DAW) took place between 15 and 22 May with a number of key events in different settings. Jersey Alzheimer’s Association (JAA) Educator Michala Graham planned a varied programme introducing the topic of dementia in a number of distinct settings within the wider community, including an “Arts Exploration Exhibition” and an “Awareness Display” at Jersey General Hospital on “Looking beyond the diagnosis”.

To launch DAW, over 100 people attended a JAA Quiz on 12 May and a raffle was held in aid of the association. The Caesarea Quilters put on a two-day exhibition over the weekend of 13/14 May at St Peter’s Parish Hall in which a beautiful charity quilt was the main exhibit. Members exhibited many other items alongside this, some of which were sold in aid of JAA. The charity quilt was raffled to raise funds also. In addition the Caesarea Quilters made further quilts for JAA to raffle in the future as well as a number of “fidget quilts” for people living with dementia.

On 22 May a group of over 40 people, including people with dementia, carers and JAA volunteers and staff enjoyed a “Dementia Friendly Community Outing” to Hamptonne Country Life Museum. Jersey Heritage and Jersey Library specialist staff provided reminiscence talks with the aid of loan boxes. Participants also explored the beautiful Hamptonne farm buildings and land.

16 May: Slovenia celebrates “Happy Volunteers’ day” and “Lifelong Learning Week 2017”

On 16 May 2017, more than 80 organisations and more than 500 volunteers held a “market” in the centre of Ljubljana (pictured) to mark the occasion of “Happy Volunteers’ Day”. Alzheimer Slovenia (Spominčica) asked the visitors to make drawings and write down some positive thoughts. Together with pictures from the event, these were published on the Spominčica Facebook page and on Instagram. Spominčica says this activity definitely helped increased awareness about dementia, as visitors approached staff to ask about caring for people with dementia in the early stages and also shared some of their fears for their own health.

“Being engaged in a public space is one step towards dementia friendly society”, affirmed Spominčica.

Spominčica also took part in “Lifelong Learning Week 2017” from 12 to 21 May, organised by the Slovenian Andragogical Institute. Spominčica participated with 5 events in Adult Education Centres: four workshops and a lecture on “Family Members Coping with Dementia: Emotions and How to deal with them”. At the beginning of the workshops, participants learned about the first signs of dementia. The second part was practical, involving serious games for training cognitive abilities. These are being developed in the Erasmus+ project AD-GAMING.

19 May: CEAFA study looks at impact on carers

Knowing the personal, social, economic and occupational situation of caregivers of people with dementia, in order to articulate the proposals that
allow them to reconcile their dimension as a caregiver with their personal life is the objective of a new study “Consequences of Alzheimer's disease in the family caregiver”, presented at a press conference on 19 May at the headquarters of the Imesro in Madrid. The study is being carried out by the Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), with the collaboration of Spanish pharmaceutical company Cinfa, as a contribution by CEAFA to the Group State Department of Dementia responsible for the preparation of the future National Alzheimer's Plan. This study reflects the need to place value on the caregivers of people with Alzheimer's and other dementias. When talking about Alzheimer's, the focus is primarily on the diagnosed person, the associated socio-health aspects and biomedical research. But Alzheimer's not only affects the person diagnosed, it also impacts on the family caregiver, who is also affected and presents symptoms or problems directly associated with the task of caregiving. Following completion of the study, CEAFA has presented 78 proposals that fall into three categories:

- The first one, centered on the dimension of the caregiver as a person, articulating proposals aimed at making the person more visible above the caregiver.
- In the second section the proposals are developed that have to do with the role of public administrations and the protection of the system.
- Finally, proposals are made with the aim of engaging society at large.

Cheles Cantabranra, president of CEAFA, thanked Cinfa and Imerso for their collaboration and said, during the press conference:

“CEAFA wanted to go a step further, seeking to understand how Alzheimer's affects a carer, as a person.

“This study was needed and so far nothing has been done in this area, because everything that has been done to date has focused on the relationship of the caregiver to the patient and to the disease (burned-out caregiver syndrome). We need to talk about the person behind the caregiver persona.”

Read more (in Spanish): [https://goo.gl/kC1kqm](https://goo.gl/kC1kqm)

22 May: Alzheimer Austria tells us about the “ProMenz” initiative

ProMenz – Initiative by and for persons with forgetfulness (memory loss):

Peculiar “mental blackouts” in everyday life, loss of orientation during vacations….Cognitive problems cause shame and loss of security in persons affected and in consequence these persons isolate themselves instead of the embarrassment being exposed in front of others. Persons with MCI have frightening visions of the future. This and the still ongoing stigmatisation makes an open confrontation even harder.

Examples of “dementia ambassadors” like Helga Rohra from Germany demonstrate that the diagnosis can mean the beginning of a new, meaningful and successful life. Information and therapy are necessary, as well as potential-oriented support.

The first, and so far only, supported self-help group in Austria was started in February 2015. Hosted, at the beginning, by Alzheimer Austria, meetings take place every other week. Getting more confident and focussing more on their potentials, participants wanted to meet in a Viennese coffee shop. In the end, it became too noisy and after ten months, meetings are now taking place at Kardianl-König-Haus in Vienna. Persons attending are handicapped in managing everyday life by cognitive deficits, with a diagnosis or suspicion of dementia, and are interested in exchanges with others.

Meetings provide a protected and confidential sphere for the participants. They can discuss their thoughts and feelings freely. They develop ideas for a good life with forgetfulness, in spite of dementia.

The slogan is: “We accept our weakness and enhance our strengths. We learn to be careful and tolerant towards ourselves and others. For participation we need understanding and support”. Their demands and perspectives are the focus of the group.

Support means management of and assistance for the group. The wish to have an impact on society led to public appearances, press conferences and participation at an artistic research project of the University for Applied Art, Vienna, led by Prof. Ruth Mateus-Berr.

ProMenz is now a non-profit organisation with persons in the early stages of dementia on the Board. It is not a financed service and is still kept alive by voluntary support, the offers of rooms and material expenses by co-operating organisations.

ProMenz was nominated for SozialMarie 2017 – a prize for social innovation.

24 May: Ireland involved in project aiming to create flexible online education for family carers of people with dementia

The project Home Based Care – Home Based Education - a small Erasmus+ project coordinated by The Alzheimer Society of Ireland (ASI) – aims to share experience and contribute to a solution for the challenge of an ageing Europe, where more people with dementia live at home (and want to remain living at home). The project was launched in September 2015 and will end on 31 August this year.

To showcase how this Erasmus+ project turned a face-to-face course into one delivered completely online, ASI has organised a seminar in Dublin, Ireland on 8 June 2017. The registration is
free of charge and special travel bursaries are available (EUR 100 bursary for each delegate), in order to assist participants travelling from mainland Europe. You can register [here](https://goo.gl/7Be77r). You can see the full programme [here](https://goo.gl/7Be77r).

Pictured: The core team (from the left): Carine Spriet, IC Dien, Belgium; Eva Vansteenkiste, IC Dien, Belgium; Kari Olstad, Flexible Education Norway, Norway; Fergus Timmons, The Alzheimer Society, Ireland.

### 24 May: Spominčica reports on its involvement in an important new Slovenian project

Alzheimer Slovenia (Spominčica) is involved in Slovenian project ADAM - Alzheimer’s Dementia Automated Monitoring - that will last until the end of July 2017. ADAM is a socially-responsible project that aims to achieve three major goals:

- Raise awareness among professionals and the public about dementia to reduce stigma
- Perform screening tests to provide early detection of cognitive decline
- Contribute to scientific research for developing new, low cost and non-invasive methods for diagnosing dementia based on EEG technology.

Over the course of three months, 450 participants aged from 60 to 90, from six Slovenian regions will be given the opportunity to test their cognitive functions using standardised screening tests (MOCA). The brain activity of each project participant will also be recorded using EEG. Participants will be told how they performed in the MOCA cognitive test. If mild cognitive impairment (MCI) or Alzheimer's disease (AD) is suspected, neuropsychologists will refer the participant to their doctor. Participants will also receive information about dementia, symptoms, rights, activities and information about forms of help that exist in the community. The Neurology Clinic Ljubljana will create a large database of electrophysiological data needed for research into new diagnostic models, and for basic scientific research.

Besides Spominčica - responsible for public awareness and to disseminate accurate and credible information, as well as support to individuals with dementia and their carers – the ADAM consortium consists of BLCKB, ltd., association for applicative neuroscience (leading partner), the Neurology Clinic Ljubljana (University Medical Centre Ljubljana, medical experts), an association of local retirement organisations and clubs in Slovenia, and Triglav Health.

In Slovenia, dementia is a big social, health and economic problem. Currently, the estimated number of people with dementia is around 33,000. Individuals, with symptoms of dementia usually visit their general practitioners (GPs) too late, meaning that dementia is usually diagnosed when is already in its moderate stages. Project ADAM is a great opportunity to recognise the first signs of dementia and to evaluate if cognitive abilities vary from the population average.

### 24 May: France Alzheimer launches its Facebook page

France Alzheimer has launched its official Facebook page. It contains useful information about the association, about Alzheimer's disease and other dementias. The page also contains advice for carers and for living better with dementia.

[https://www.facebook.com/francealzheimer/](https://www.facebook.com/francealzheimer/)

### 26 May: The Alzheimer’s Society reports on “The Dementia Statements”

The ‘I’ statements, or the National Dementia Declaration, were formed back in 2010 when Alzheimer’s Society and 42 other organisations came together to form the Dementia Action Alliance (DAA). A huge amount has changed since then and as a result, Alzheimer’s Society led a review on behalf of the DAA to make sure they reflect what people with dementia want now.

**What we did**

We reached over 80 people with dementia and carers through 15 different groups, to find out what was important to people, and what things they would change if they could. The thing that came through most clearly was that everyone is different. For one woman, it was really important for people to see her ‘just going on being me.’

After summarising the evidence, we held a Drafting Event, which was attended by nine people with dementia (three of whom were accompanied by their carers) and three former carers. Members of the group produced draft statements based on the themes that had come through during the evidence gathering - identity, care, community, carers and research.

We then held a Consensus Event, where the final set of statements – the ‘Dementia Statements’ were agreed. This
was attended by people with dementia and carers as well as representatives of DAA organisations.

The statements were officially launched at Alzheimer’s Society’s Annual Conference on Thursday 18th May, as part of Dementia Awareness Week. Five people with dementia that were involved in the review were part of a panel discussion with broadcaster, Bill Turnbull, where they talked about the importance of the different statements and how they want them to change things for people with dementia and their carers.

What next?

We are now working to ensure that the statements will be understood and implemented across a range of different settings. We will also be developing a guidance document which explains the legal background to the statements as well as some additional helpful information.

By championing the rights of people living with dementia we will transform the landscape of dementia forever.

Read the Dementia Statements on the DAA website here: [http://www.dementiaaction.org.uk/news/23236_news_launching_the_dementia_statements](http://www.dementiaaction.org.uk/news/23236_news_launching_the_dementia_statements)

26 May: Panhellenic Federation writes about Caregivers Day 2017

There are 200,000 people living with dementia in Greece and 400,000 family caregivers looking after them. Compared to existing needs, services provided to them are woefully inadequate. In order to support the challenging role of family caregivers, Athens Alzheimer’s Association has established, for the past 10 years, an annual event called Caregiver’s Day, dedicated to the education of caregivers.

The motto for this year was: “Caring Does Not Mean Falling to Pieces”. The event took place at a central auditorium in Athens, on 18 March 2017. The programme included Dr Paraskevi Sakka’s lecture on dementia, followed by caregivers’ sessions. Caregivers were divided into groups and had the chance to discuss their difficulties with experienced health professionals, and to share their burden with other caregivers.

The day was a great success, with a total of 600 caregivers participating and many new members joining our Association. We are glad of the fact that many other Greek Alzheimer’s associations all over the country have adopted “Caregiver’s Day” and organised events dedicated to caregivers for people with dementia or Alzheimer’s disease, during the month of March.

26 May: Panhellenic Federation reports on a project promoting active and healthy ageing in Serres, Greece

The project “Promotion of active and healthy ageing” refers to a promising initiative of the Greek Association of Families/Caregivers and Friends for Mental Health, Alzheimer’s disease and related disorders SOFPSI N. SERRON. The aim of the project is to improve health and quality of life for the elderly by improving their health literacy, changing their behaviour from passive survival to active control and enabling them to participate in social activities. The project recognises that elder persons have capacities and skills that can be channelled into creative activities, strengthening thus their feelings of personal value and giving, and preventing the development of psychopathologies.

The third round of the project is still in progress but evaluation of the first two rounds shows that the project’s beneficial outcomes can be structured upon the following axes: improved well-being and number of new friends, alleviated loneliness, new ways of communication, healthy relationships with self and others, improved functional capacity, participation in social activities.

From the spectrum of personal empowerment, it is qualitatively shown that the “Promotion of active and healthy ageing” has a positive effect on the participants’ self-esteem and self-confidence levels, as well as on their capacities.

29 May: Muistiliitto tells us about its Peer Support Phone Line and invites volunteers

The Peer Support Phone Line is a helpline that provides helpful conversation, personal tips, and peer support for friends and families of people with memory-related diseases. Calls are answered by experienced and trained former informal carers.

The service is based on volunteer work and is organised by the Alzheimer Society of Finland (Muistiliitto). The free phone line is open every night, including holidays, from 5pm to 9pm. All conversations are confidential and callers may remain anonymous if they wish. The operators sign a confidentiality agreement and commit to following the ethical principles of the Peer Support Phone Line.

The service provided by phone consists of active listening, conversation, and direction to provide callers with the opportunity to discuss and share with peers. The Peer Support Phone Line does not provide professional support or medical advice. Questions related to care and the service system, for example, are directed to the Memory Advice phone service, where calls are answered by professionals in the memory field.

The most typical Peer Support Phone Line caller is the spouse or child of a person with Alzheimer’s disease. Often, the caller wants to share their feelings on everyday issues on the Peer Support Phone Line, or callers want to discuss symptoms or hear solutions to everyday challenges. Tips received from the operators of the Peer Support Phone Line, based on personal experience of resolving similar situations as a close relation, are inestimably valuable to the callers.

The participants are usually people who have already been active within Muistiliitto and have previous experience of peer
support groups and other activities based on mutual support. People can apply to become support phone-line operators by contacting Muistiliitto. To become a volunteer operator, the applicant must have been a family member or close relation of a person with a memory-related disease and have been through the related crises, allowing them to help and support other people in the same situation, based on their experiences.

The number of calls received has increased in the past few years. In 2015–2016, the number grew by more than 300 calls, amounting to a total of 1,091 calls answered.

29 May: Alzheimer Italia reports on its new national Dementia Friendly Community recognition programme

After the great success of the pilot project in the town of Abbiategrasso for the first Dementia Friendly Community (DFC), Federazione Alzheimer Italia (FAI) has developed a national recognition process for communities wishing to start a pathway to support people with dementia. Through the implementation of internationally recognised guidelines and suitably adapted to the Italian context, it is now possible to submit a request to FAI, to be recognised as a DFC.

In less than three months, following the completion of the first year of the pilot project and its disclosure, six new communities followed Abbiategrasso’s model and received the official logo that accredited them as communities committed to raising awareness of dementia.

These communities, located throughout Italy, are Albino, Conegliano, Giovinazzo, Scanzorosciate, Tradate and Valpolicella and, good news, other cities have already expressed interest in the project.

For the realisation of a DFC, the steps to be taken are first of all the formation of a promoter group, the creator and engine of initiatives that monitors how much is being done to meet the needs of people with dementia and their families. FAI, working alongside organisations, provides official guidelines, materials for the implementation of customised activities, suggestions and recommendations as well as tools for assessing consistency and effectiveness of all interventions.

FAI has created a working group, tasked with identifying valid indicators to measure progress and assess the impact of the work done and the initiatives in place: the basic tool used in this case is a self-assessment questionnaire based on internationally shared guidelines and delivered to the individual accredited communities.

Upon receipt of the completed questionnaire by FAI, the communities have access to the personalised logo, only if they have demonstrated commitment in working and supporting people with dementia within the community.

The achievement of the logo represents an acknowledgment to the communities of what has been done and represents a promise to continue working hard to reduce stigma and increase awareness among its citizens, by including more and more stakeholders.

30 May: “Turning up the volume of the voices of people with dementia” – an initiative from the UK Alzheimer’s Society

Society often fails to listen to the voices of people affected by dementia. “Turning Up the Volume: unheard voices of dementia” is an unprecedented look at the real picture of living with dementia today, from the people who know. It dials up the voice of people who are affected by the condition - telling their stories, and presenting a picture of their day-to-day life.

Evidence gathering covered four different strands resulting in a total of nearly four thousand people providing some form of evidence, many of whom live with the condition.

“I just had to stand there and watch and think ‘I could have done that’. I’d done it before, but I can’t now.”- Person with dementia

Worryingly the evidence told us that for many people there is a real gap between the things that people living with dementia have told us they need to live well and their day-to-day reality.

It highlighted that they or their carers often find care not only hard to come by but have to shoulder the cost too. It revealed how ingrained views and misconceptions of the condition can make life more difficult for those who are diagnosed with the condition.

The impact of symptoms, stigma and what people feel they are no longer able to do negatively affects people’s sense of worth, sense of self-identity and increases their feeling of isolation.

“I won’t answer the phone and I don’t answer the door unless there is somebody coming who I know.”- Person with dementia

However some people with dementia also told us that when well supported, in part by services from Alzheimer’s Society, they can live well.

We need to see change so more people can experience these benefits. By uniting against dementia we can all make a difference. Turning Up The Volume is clear on what is needed from Government and from Society, but we also need you. Alzheimer’s Society’s movement and help to find a cure, improve care, and offer help and understanding to everyone affected.

“Remember yesterday, look forward to tomorrow, live for today.”- Person with dementia

*32 in-depth interviews with people living with dementia and 5 interviews with carers of those living with dementia. Interviews with people living with dementia were conducted
face to face in locations across England, Wales and Northern Ireland. Interviews with carers were conducted over the phone.

30 May: Alzheimer Slovenia reports on Demenca aCROsSLO project website

The Demenca aCROsSLO project is implemented in the border area of the Slovenian and Croatian Istra, in the framework of the international INTERREG project between Slovenia and Croatia, and is aimed at the improvement of the quality of life of persons with dementia in the cross-border area.

By educating in the field of dementia, we contribute to better knowledge of those, who work with persons with dementia every day, and thus, we follow the project objectives, which include the optimisation of social care services, destigmatisation of these diseases in society, and the prevention of social exclusion of persons with dementia and their families.

In Izola and Umag, homes for the elderly have held several lectures and workshops on dementia for professional and nursing staff. The abstracts of lectures and announcements of other events for raising awareness of dementia as well as other useful information are available on project web page.

Dana Hradcová coordinated the programme and the public was made up of a variety of people, including caregivers, MPs, journalists, physicians, pharmacists and social workers.

19 April: Alzheimer’s Society of Ireland publishes discussion document on statutory home care scheme

The Alzheimer Society of Ireland (ASI) has come together with 12 other NGOs to release a discussion document, dated 19 April 2017, on an upcoming public consultation that will lead to the development of a statutory home care scheme. This scheme will be similar to the Fair Deal Scheme and will give people the right to access home care, which at the moment is discretionary.

The Minister of State for Mental Health and Older People, Helen McEntee TD, has announced that she will be starting this consultation process in May and the ASI will be consulting with staff, branches, people with dementia and carers to prepare a submission.

This initial discussion document sets out the issues that must be addressed during the consultation and highlights how people living with different conditions, including dementia, and carers can be involved.

Pictured: ASI and other NGOs calling for increased investment in home care in September 2016.

20 April: UK Dementia Research Institute reveals its first research programmes across six centres

On 20 April, the first 27 foundation research programmes at the UK Dementia Research Institute (UK DRI) were announced. Worth a combined investment of GBP 55 million (EUR 63.5 million), the programmes will provide answers to some of the most pressing questions in the field of neurodegenerative disease.

Five new UK DRI centres are to join the headquarters at University College London (UCL), laying the foundations for an eventual 400-strong community of UK DRI researchers. Centres will be established across the country at the University of Cambridge, Cardiff University, The University of Edinburgh, Imperial College London and King’s College London.

Utilising state-of-the-art research ad imaging facilities at these leading UK Universities, the foundation programmes will broaden out the traditional view of neurodegenerative disease as a disorder of mis-folded proteins, to consider the proteins in the complex environment of the brain. By investigating new molecular and cellular mechanisms responsible for neurodegenerative brain diseases, the institute hopes to reinvigorate the discovery pipeline for dementia drugs.
UK DRI researchers will explore ways to manipulate the brain’s natural defence mechanisms such as the cold shock response, autophagy and innate immunity to identify novel drug candidates that can be put to the test. They will also turn their attention to the role of metabolism, sleep and bacteria in the gut, all of which are increasingly implicated in determining the likelihood of developing dementia.

https://goo.gl/8G5dpI

3 May: The Economist publishes report on how healthcare systems in Europe and Canada are responding to the impact of dementia

On 3 May, The Economist published a report called “Assessing the socioeconomic impact of Alzheimer’s in western Europe and Canada”, sponsored by Eli Lilly. It examines how healthcare systems and governments in Western Europe and Canada are responding to the growing impact that Alzheimer’s disease (AD) and other causes of dementia are having on economies, healthcare systems and society in general. The research consists of a cost analysis of dementia in six countries—Canada, France, Germany, Italy, Spain and the UK.

Insights from interviews with leading dementia experts in academia, the medical profession and patient organisations—conducted by The Economist Intelligence Unit in late 2016 and early 2017—appear throughout the report. Interviewees include Jean Georges, Executive Director of Alzheimer Europe.

Key findings include:

- Rapidly ageing populations are adding to the rising number of people with dementia. This is putting severe pressure on countries’ healthcare systems and budgets, and importantly also on families and informal caregivers. If current levels of informal care are to continue, governments will need to increase the amount of support they give these carers in order to manage the rising number of people with AD.
- The cost of dementia is mounting.
  - The majority of direct medical costs fall on the health system of each country studied.
  - These indirect costs are in addition to the emotional burden of the disease, which has a major impact on those caring for someone with dementia.
- Developing national strategies on dementia is necessary to improve co-ordination across service providers. Moreover, national strategies will help to inform regional policies.
- More research is needed.
- There is a lack of understanding between what people consider symptoms of old age and what are, in fact, indicators of dementia.

Regarding Key Finding 1, Jean Georges points out that “better support and training for carers is needed so they are better able to provide care at home, which would save substantial costs to governments in the long run”. Later in the report, concerning the co-ordination of health and social care, Jean Georges also stressed the problems caused by a lack of linkages between the two sectors. He goes on to say that while many countries have universal healthcare, social care is not always included in this.

“Long-term care also needs to be funded and better supported,” he emphasises.

The Economist is an English-language weekly magazine-format newspaper. In 2015 its average weekly circulation was a little over 1.5 million, about half of which is in the US. The report can be downloaded in full, here:

https://goo.gl/6WJPW

5 May: US Alzheimer’s Association leads the way to secure USD 400 million federal research increase

On 5 May, the Alzheimer’s Association (US) announced that the historic USD 400 million (EUR 358 million) increase in Alzheimer’s research funding, approved by the US Senate in 2016, has been passed into US law.

http://www.alz.org/news_and_events_104875.asp

7 May: France elects new President, France Alzheimer continues its election campaign to improve the lives of carers

The 2017 French presidential election was held on 23 April and 7 May 2017. As no candidate won a majority in the first round on 23 April, a run-off was held between the top two candidates, Emmanuel Macron of En Marchel and Marine Le Pen of the National Front (FN), which Macron won by a decisive margin on 7 May. Mr Macron took office on 14 May and named Édouard Philippe as Prime Minister on 15 May; the government was assembled on 17 May, with the legislative elections to follow on 11 and 18 June.

In the run up to these elections, France Alzheimer launched its election campaign, addressing 23 concrete proposals to the candidates, each designed to improve the care sector and the lives of carers of people with dementia. The 23 proposals fall into the following six categories:

1. Changing perceptions of dementia
2. Better diagnosis for better care
3. Adapting the care pathway
4. Recognising and supporting carers
5. Reducing the costs of dementia
6. Reinvesting for research.

Despite the election being over it is still possible to support the proposals made by France Alzheimer, via:

www.touscandidatsalamaladie.fr

11 May: The Alzheimer’s Society reports on the impossible cost of UK dementia care

On 11 May, the Alzheimer’s Society in the UK published a report, entitled “Impossible cost: dementia care bill would...
take 125 years to save for”. Some of the key points covered are:

- People are unprepared for astronomical dementia costs, with nearly half of adults aged between 16-75 years old not having started saving for the care and support they might need in the future.
- Successive governments have placed funding of dementia care squarely on the shoulders of people affected, but the society’s calculation reveals that even if people preemptively saved as they do for their pension, it would be impossible to prepare for. The charity warns the bill will topple “generation rent”, who have fewer assets than previous generations, and are at higher risk of developing dementia as people continue to live longer.
- When asked whether the Government should pay for their care and support if they developed dementia, more than half of those interviewed agreed that the Government should pay, while just 5% disagreed.

Jeremy Hughes, Chief Executive of Alzheimer’s Society said:

“The social care crisis is a dementia crisis. Many people with dementia and their families are buckling under the inordinate pressure of propping up a failing social care system that has been starved of funding for decades. Too many people are forced to give up everything they own in order to care day in and day out for their mother, father, husband or wife.”

“Repeatedly governments have failed to put a long term plan in place. On behalf of people with dementia, I challenge the next Government to create a long term, sustainable system for funding dementia care.”

The final words went to Tania Dussey-Cavassini, Swiss Ambassador of Global Health and Vice-Director General, Federal Office of Public Health, who echoed calls for dementia funding, “I ask all of you, especially Member States to step up to the plate, to put money in the right place, to support research so tomorrow we can have a cure.”

Following this event, the Action Plan was unanimously adopted at WHA70 on 29 May:


**29 May: The World Health Organisation (WHO) adopts a global plan on dementia**

On 29 May 2017 “Global Plan of Action on the Public Health Response to Dementia 2017- 2025” has been unanimously adopted by 194 countries of WHO during the 70th World Health Assembly (WHA 70) in Geneva Switzerland. The plan supports the urgent message that countries need to develop practical and ambitious national strategies. Only 29 out of 194 the WHO Member States have already developed a plan on dementia.

Alzheimer Europe (AE) and people living with dementia were consulted on the development of the plan, which includes a set of seven global targets:

1. Dementia as a public health priority
2. Dementia Awareness and Friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation.

The plan calls on all governments to meet these targets. Currently it is estimated that 8.7 million people live with dementia in Europe and that world-wide 47.5 people live with dementia. It is a major cause of disability and dependency among older people world-wide and with the ageing demographic this figure is expected to increase further. The plan acknowledges that dementia is not a normal part of ageing and that governments should act now.

Jean Georges, Executive Director of AE said “Alzheimer Europe welcomes the adoption of the Global Action Plan on Dementia by the World Health Organisation. At a time when the number of countries in Europe developing national dementia strategies
continues to grow, it is encouraging to see this call for greater global collaboration. The Global Dementia Observatory, to be set up by the WHO following this Action Plan, will be a useful system for countries to compare and benchmark the readiness of their health and care systems to address the dementia challenge. We hope that the European Union will follow this example and start the development of a European dementia strategy which promotes greater research collaboration and the exchange of good practices between countries on care and support systems.”

BEHIND THE HEADLINES

Repurposing cancer and depression drugs for use in dementia - Dr Lucy Stirland comments

Dr Lucy Stirland is a Clinical Research Fellow in the Centre for Dementia Prevention at the University of Edinburgh. She is also an honorary specialty registrar in Old Age Psychiatry in Edinburgh. Currently undertaking a PhD, she is looking at the links between physical and mental health in later life using big data. Her aims are to find out whether having numerous physical conditions or taking several medications at once are associated with mental health problems including dementia.

Find out more about Dr Stirland here: http://edin.ac/2qdj7bE

Dr Stirland provided her commentary on recent headlines claiming it may be possible to repurpose two existing drugs - a Cancer drug and a drug for depression – for use against dementia, versus the findings of the study to which they refer.

Were the headlines right or were they misleading in some way?

This research paper attracted attention as it reports a promising step towards finding a new treatment for dementia. However, this was laboratory based experimental work in mice and the treatments in question are very far from being ready for use in people. The news reports were generally balanced and included quotes from scientists both optimistic and more cautious. Some headlines such as “Experts ‘excited’ at HUGE breakthrough in hunt for cure” were perhaps exaggerated. There are no suggestions that these drugs would cure dementia, only that they could protect against brain cell death. Speculation that the drugs may be ready for public use in as little as two years is also very optimistic, given the length of time taken to set up a clinical trial.

Most of the reports stressed the fact that these findings in mice do not automatically translate to the same effects in humans, therefore tempering any disproportionate enthusiasm.

How important is this story/study for furthering dementia research? Should we be excited?

This study was very thorough. The researchers used a library of 1,040 existing substances and tested these first in worms, then 20 promising ones in cell models, before choosing the two drugs they tested in mice: trazodone and dibenzoylmethane. Trazodone is already used as an anti-depressant. As some of the news articles mention, it is sometimes given to people with dementia to alleviate symptoms including sleep disturbance and agitation. However, it causes sedation so is usually used in small doses and some people find it too sedating to be helpful. Dibenzoylmethane has been used in studies for some cancers but is not currently used in clinical practice. Neither of the drugs studied have previously been found to protect brain cells.

The mice in this study had already a developed brain disease, which behaves in a similar way to frontotemporal dementia. The behaviour and memory of most of the mice improved with the drugs and there was evidence that their brain cells were protected from death. Most of the mice given the drugs survived longer than those without them.

This is potentially exciting news because one of the drugs in question is already prescribed in humans and is therefore known to be safe in its current usage. If the protective effects are found to occur in humans too, then the drug could be used in practice much more quickly than a completely new compound which would have to go through years of safety testing.

What might be the impact of this story/study in the scientific community?

The study was based on prior understanding of a process that protects brain cells. It used efficient methods to screen over 1,000 existing substances for effectiveness, before doing more detailed tests on just two compounds in mice. These methods, allowing existing medications to be “repurposed”, are being used in studies of other diseases and will be useful in finding new treatments more quickly and cheaply.

Now that these drugs have been identified as potentially useful, there will likely be more studies involving them and eventually testing them on humans.

What are the next steps?
As with all new findings, these need to be replicated in further research. This study has made an important step by finding a benefit from these drugs in mice. The study’s authors have called for clinical trials of trazodone and dibenzoylmethane to test whether their protective effect will also be seen in humans. It is likely to take several years before we know whether the drugs will be helpful treatments for dementia.

There are several different disease processes which contribute to developing dementia and this study only focussed on one; therefore parallel work needs to continue looking at other pathways.

**Should I/my relative with dementia seek a prescription of trazodone if it is already available?**

This study has found some benefit from using trazodone in mice with brain diseases. At this early stage, we do not know if this will be beneficial or safe for treating dementia in people. As with all drugs, it has side effects and its interactions with other prescriptions must be considered. It should therefore not be used as a treatment for dementia until results of studies of its use in humans are available. It would also need to be licensed for its new use by the appropriate regulatory bodies.

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**Diet fizzy drinks linked to dementia and stroke? Dr Hinesh Topiwala comments**

Dr Hinesh Topiwala is a Clinical Research Fellow at the Centre for Dementia Prevention, University of Edinburgh. He works on the European Prevention of Alzheimer’s Dementia (EPAD) Longitudinal Cohort Study. EPAD aims to identify warning signs of Alzheimer’s disease that are present in midlife that may predict which people are likely to develop dementia in later life. Hinesh’s main research interest is lifestyle and neurodegeneration in midlife and he has previously completed Psychology (BSc) and Medicine (MBBS) degrees at University College London. He is member of the Royal College of Psychiatrists (MRCPsych) and has worked as a clinician for the NHS since 2008.

Find out more about Dr Topiwala here: [https://www.researchgate.net/profile/Hinesh_Topiwala](https://www.researchgate.net/profile/Hinesh_Topiwala)

Dr Topiwala provided his commentary on recent headlines claiming diet fizzy drinks are linked to dementia and stroke, versus the findings of the study to which they refer.

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**Were the headlines right or were they misleading in some way?**

This original study was published in Stroke, a peer reviewed journal of the American Heart Association in May 2017. The findings of the study were widely disseminated via the media, including newspapers. The headlines in the New York Times and Telegraph were both fair and balanced. The headlines highlight an interesting trend that warrants further investigation.

The bold and eye catching headline in the Daily Mail was somewhat misleading. The first part of the headline ‘Diet drinks TRIPLE your risk of stroke and dementia’ is based on data which had not taken into account the numerous health and lifestyle factors which may influence the relationship between diet drinks and dementia and stroke. The second part of the headline, which states that diet drinks ‘are FAR more dangerous than drinks sweetened with sugar’ is not supported by the data in this study.

**How important is this story/study for furthering dementia research? Should we be excited?**

This study has identified an exciting platform from which further research can take place into the relationship between sweetened soft drink consumption and the risk of stroke and dementia. The study had a large sample size, participants were regularly followed up, the researchers used statistical modelling to adjust for a number of possible alternative explanations for correlations in the data and the study used well established data collection tools such as the Harvard semiquantitative food-frequency questionnaire (FFQ).

Nevertheless, the findings from this study should be interpreted with caution. The authors of the study acknowledge that they cannot exclude the possibility that they have not accounted for all possible alternative explanations for correlations identified in the data and that some of the findings may be attributable to chance. Also, there is an absence of ethnic minorities in the sample which limits the generalizability of the findings and the FFQ, a self-reported questionnaire may be subject to inaccuracies, as participants may not precisely remember their food and beverage consumption over the past year.

**What might be the impact of this story/study in the scientific community?**

This forward-thinking study into stroke and dementia is certainly a step in the right direction and we need to build upon these study findings. There has been very little research looking at the relationship between sweetened beverages and the risk of stroke and dementia. Additionally, the findings from previous research have been conflicting. This large observational study adds to the current evidence base.
What are the next steps?  
The authors of the study have concluded that artificially sweetened soft drinks consumption was associated with a higher risk of stroke and dementia. However, when the authors used an adjusted statistical model taking into account demographic, lifestyle and health factors, the association between artificially sweetened drinks and risk of dementia and stroke was less robust. Further research is needed to replicate the study findings in a different population and to investigate the possible mechanisms underlying the reported associations. In the future, clinical trials may be helpful to establish whether the consumption of artificially sweetened beverages is causally related to dementia and stroke.  

The OASIS communication training program for nursing home staff focuses on treating the residents as human beings with needs, instead of patients with problems. The OASIS program asks nursing staff to create care plans that include what residents can do, shifting away from the model that focuses on what they can't do. The rate of off-label antipsychotic use was examined from 2011 to 2014. Among the facilities that conducted the OASIS programme, the prevalence of antipsychotic medicine prescriptions was cut from 34.1 at baseline to 26.5% at the study end (absolute reduction of 7.6 %). In comparison to facilities that did not conduct the training, the drug use dropped from 22.7% to 18.8% (absolute reduction of 3.9%). However, the researchers stated that the decreases in “OASIS” facilities did not continue in the maintenance phase.  

http://www.cell.com/neuron/fulltext/S0896-6273(17)30286-6

1 April: Neurotrope announces encouraging results from experimental AD drug Phase 2b study

The biotechnology company Neurotrope BioScience develops novel therapies to treat neurodegenerative diseases. One of them is based on Bryostatin-1 for the treatment of Alzheimer’s disease (AD) is growing. Preliminary research conducted by Toronto-based scientists adds further indications that “brain-friendly” diets could help people approaching middle age and older citizens to reduce their risk. The Canadian Brain Health Food Guide advises individuals and institutions to focus more on foods like beans, whole grains, and nuts instead of pre-packaged foods, which often lack nutrients that are needed to protect brain cells. One of the leaders in the creation of the Brain Health Food Guide, Prof. Carol Greenwood (professor of nutrition at the University of Toronto) explained that her research group aimed to further refine the concepts of the Mediterranean diet to be better suited for people living in metropolitan areas. 


17 April: Communication training in nursing homes can to help reduce the use of antipsychotics

On 17 April, a research team published results on the significant reduction of antipsychotic medication in 93 nursing homes, following staff training to recognise that behavioural and psychological symptoms of dementia are the communication of unmet needs. Typically, antipsychotic drugs are used to relieve anxiety, depression, psychosis and aggression in people with dementia and come with a number of side effects such as an increased risk of stroke and death. This quasi-experimental longitudinal study, led by Dr Jennifer Tjia, associate professor of quantitative health sciences, was published in JAMA Internal Medicine. 93 nursing homes (NH) enrolled in the OASIS intervention (27 of which had a high prevalence of antipsychotic use) compared with 831 without such intervention.

19 April: Scientists generate new brain cells from skin stem cells

In a study published in the journal Neuron on 19 April, researchers at University of California, Irvine have created a method to generate new brain cells called microglia using human skin cells. Microglia, the immune cells of the brain, are key cells protecting the brain and responding to injury. In addition, microglia play important roles in brain maintenance and neural networks. In the published study, scientists used skin stem cells to generate microglia efficiently in a dish over 5 weeks, which were very similar to human microglial cells. These new cells expressed many microglial characteristics such as morphology, microglial-enriched proteins and genes. They also acted like human microglial cells. The generation of microglia could help to study their role in neurodegenerative diseases including Alzheimer’s disease (AD). Indeed, previous findings have shown that microglia play important roles in AD and that AD risk genes could influence microglia behaviour. 

http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2618819

14 April: Canadian Brain Health Food Guide published

The body of studies investigating different lifestyle aspects that could lead to a diminished risk to develop Alzheimer’s disease (AD) is growing. Preliminary research conducted by Toronto-based scientists adds further indications that “brain-friendly” diets could help people approaching middle age and older citizens to reduce their risk.

disease (AD). This potent modulator of protein kinase C could activate synaptic growth factors and amyloid-beta-degrading enzymes.

On 1 May 2017, the company announced results from its Phase 2b clinical trial of Bryostatin-1 for AD treatment. The Phase 2b trial was a randomised, double-blind, placebo-controlled study to evaluate the safety, tolerability and efficacy of Bryostatin-1 in the treatment of moderate to severe AD. Two doses of Bryostatin-1 (20 or 40 µg) versus placebo were administered intravenously in a total of 147 participants. Bryostatin-1, at the 20 µg dose, was found to be well tolerated by participants with moderate to severe AD except a high incidence of diarrhoea. This dose appeared to improve cognition and the ability to perform activities of daily living. Further analyses are ongoing and Neurotrope plans to present more data at future conferences.

1 May: Researchers suggest that low levels of SIRT6 protein may contribute to AD

In a recent study published in the journal Cell reports, Israeli scientists from Ben-Gurion University of the Negev reported that a protein called SIRT6 has neuroprotective effects, and that reduced levels can be observed in people with Alzheimer’s disease (AD).

Researchers showed that deletion of SIRT6 in mouse models was linked to DNA damage in the brain as well as learning deficits. In addition, the lack of SIRT6 increased Tau hyperphosphorylation, which is a major AD hallmark. Furthermore, scientists analysed the SIRT6 level in AD brain samples. They noticed that this protein is highly expressed in human brains but reduced in people with AD, which may contribute to AD onset.

2 May: Schizophrenia treatment brexpiprazole may reduce agitation in AD

Lundbeck and Otsuka announced results from two Phase 3 trials of brexpiprazole, which may reduce agitation in people with Alzheimer’s disease (AD).

Brexipiprazole is currently indicated for the treatment of schizophrenia and major depressive disorder. It is well known that agitation is a behavioural symptom observed in the majority of people with AD. Two Phase 3 trials were investigated to evaluate the safety and efficacy of brexpiprazole in the treatment of people who have agitation due to Alzheimer’s dementia. Studies were 12-week, double-blind and randomised trials enrolling approximately 700 participants between 55 and 90 years of age with a diagnosis of probable AD. One trial studied fixed doses of brexpiprazole (1 or 2 mg) and the second evaluated a flexible-dose range (0.5, 1 and 2 mg).

Results from both studies confirmed the safety and tolerability profile of brexpiprazole while the most adverse events observed were insomnia, agitation and somnolence. Data demonstrated that treatment with brexpiprazole showed improvements in symptoms of agitation compared to placebo, by using two tools to evaluate agitation.

3 May: Dementia Platform UK organises pre-conference workshop for Early Career Researchers

On 3 May, the Dementias Platform UK (DPUK) Annual Conference and a half-day pre-conference workshop for Early Career Researchers (ECRs) took place in London. DPUK’s goal is to create the context for a new generation of highly-targeted, highly-informative clinical trials. It is funded by the Medical Research Council (MRC).

The pre-conference was chaired by Prof. John Gallacher, DPUK Director and the meeting objectives were to provide an initial networking, collaboration and input platform for ECRs and to empower exchange opportunities with principal investigators (PIs), with regard to DPUK’s data-sharing platform and scientific work in the broader sense. The overarching goal of the pre-conference was to create better opportunities for ECRs and to empower them in the pursuit of good quality science.

The programme began with a networking lunch at the Royal College of Obstetricians and Gynaecologists. This was followed by an overview of DPUK by Prof. Gallacher, which included an introduction to the experimental medicine challenge as well as how DPUK integrates into the research environment, with its core enabling utilities, to provide rapid data access. Prof. Gallacher closed his presentation with an outlook and call to ECRs, stating that they are seeking to equip ECRs for new challenges presented by a new dementia science environment, which will not only be multi-disciplinary but also cross-institutional.

The introduction led to a roundtable discussion on DPUK’s plans for ECRs and the opportunity for feedback revolving around the areas of networking, visibility of the project’s ECR programme, collaboration opportunities for the attendees, but also possible additional researchers that could join the network. DPUK aims to foster greater interaction between senior and junior dementia researchers, provide greater knowledge of its activities, ensure enhanced training, and facilitate access to career-targeted support.

After a break and vivid discussions, three invitees gave “top tips” for grant and fellowship writing. Each invitee explained how their organisation supports researchers and concluded with their tips for grant and fellowship writing. The presentations included speeches from; Kim Graham, ECR Champion for DPUK and representing the MRC; Rosa Sancho, Head of Research at Alzheimer’s Research UK (ARUK); and Katherine Gray from the Alzheimer’s Society.
Following the presentations, Prof. Monique Breteler, Director of Population Health Sciences at the German Centre for Neurodegenerative Diseases gave a powerful and inspirational speech about her personal experience as part of the scientific community, referring to her experiences in the Rotterdam Study but also the Rhineeland Study, bringing not only an informational but also advisory depth to the programme.

Cindy Birck and Christophe Bintener represented Alzheimer Europe at this event.

Read more about ECR:
http://www.dementiasplatform.uk/research/early-career-researchers/

6 May: People with higher risk of dementia may have poorer navigational skills

Research of the PREVENT project (based at Edinburgh University) focuses on people in middle age to identify biological and psychological factors which may increase the risk of dementia in later life. Once identified, the factors that are changing will be used to select people at high risk, so that interventions may be carried out accordingly. These interventions might be lifestyle changes or measures to affect the risk of an individual developing dementia.

On 6 May, early findings outlined in a paper to be published in the journal of Alzheimer’s and Dementia showed that those who were at higher risk of dementia were poorer at tests that measured the ability to visualise a position in space.

A key element of the test battery the researchers administered was the Four Mountains test. The test challenges the capacity to recognise places and imagine them from alternative points of view. This skill is thought to depend on the hippocampal formation. Indeed, another finding was that these people also tended to have a small hippocampus.

It remains to be seen how effective measuring the navigational skills of people deemed at higher risk of dementia will be, in predicting its development in later life, and how these factors might lead to preventive strategies.

https://www.theguardian.com/society/2017/may/06/getting-lost-may-be-first-sign-of-alzheimers

8 May: Cannabinoid treatment improves cognition in older mice

On 8 May, scientists from Germany and Israel (University of Bonn, Limes Institute and Hebrew University) reported that the psychoactive ingredient of marijuana tetrahydrocannabinol (THC) might help to restore cognitive functions in older mice. In their article, published in the journal Nature Medicine, the researchers analysed the effects of a chronic dose of THC (3 milligrams per kilogram) which was administered through an implanted minipump for 28 days to mice aged two months (young), 12 months, (mature), and 18 months (old).

As part of the tests, the scientists conducted three standard tasks for cognition. These included; the Morris water maze test, which assesses spatial memory, an object recognition test, and a partner recognition test. Their examination revealed that the treatment led to an impaired performance in the sample of young mice, yet reduced performance deficits in mature and older mice, in comparison to mice that did not receive the drug.

The team found gene expression changes in the hippocampus of the mice, four weeks after cessation of the THC treatment. “It seems that the young brain becomes old and the old brain becomes young,” co-author Andras Bilkei-Gorzo, of the Institute of Molecular Psychiatry at the University of Bonn in Germany, told The Scientist. “At first sight it was totally illogical, but I realized when we gave the same drug to a young [animal], it overdrives the cannabinoid system—it’s [non-typical] hyperactivity and they have to bear the consequences. [But] in the old, the same treatment normalizes pathological low activity.”

So far, it is unknown how the effect of THC will translate into humans, but the team is already planning to see whether THC administration to older humans may improve their cognition as well.

https://goo.gl/Yg9Yim

11 May: Study reveals distinct roles for two structurally-similar Tau proteins in the adult brain

In a study published in the journal Neurobiology of Disease on 11 May, researchers from the University of Southampton, UK, University of Plymouth, UK, and the Alexander Fleming Biomedical Sciences Research Center, Greece, described two types of Tau proteins in the adult brain, which play distinct roles in the development of dementia.

Tau is a critical protein for stabilising microtubules that are very important in a number of cellular processes. Abnormal Tau proteins are well associated with brain pathologies such as Alzheimer’s disease (AD) and certain forms of dementia. Scientists studied two forms of human Tau in nerve cells of the Drosophila (fruit fly) brain. They reported that both types have different effects. One has been linked to movement and locomotor defects while the other has been linked to greater neurodegeneration and impairments in learning and memory.

The authors underlined that although the six know Tau forms are often regarded as the same protein, they possess different functional properties, which must be considered to interpret all related data correctly.


16 May: Study investigates the propagation of tau pathology among people with AD

The accumulation of the tau protein is described as a major hallmark of Alzheimer’s disease (AD). New research published on 16 May in the journal...
Molecular Psychiatry reported, for the first time, how to measure tau protein spread in the brains of people with AD. Researchers from Karolinska Institutet, Sweden used PET brain imaging and a well-characterised tau-specific tracer, THK5317, to investigate the propagation of tau pathology in adult brains. The study included 16 participants at different AD stages, who were scanned at the start of the study and then again 17 months later. They performed neurological memory tests, brain glucose metabolism measures and PET scans. The findings reported heterogeneous changes in tau accumulation and propagation in the symptomatic stages of AD, in contrast to significant decreases in glucose metabolism among people with AD. In addition, scientists suggested that tau accumulation is linked to episodic memory impairment while changes in brain glucose metabolism were related to both overall cognitive decline and episodic memory impairment.

“Our results can improve understanding of tau accumulation in Alzheimer’s disease, help ongoing research to quantify the effect of tau vaccines, and enable early diagnosis”, the study’s senior author Professor Nordberg commented. https://www.nature.com/mp/journal/vaop/ncurrent/full/mp2017108a.html

23 May: United Neurosciences announces positive results for its experimental AD Vaccine Phase 1 study

The biotechnology company United Neurosciences develops novel therapies to treat Alzheimer’s disease (AD) and other neurological disorders. On 23 May, the company announced results for its vaccine UB-311 Phase 1 trial. UB-311 is a novel synthetic peptide vaccine targeting beta-amyloid (Aβ), a peptide crucially involved in AD. Previous experiments in AD mouse models demonstrated that UB-311 reduced the levels of Aβ in some brain regions. In the Phase 1 study conducted in Taiwan, 19 participants with mild to moderate AD received 3 doses of UB-311 at 0, 4 and 12 weeks. After 48 weeks, the vaccine was shown to be safe and well tolerated. Data revealed that UB-311 induced a high response rate and strong anti-Aβ antibody titers in all participants. In addition, UB-311 may have a cognition improvement in mild AD participants. These findings were published online in the journal Alzheimer’s Dementia: Translational Research & Clinical Interventions. United Neuroscience reported that an ongoing Phase 2 trial was initiated to evaluate the safety, tolerability, immunogenicity and efficacy of UB-311 in mild AD participants. Results are expected in mid-2018.


26 May: Scientists reveal link between NPTX2 protein and cognitive decline in AD

In a recent study published in the journal eLife, scientists from the Johns Hopkins University School of Medicine, US, identified that low levels of NPTX2 in the brain is linked to cognitive decline in Alzheimer’s disease (AD). NPTX2 is a memory protein expressed by pyramidal neurons and involved in excitatory synapse formation. In the published study, researchers noticed that NPTX2 was reduced in brain of people with AD. Using a mouse model deficient in NPTX2, they demonstrated that NPTX2 was also correlated with the size of the hippocampus, which is the brain region responsible for memory. Scientists showed that NPTX2 expression was linked to cognitive performance because its downregulation led to learning and memory loss that are both hallmarks of AD.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5404919/

LIVING WITH DEMENTIA

Carol Hargreaves, member of the EWGPWD, updates us on her situation

Hi everyone, thought I would let you all know how my life is going. I had to go for an MRI at the end of last year as things weren’t going well with me. Anyway, although I knew it, I was told it had advanced, but the difference in me is I didn’t react. I have just learnt to be more alert and careful. My wee mum is 87 and struggling with life. All her family are gone and she had 9 siblings. It’s very hard on my sister and myself - we do our best. Mum is very stubborn and won’t accept any outside help, so it can be draining. We think she is getting a bit confused herself. I must say our cousins are great they visit a lot, although she’s like a different person with them. She wants myself and Margaret to be there all the time - my sis works full time and I am very much invoked with SDWG (Scottish dementia working group) so it can be difficult.

It was my 60th birthday on Tuesday and my family took me away to celebrate -it was fantastic!

As for our recent EWGPWD meeting in Luxembourg, I hope everything we discussed will be put into action. We worked very hard and agreed with so much. The workshops were amazing. May I also mention my step daughter Jayne, as she added so many good suggestions and had a group of us doing gentle excises before breakfast, which we all enjoyed and it gave us a pleasant start to another busy day.
Always great to meet up with everyone. I feel we’re getting very close to each other and that makes it easier to speak, learn and also be friends that understand each other.

That is my life up until now bye everyone take care and don’t stop people for illnesses that they can’t seem to get out of.

Ronan Smith, Chair of the Irish Dementia Working Group, advocates for people with dementia and for carers in equal measure

This current period following my own diagnosis in 2014 is in fact my second experience of being an advocate for those whose lives are affected by Alzheimer’s disease. In the 1980s I was a carer for my father who died from the condition in 1989. Awareness and understanding were very limited at this time, and as my father had a certain public profile, I involved myself in active advocacy to remedy this (media contributions -press, radio, TV). I also joined the then-entirely-volunteer committee to help the process of professionalising The Alzheimer Society of Ireland. I retired from the committee after 4 years having seen in the appointment of the first full-time salaried Director.

My second engagement with the Alzheimer’s Society of Ireland followed my own diagnosis of early on-set dementia in 2014, confirmed by genetic analysis as Familial Alzheimer’s Disease. I have just recently been appointed the Chair of the Irish Dementia Working Group, continuing to advocate actively for, and promote the interests of, people living with dementia and carers.

I believe that the voice of the person and the carer must be heard and given weight, and must then be entered into the deliberations regarding social policy and care provision.

I am committed and passionate in my belief that much can be done to support the role of people with dementia in policy development and promoting public understanding of the condition. I have taken on responsible roles in a variety of organisations during my working life and would like now to commit my time and energy to this important work in the role of Chair of the Irish Dementia Working Group.

Alv Orheim, Vice-Chair of the EWGPWD, writes “Brief observations from the Norwegian working group”

The group was established in 2014, and I attended my first meeting in May of that year. Since then we have grown to 8 members. We meet 4 times a year in Oslo, at the headquarters of the National Health Organisation.

Among our most important contributions have been input to our second national dementia strategy, which was adopted in December 2015. People affected by dementia, both within the national working group and beyond, were involved in formulating the strategy.

Our current topics touch on much the same issues as we see in the EWGPWD. E.g. at our last meeting, May 8th, we gave the final comments to a revised national booklet on dementia, and we offered input to a project identifying areas that should be considered in city and environment planning making our surroundings more dementia friendly.

We also gave input to a project to make hospitals more dementia friendly.

The group was presented with a new picture book, designed to evoke memories and to promote conversation and social interaction. The book may be used in both private homes and institutions.

DEMENTIA IN SOCIETY

15 May: Paola Barbarino joins Alzheimer’s Disease International as CEO

Paola Barbarino has been appointed as the new CEO of Alzheimer’s Disease International (ADI), after assuming the position on the 15 May 2017. Marc Wortmann, former Executive Director of ADI, will continue to assist her in this role during a transition period from May to July 2017.

Ms Barbarino said "I am delighted to be joining ADI at this key juncture in the organisation’s history. I look forward to working with the Board and ADI’s membership to achieve our vision of prevention, care and inclusion today, and cure tomorrow.”

Mr Wortmann is leaving his position after more than ten years as the executive director of ADI, including leading successful advocacy for global action on dementia by the World Health Organisation (WHO) and United Nations (UN).

Prior to her start at ADI, Ms Barbarino was the Managing Director of Opaline Limited, a consultancy company specialising in strategy and governance. Until September 2016 she was the CEO of LIFE, a London-based membership organisation gathering Lebanese financiers in the diaspora, running an educational charity and supporting an enterprise-promoting NGO. At LIFE, she trebled the size and reach of the organisation over the course of her tenure.

She joined LIFE from Cass Business School, where she was the Director of Development & External Relations. She is a Trustee
of The Postal Museum and Lauderdale House and was previously a Trustee of Shelter, the UK housing and homelessness charity and of MLA London. She holds a degree cum laude in Classics from the University of Napoli Federico II, an MA in Field and Analytical Techniques in Archaeology and an MA in Library and Information Science both from University College London. As well as English and Italian, Ms Barbarino is fluent in French and has a working knowledge of Spanish and German.

28 May: Much-loved UK children’s TV presenter John Noakes dies with Alzheimer’s dementia

On 28 May, British television presenter John Noakes passed away at the age of 83, following a long battle with Alzheimer’s dementia. Mr Noakes shot to fame in the 1960s as the much-loved host of BBC One children’s show “Blue Peter”, becoming the show’s longest-serving presenter after remaining throughout the 70s and 80s.

In a statement, his family said: “John Noakes, died peacefully on Sunday morning May 28th...whilst he will be greatly missed by his wife, family and many friends his release from continuing ill health must be counted as a blessing.”

Mr Noakes was famous for his many escapades with faithful companion, Shep, the Blue Peter dog (pictured, with the presenter), entertaining children all over the UK as he tried to keep the mischievous Shep in line, with his unofficial catchphrase: “Get down, Shep!”


27 April: Brochure on dementia-related sensory disorders published in France

France Alzheimer has published a brochure on sensory disorders related to dementia, with input from professionals in the medical and social sectors and the Fondation Médéric Alzheimer.

Download the brochure on sensory disorders (in French) here: http://www.francealzheimer.org/sites/default/files/Brochure%20troubles%20sensoriels_BD.pdf

NEW PUBLICATIONS AND RESOURCES

19 April: UK video series shows what it is like to take part in clinical research

Want to know what taking part in research is like? You can now watch a series of videos on some of the procedures involved in clinical dementia studies, including lumbar puncture (spinal tap) and magnetic resonance imaging (MRI) scan. The series of five videos follows three individuals, Gary, Eva and Martin as they undergo assessments that are common in dementia research studies. It was created by the Alzheimer’s Society (UK).

https://goo.gl/qMygZl

29 May: Leeds Beckett University seeks Reader in Dementia Research

Leeds Beckett University has a growing portfolio of internationally recognised applied dementia research and has recently created a formal Centre for Dementia Research to support and develop research in this area across all University Schools.

The Centre is seeking to appoint a Reader to join the core dementia team, who are located in the School of Health and Community Studies. The post holder will work alongside the Centre for Dementia Research Director/Professor of Dementia Studies and two Research Fellows as well as fostering research collaborations across the Institution.

To be considered for interview applicants are required to have a PhD in an area related to dementia and a significant and sustained track record of high quality dementia related research publications and grant capture.

For an informal discussion about this post, please contact Claire Surr, Professor of Dementia Studies c.a.surr@leedsbeckett.ac.uk

Further details about the post, role specification and how to apply can be found at the following link: http://bit.ly/2r0cM4Q

27th Alzheimer Europe Conference
Contact Alzheimer Europe:
Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org, www.alzheimer-europe.org

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AE CALENDAR

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<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>2 June</td>
<td>Annual Alzheimer Scotland Conference 2017 (Edinburgh, Scotland),</td>
<td>Jean</td>
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<tr>
<td>7 June</td>
<td>European Parliament Lunch meeting with Sirpa Pietikäinen MEP and Kanta-Hämeen Muistikyhistyyny (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>7 June</td>
<td>“The inclusion of persons with disabilities in the implementation of the Sustainable Development Goals by the European Union” European Parliament Disability Intergroup (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>9 June</td>
<td>6th NILVAD General Assembly Meeting (Dublin, Ireland)</td>
<td>Jean</td>
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<tr>
<td>9 June</td>
<td>European Commission ‘Health Research in a Connected and Participative Society’ (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>12-13 June</td>
<td>3rd ROADMAP General Assembly Meeting (Barcelona, Spain)</td>
<td>Jean, Dianne and Chris</td>
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<tr>
<td>14 June</td>
<td>EPF Policy Advisory Group (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>17 June</td>
<td>Future day at the University of Vechta (Vechta, Germany)</td>
<td>Chris</td>
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<tr>
<td>19-20 June</td>
<td>HTAI Conference (Rome, Italy)</td>
<td>Jean</td>
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<tr>
<td>21 June</td>
<td>JPND Workshop on Public Health in Neurodegenerative Disease (Paris, France)</td>
<td>Ana</td>
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<tr>
<td>26-27 June</td>
<td>AE Board (Brussels, Belgium)</td>
<td>AE Board and staff</td>
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<tr>
<td>27 June</td>
<td>Lunch Debate and Company round table meeting (Brussels, Belgium)</td>
<td>AE Board, members, staff and sponsors.</td>
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<tr>
<td>28 June</td>
<td>AE Public Affairs meeting</td>
<td>AE Board and staff</td>
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<tr>
<td>30 June</td>
<td>EFPIA Think Tank Meeting (Brussels, Belgium)</td>
<td>Vanessa</td>
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CONFERENCES

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>2 June</td>
<td>Alzheimer Scotland Annual Conference, <a href="http://www.alzscot.org/training_and_conferences/conferences">http://www.alzscot.org/training_and_conferences/conferences</a></td>
<td>Edinburgh, UK</td>
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<tr>
<td>4-8 June</td>
<td>21st International Congress of Parkinson’s Disease and Movement Disorders (MDS), <a href="http://www.mdscongress2017.org/Congress-2017.htm">http://www.mdscongress2017.org/Congress-2017.htm</a></td>
<td>Vancouver, Canada</td>
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<tr>
<td>8-11 June</td>
<td>93rd Annual Meeting of the American Association of Neuropathologists (AANP), <a href="https://aapn.memberclicks.net/meetings">https://aapn.memberclicks.net/meetings</a></td>
<td>California, USA</td>
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<tr>
<td>24-27 June</td>
<td>3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a></td>
<td>Amsterdam, Netherlands</td>
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<td>27 June</td>
<td>Arts, dance, music and dementia: from Professional Practice to Social Prescription, <a href="http://www.creativedementia.org">www.creativedementia.org</a></td>
<td>Sheffield, UK</td>
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<tr>
<td>16-20 July</td>
<td>Alzheimer’s Association International Conference (AAIC), <a href="https://www.alz.org/aaic/">https://www.alz.org/aaic/</a></td>
<td>London, UK</td>
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<tr>
<td>23-27 July</td>
<td>World Congress of Gerontology and Geriatrics (IAGG), <a href="https://www.iagg2017.org">https://www.iagg2017.org</a></td>
<td>San Francisco, USA</td>
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<tr>
<td>26 July</td>
<td>The First Montessori Aging &amp; Dementia Symposium Prague 2017, <a href="http://agingsymposium.com/">http://agingsymposium.com/</a></td>
<td>Prague, Czech Republic</td>
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<tr>
<td>11-12 September</td>
<td>18th International Conference on Alzheimer’s Drug Discovery, <a href="http://neurochemistry.org/adtf18d">http://neurochemistry.org/adtf18d</a></td>
<td>New Jersey, USA</td>
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<td>17 September</td>
<td>Innovations and state of the art in dementia research, <a href="http://alzheimers-dementia.org/">http://alzheimers-dementia.org/</a></td>
<td>Rome, Italy</td>
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<tr>
<td>16-18 October</td>
<td>9th International Conference on Alzheimer’s Disease &amp; Dementia, <a href="http://alzheimers-dementia.conferenceseries.com/">http://alzheimers-dementia.conferenceseries.com/</a></td>
<td>Rome, Italy</td>
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<tr>
<td>15-16 February 2018</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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<tr>
<td>1-3 March 2018</td>
<td>Nutrition and maintaining functions with aging (IANA 2018)</td>
<td>Miami, USA</td>
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<tr>
<td>15-18 March 2018</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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<tr>
<td>22-25 March 2018</td>
<td>12th World Congress on Controversies in Neurology (CONy)</td>
<td>Warsaw, Poland</td>
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<tr>
<td>3-6 October 2018</td>
<td>Croatian Congress on Alzheimer’s Disease with International participation, CROCAD-18</td>
<td>Novigrad, Croatia</td>
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27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017

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

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