ALZHEIMER EUROPE
NEWSLETTER

WELCOME

A warm welcome to the last Alzheimer Europe newsletter before the summer holidays.

As every year, June has been a particularly busy period and in this newsletter we report on a number of meetings which Alzheimer Europe conducted in Brussels at the end of the month: our Board meeting, our company round table meeting, a meeting with the public affairs representatives of our national organisations, our European Working Group of People with Dementia and our lunch debate in the European Parliament dedicated to dementia care in the European Union.

I am particularly proud of a truly impressive piece of research which Alzheimer Europe conducted together with Bangor University and our national members from the Czech Republic, Italy, Finland, the Netherlands and Scotland, UK. Our five-country carers’ survey provided some remarkable insights into the existing barriers which prevent people with dementia from getting a timely diagnosis.

Some of the statistics are very disappointing as carers reported an average of 2.1 years between noticing symptoms and receiving a diagnosis. Not surprisingly, 47% of carers would have preferred the diagnosis to have been made earlier. Additional information on the survey is included in this month’s newsletter and in the special report which we published and which can be bought in our e-shop. My thanks go to Professor Bob Woods from Bangor University who provided the academic lead on this survey and presented the results at our lunch debate in the European Parliament. Special thanks also go to Roche who provided us with the educational grant which made this research possible.

At its June meeting, the Alzheimer Europe Board also gave its full support to the campaign of our French colleagues calling for the continued reimbursement of Alzheimer’s medicines and you can find our full position in this newsletter.

On the positive side, I am delighted to report that Portugal just announced the launch of its national dementia strategy. Big congratulations are due to our colleagues from Alzheimer Portugal for their successful campaign in making dementia a national priority.

We also report on the progress of our European projects such as EPAD, PARADIGM and ROADMAP and our colleagues from the 2nd Joint Action on Dementia also provide an update on their activities.

As we are going to press, I am happy to report that we are already close to 500 registrations for our Annual Conference in Barcelona in October.

I hope you enjoy reading our newsletter packed with news from our members and research updates. Our next newsletter will come out in early September after the summer break.

Jean Georges
Executive Director
18 May: AE working group meets in Bradford to discuss dementia and minority ethnic groups

Alzheimer Europe has set up a working group to improve the situation of people with dementia, their supporters and professional carers from minority ethnic groups through the identification and promotion of inter-cultural/culture sensitive care, support and services. The group met for the first time in Bradford in the United Kingdom on 18 May. AE would like to thank the University of Bradford for kindly hosting this meeting. We would also like to thank the European Commission and the Robert Bosch Stiftung for funding this project.

The group has experience working with people with dementia from several minority ethnic groups covering many different languages, religions and cultural traditions. Members of the group have expertise in connection with minority ethnic groups in the fields of service provision, screening and diagnosis, advocacy, informal care and linguistics. Members of the European Working Group of People with Dementia (EWGPWD) and representatives of Alzheimer Europe’s member associations have also been involved in the project, sharing their knowledge, experience, contacts and information about good practices (during two meetings held in March and February, respectively). Feedback about this work from people with dementia and informal carers from minority ethnic groups will also be sought through the intermediary of some of the members of the working group and Alzheimer Europe’s member associations.

A number of issues have already been identified in the literature review. These include, amongst others, the need for culture-sensitive screening and diagnostic tools, different perceptions of dementia and attitudes towards help seeking, familialism and filial responsibility, gender issues, lack of trust in health and social care providers, stereotyping by health and social care professionals, difficulties linked to interpretation in the context of diagnosis and care, and stigma, especially surrounding the provision of care from outside the family.

A second meeting is planned in August at which members of the working group will discuss the literature review and preparations for the first draft report. The first findings of the project will be presented and discussed with member associations and members of the EWGPWD at the AGM in Barcelona in October. The results of the project will include a report and guidelines, mainly targeted at policy makers, service providers and health and social care professionals, as well as a database with information and links to good practices and initiatives.

Members of the working group, who can be seen on the photo, include: From left to right on the back row: Akhlak Rauf (UK), Siiri Jaakson (FIN), Michal Herz (UK/ISR), Daphna Golan Shemesh (ISR), Thomas Rune Nielsen (DK), Dianne Gove (LU) and Sahdia Parveen (UK). From left to right on the front row: Charlotta Plejert (SWE), Ripaljeet Kaur (UK) and Carolien Smits (NL). Jean Georges is not in the photo (as he took it).

15 June: Alzheimer Europe says farewell to policy officer Vanessa Challinor

On 15 June, Vanessa Challinor left Alzheimer Europe as the organisation’s policy officer. She had been working for Alzheimer Europe since 15 August 2015 and been coordinating the European and public affairs of the organisation.

In her position, she successfully developed the European Alzheimer’s Alliance comprised of Members of the European Parliament supporting the campaign of Alzheimer Europe to make dementia a European priority, edited the organisation’s Dementia in Europe Magazine, represented Alzheimer Europe with our sister organisations such as the European Patients’ Forum and European Disability Forum. She decided to leave Alzheimer Europe for family reasons and the whole team wishes her well in her future endeavours and adventures. She will be replaced by Owen Miller who will take up his position as the new policy officer of Alzheimer Europe on 1 August.

18 June: Alzheimer Europe and European Academy of Neurology discuss future collaboration

In the framework of the conference of the European Academy of Neurology (EAN) in Lisbon, Iva Holmerová, Chairperson and Jean Georges, Executive Director of Alzheimer Europe met with EAN representatives to discuss the future collaboration between the two organisations.

The Alzheimer Europe representatives participated in the EAN Dementia Panel and had, earlier in the month, attended the task force for the development of the EAN guideline on medical management issues in dementia.
Alzheimer Europe also met with an EAN delegation comprised of EAN President, Günther Deutschl, EAN Treasurer, Marianne de Visser, Dementia Panel co-chairs Jakub Hort and Reinhold Schmidt and EAN office representatives Julia Mayer and Kalliopi Christoforidis.

During the very productive meeting, the representatives of the two organisations updated each other on their respective priorities and explored areas for mutual collaboration, such as the development of guidelines, advocacy for greater investment in brain research at EU level and the organisation of joint events during the Annual Conferences of both associations.

19 June: Alzheimer Europe receives operating grant from EU health programme for its 2018 activities

On 19 June, Alzheimer Europe was informed by the European Commission that its request for core funding under the EU health programme had been successful. For its 2018 activities, Alzheimer Europe will receive an operating grant of EUR 472,785 which will support the five strategic objectives of the organisation. In particular, Alzheimer Europe will be able to organise the meetings of its European Working Group of People with Dementia, develop a report on the needs of people with dementia, carers and professional carers from ethnic minorities, dedicate its 2018 Yearbook to a comparison of national dementia strategies, organise its 28th Annual Conference in Barcelona under the motto “Making dementia a European priority” and involve its national member organisations in capacity-building workshops of the Alzheimer’s Association Academy.

20 June: Article on meaningful outcomes for people with dementia is published

The article, which was published in June in the Journal “Health Expectations”, highlights the need for outcome measures in dementia research which truly reflect what is meaningful to people living with the condition. Based on this premise, researchers from INTERDEM and Alzheimer Europe conducted a series of consultations with people with dementia in four different countries. The members of the European Working Group of People with Dementia participated in one of these consultations. The other consultations were held in Denmark, Italy and the UK. The consultations focused on “what people with dementia consider to be meaningful approaches to capture the essence of psychosocial interventions through research”.

A main conclusion of this work was that any activities and psychosocial interventions for people with dementia should, in addition to considering health in a broad sense, also focus on enhancing dignity through social engagement and reciprocal contribution to society, and should take into consideration individual needs, preferences and rights. The authors explained that “these values are embedded in concepts of social health and positive psychology, which are emerging within the field of psychosocial interventions for people with dementia”. Two staff members from AE were actively involved in this work and are co-authors of the paper. The article has been published as open access and can be downloaded at: https://onlinelibrary.wiley.com/doi/epdf/10.1111/hex.12799

21 June: Alzheimer Europe publishes new issue of Dementia in Europe magazine


In this issue, AE presents its most recent lunch debate at the European Parliament, revolving around the question if we will be able to prevent Alzheimer’s dementia as well as the potential for interventions, including comments from MEPs Deirdre Clune (Ireland) and Rory Palmer (United Kingdom).

We also present our involvement in two innovative projects in Europe and beyond. PRODEMOS is a new collaborative aiming to prevent dementia using mobile phone applications targeting socio-economically deprived populations in the EU and a population at risk of dementia in China. Further, we introduce you to the recently finalised five-year EMIF project, which lived up to its ambition of providing and enabling access to an unprecedented volume of healthcare data leaving a legacy that accelerates research in Alzheimer’s disease.

On a national level, Cabinet Secretary for Health and Social Services, Vaughan Gething talks about the new Dementia Action Plan for Wales aiming to transform dementia care. We also glance at the mid-term achievements of Luxembourg’s national dementia strategy, including a comment from Minister of Health, Lydia Mutsch.

We and our members from the Alzheimer’s Society of Ireland are also pleased to inform you about the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). At European level, MEP Françoise Grossetête discusses the future of the EU Health Programme and MEP Deirdre Clune asks the European Commission in a
written question why the Expert Group on Dementia has been disbanded.

Our members from Alzheimer’s Society UK introduce you to possible implications of Brexit for people with dementia. Further, we look at the effects of the New General Data Protection Regulation (GDPR) on data sharing and potential implications for the Alzheimer’s community.

In the Dementia in Society section, actress Carey Mulligan shares her own personal experiences of dementia and her hopes for the future by being part of the global dementia movement. Croatia and Slovenia present the EU cross border project results of “Demenca aCROsSLO” and Finland’s Memory Activists report on their involvement in the development of palliative and end-of-life care.

Finally, we take a look “behind the headlines” at recent reports on a blood test to diagnose AD with Dr Philip Scheltens.

The Dementia in Europe magazine appears in print twice per year with a circulation of around 3,000-3,500. It is distributed to all the Members of the European Parliament (MEPs) and many high-level decision makers in the European Commission, among others.

You can buy the magazine via our E-shop: http://alzheimer-europe.org/Publications/E-Shop.
Past issues can be freely downloaded here: http://alzheimer-europe.org/Publications/Dementia-in-Europe-magazines

26 June: Alzheimer Europe Board meets in Brussels

The Alzheimer Europe Board members convened in Brussels on 25-26 June. The meeting agenda included various financial and operational matters, including preparations for the 28th Alzheimer Europe Conference, which will be held in Barcelona, Spain from 29 to 31 October 2018 and the progress of the organisation’s 2018 Work Plan including the report on intercultural care and the Yearbook on national dementia strategies.

The Board also discussed a number of recent policy developments such as the Commission’s decision to disband the European expert group on dementia or the decision of the French authorities to discontinue the reimbursement of anti-Alzheimer medicines (see below for the full press release on this subject).

Finally, the Board agreed on the preparations for the next Annual General Meeting in Barcelona where there will be elections to the Board.

The next Board meeting will take place on 29 October in Barcelona and will be followed by AE’s Annual General Meeting.

26 June: Alzheimer Europe calls on French health authorities to continue reimbursing anti-Alzheimer’s medicines

Brussels, 26 June 2018 – At its meeting of 26 June 2018, the Alzheimer Europe Board condemned the recent decision of the French government to exclude current medicines licensed for the treatment of Alzheimer’s disease from the reimbursement system.

The organisation also expressed grave concerns about the sensationalist and scientifically baseless media coverage in some media claiming that these drugs “killed more people than they ever helped”.

Whilst recognising that these medicines “only” provide symptomatic relief for a group of patients for limited periods, Alzheimer Europe reiterated its position for the continued reimbursement of these drugs:

- Enough clinical evidence exists to support their use since clinical trials have shown them to be effective not only in improving memory, but also for beneficial effects on behaviour, activities of daily living and well-being. Subsequent meta-analyses and Cochrane reviews have all confirmed this efficacy.
- This clinical data on the effectiveness of anti-Alzheimer drugs is supported by testimonies of great numbers of people living with the condition and their carers.
- All clinical guidelines such as the European Federation of Neurological Societies (EFNS) Guideline for the diagnosis and management of Alzheimer’s disease support the use of these medicines.
- No significant safety issues have been identified through the pharmacovigilance system of the European Medicines Agency.
- The existence of these medicines has contributed to the development of dementia care through an expansion of memory clinics and other specialised services offering timely diagnosis, advice and support for people with dementia and their carers.
- The discontinued prescription of these medicines would take away one of the main reasons for people coming forward for an early diagnosis of their condition who would therefore no longer benefit from other significant advantages of an early diagnosis.
- European citizens should have equal rights to protection and access to health care regardless of their country of residence and Alzheimer Europe regrets that people with Alzheimer’s disease in France are excluded from accessing medicines reimbursed in other European countries.

Therefore, Alzheimer Europe and its member organisations fully support the campaign and on-line petition of France Alzheimer which calls for the continued reimbursement of these medicines.
The full position of Alzheimer Europe on the reimbursement of anti-Alzheimer medicines can be found here: https://www.alzheimer-europe.org/Policy-in-Practice2/Our-opinion-on/Anti-dementia-drugs

26 June: Alzheimer Europe organises lunch debate on “Dementia Care in the European Union”

Alzheimer Europe and the European Alzheimer’s Alliance organised a lunch debate in the European Parliament which was hosted by MEPs Olga Sehnalová (Czech Republic) and Sirpa Pietikäinen (Finland).

The lunch debate was dedicated to “Dementia care in the European Union” and was opened by MEP Olga Sehnalová who welcomed over 70 delegates from national Alzheimer’s associations including the members of the European Working Group of People with Dementia and representatives from different EU institutions, organisations and companies.

Mario Possenti, the General Secretary of Federazione Alzheimer Italia highlighted the personal impact that a diagnosis of Alzheimer’s disease has on family members and carers on an emotional level (feelings of stress, depression, fear and anger), but also on a physical, social and economic level. He stressed the need for greater information, training and support for informal carers in order to break the social isolation experienced by many of them.

Professor Bob Woods from Bangor University presented the results of Alzheimer Europe’s carers’ survey in five European countries (see below for full details on the survey results).

Sarah Schinazi from DG EMPL of the European Commission then gave a presentation on how the European Union can support carers. She highlighted the work of the European Pillar of Social Rights and the Work-Life Balance Initiative which would propose a right to carers’ leave of 5 days per year and a right to request reduced and flexible working hours for carers.

During the ensuing discussions, Nessa Childers, MEP (Ireland) questioned how the European Union could support a greater gender balance when it comes to people caring for dependent elderly as she was particularly struck that over 80% of the respondents of the carers’ survey had been women.
26 June: New Alzheimer Europe survey highlights significant barriers to timely diagnosis of dementia and access to post-diagnostic support across five European countries

On 26 June, Alzheimer Europe presented a report at a lunch debate hosted by MEPs Olga Sehnalová (Czech Republic) and Sirpa Pietikäinen (Finland) in the European Parliament, Alzheimer Europe highlighted significant barriers to timely diagnosis across Europe.

The findings of the five-country study were presented by the academic lead of the research Prof Bob Woods (Bangor University, Wales, UK).

- Carers reported significant delays in diagnosis as it took an average of 2.1 years to receive the diagnosis (ranging from 1.6 years in the Czech Republic and Italy to 2.5 years in Scotland). A quarter of the people with dementia had been diagnosed with another condition prior to dementia.

- At the time of diagnosis, around half of people were at the mild stage of dementia (53%), a third at moderate (36%) and 4% at severe stage. Almost half of the carers (47%) felt that the diagnosis would have been better earlier (ranging from 36.5% in the Netherlands to 52.1% in Italy).

- Amongst the key identified barriers to earlier diagnosis, carers reported the first professional saw not considering that anything was wrong (33%) or believing it was not worth pursuing a diagnosis (6.6%) and the refusal of the person with dementia to seek help (37.9%).

- Overall, one in five people with dementia were not informed of their diagnosis. Important differences exist in this respect across countries. In Finland, Scotland and the Netherlands almost every single person with dementia had been informed of their diagnosis (98.9%, 95.6% and 91.8% respectively), whereas in the Czech Republic and in Italy, several people with dementia had not been told about it (23.3 % and 59.3% respectively).

- Post-diagnostic support is still a major issue across Europe. 19% of the carers and 27.9% of people with dementia did not receive any information at the time of diagnosis. The need for information on coping and living well with dementia and on available services was particularly high (51.1% and 46% respectively). Carers in Finland and in the Netherlands were overall the most satisfied with the information received. Carers in Italy were less happy for all types of information received.

- The services which carers were most often offered at the time of diagnosis included a contact with a named person or service who could assist them in signposting services or whom they could contact as needed (20.9%), day care (19.2%) and dementia cafes (18.7%). Several carers did not have access to an assessment of their own needs (50.9%), a care plan for the person with dementia (44.6%), and counselling services (44.6%), but would have liked to have used these services.

Olga Sehnalová, MEP (Czech Republic) welcomed the survey findings: “As a Member of the European Parliament and the European Alzheimer’s Alliance, I am interested in how European countries differ in their approaches to dementia. Despite the growing recognition of dementia as a public health priority and the development of national dementia strategies, the Alzheimer Europe survey highlighted that important barriers to timely diagnosis continue to exist. Although in the Czech Republic, the time to diagnosis is relatively short compared to other countries, we cannot consider it a success that it takes more than one year and half. I hope that EU initiatives such as the EU Joint Action on Dementia will identify good practices and make recommendations on how to improve timely diagnosis and post-diagnostic support across all European countries.”

Sirpa Pietikäinen, MEP (Finland) and Vice-Chairperson of the European Alzheimer’s Alliance stressed: “I was delighted to see that people with dementia in Finland were systematically informed about their diagnosis and included in care planning decisions. Despite this, the delays before receiving a formal diagnosis on dementia remain significant. Across Europe, we need to continue to invest in awareness raising campaigns of the general public, medical training of general practitioners and specialists and address some of the system delays when it comes to referrals and access to diagnostic services.”

The full report “European Carers’ Report 2018: Carers’ experiences of diagnosis in five European countries can be bought online from Alzheimer Europe at EURO 5.20 here.

26 June: Alzheimer Europe meets with its corporate sponsors

On 26 June, Alzheimer Europe organised one of its regular company round table meetings bringing together the Alzheimer Europe Board with representatives of the organisation’s corporate sponsors and national member organisations.

During the meeting, Cindy Birck, AE Project Officer updated the participants about recent clinical trial developments and gave an update on the organisation’s Clinical Trial Watch programme which provides information on phase III clinical trials conducted in Europe in an easy-to-understand language.

Additional presentations were made by André Trottier from Roche on the new NIA-AA diagnostic research criteria for

After the meeting, Essity and Alzheimer Europe co-organised a workshop on the important subject of incontinence and good continence care.

**27 June: Alzheimer Europe organises Public Affairs meeting**

On 27 June, Alzheimer Europe (AE) organised a Public Affairs meeting in Brussels. 18 representatives from AE member organisations and, 4 AE staff members were in attendance. AE Executive Director Jean Georges led the meeting.

The full day meeting was dedicated to:

- A presentation of the PARADIGM project and Alzheimer Europe’s involvement in it (presented by Nicola Bedlington, Secretary General of the European Patients’ Forum and Ana Diaz from Alzheimer Europe)
- Campaigning opportunities provided by national and European elections with examples from Finland, Ireland and the Netherlands and a discussion on Alzheimer Europe’s campaign for the 2019 EP elections
- An overview of recent EU and international policy developments
- A discussion of the development and evaluation of national dementia strategies in Italy, Malta and Scotland, UK and AE’s 2018 Yearbook on national dementia strategies.

The next Public Affairs meeting will take place in Brussels on 4 December.

**Alzheimer Europe Networking**

On 5 June (Brussels, Belgium), Dianne and Ana attended a PARADIGM WP1 meeting.

On 5 and 6 June (Vienna, Austria), Jean participated in the European Academy of Neurology (EAN) task force for the guideline on the medical management of dementia.

On 14 June (Esch/Belval, Luxembourg), Jean participated in the Expert Advisory Board of the CLINNOVA project.

On 18 June (Lisbon, Portugal), Iva and Jean participated in the Dementia Panel of the European Academy of Neurology.

On 21 June (Luxembourg, Luxembourg), Jean and Dianne met with Nicole Huige from Essity.

On 25 and 26 June (Brussels, Belgium), the Alzheimer Europe Board met.


From 26 to 28 June (Brussels, Belgium), AE organised a meeting of its European Working Group of People with Dementia.

On 26 June (Brussels, Belgium), AE organised a company round table meeting with AE members and sponsors.

On 26 June (Brussels, Belgium), Alzheimer Europe and Essity organised a meeting on incontinence and continence care.

On 27 June (Brussels, Belgium), AE organised a public affairs meeting with its national member organisations.

**EU PROJECTS**

1 June: EPAD Longitudinal Cohort Study marks best month to date for recruitment of research participants

The European Prevention of Alzheimer’s Dementia (EPAD) consortium is delighted to announce that 75 new research participants were enrolled in the EPAD Longitudinal Cohort Study (LCS) in May. This made May its most successful month to date as it continued the positive trend in recruitment of research participants by exceeding the 73 research participants enrolled in April and the 66 in March.

Congratulations are due to BBRC (Barcelona, Spain) who screened 11 research participants in May for their inclusion in the EPAD study making it the most successful centre this month. Congratulations for being the most successful trial delivery centre for a second month this year to the team of José Luis Molinuevo (pictured on the left) and his colleagues Laia Tenas, Anna Soteras, Anna Brugulat, Carolina Herrero, Laura Hernández, Oriol Grau, Tania Menchón and Montserrat Vila.

Special mentions this month go to Giovanni Frisoni’s team in Geneva (Switzerland) and Craig Ritchie’s team in Edinburgh (United Kingdom) who recruited 10 and 9 new research participants respectively. In addition, the EPAD family of trial delivery centres grew to 17 sites in May with Manchester and NHS Grampian (UK) both enrolling their first research participants.

The project expects three additional sites to become operational in UK and Italy in the coming weeks. EPAD is also pleased to have reached an exciting milestone with 700 screened research participants in the LCS. The EPAD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736,
resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007-2013) and EFPIA companies’ in kind contribution.

1 June: Survey on patient engagement launched

The IMI-funded project, PARADIGM, has launched a survey about patient engagement in the medicines lifecycle, particularly during the following phases:

- research priority setting
- design of clinical trials
- early discussions with regulators and Health Technology Assessment bodies.

The survey can be completed by different people who may be involved in the process of developing medicines e.g. healthcare professionals, researchers, pharmaceutical companies, regulatory and HTA bodies etc. In addition to these, we would especially like to hear from patients living with different conditions and from many different countries in Europe. The survey is available online, in all different languages of the European Union and will be live until 31 July 2018.

PARADIGM is particularly interested in understanding patient engagement in the process of developing medicines for people with dementia and other potentially vulnerable groups (e.g. children and young people living with a medical condition). If you are a person with dementia, an informal carer, a patient representative or an advocate from an Alzheimer’s association, and have experience in patient engagement in the process of developing medicines, please help us out by completing this survey. Your views are extremely important and will be much appreciated. Thanking you in advance for your support. Link to the survey: imi-paradigm.eu/survey/

Read more about PARADIGM: http://imi-paradigm.eu/

7 June: Great success of the concert organised by the Gerontopole of Toulouse University Hospital for EPAD research participants

The European Prevention of Alzheimer’s Dementia (EPAD) project recruited its first French research participant in September 2016 via the Gerontopole of Toulouse University Hospital. It was the first site to open in France and the fourth in Europe and has currently recruited over 110 participants.

On 7 June, the Gerontopole of Toulouse University Hospital organised a concert honouring Claude Nougaro for the EPAD research participants in Toulouse. It was a great success with more than 200 attendees.

The EPAD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007-2013) and EFPIA companies’ in kind contribution.

8 June: Health Economics team of ROADMAP project publishes third review protocol on economic models across the spectrum of AD and dementia

Since the beginning of 2018, ROADMAP’s Health Economics team published three protocols on the methods for systematic literature reviews they are currently conducting. This work is part of an information gathering and combination process with the purpose to inform a new economic model throughout the whole span of Alzheimer’s disease (AD) and dementia. The model aims to integrate information on disease progression, quality of life and the use of resources. The protocol published on 8 June in BMJ Open, provides information on how the team is identifying, describing and assessing the quality of existing economic models across the full spectrum of dementia including Alzheimer’s disease from apparently healthy respectively preclinical stages through disease progression to end of life care.

22 June: The MinD team is working on the development of their first prototypes to empower and support people with dementia

In June 2018, colleagues from the designing for people with dementia mindful self-empowerment and social engagement (MinD) team have met in Germany. Alexianer St Hedwig Hospital, Berlin, and Technische Universität Dresden, jointly hosted visiting researchers from the UK, Russia and Italy to work on the realisation of the design ideas.

During the two weeks, the designers and programmers worked on the design development of the ‘Good Life Kit’ and the ‘We Connect - Social Engagement Map’. The Social Engagement Map aims to support people with dementia to stay socially connected and engaged, and in control of their social life. The Good Life Kit aims to support people with dementia in managing everyday life confidently. The design concepts had been selected in October 2017 from a shortlist with the help of people with dementia, caregivers and healthcare professionals from Germany, Spain and the UK.

Based on the feedback received from people with dementia on the Social Engagement Map during the previous secondment in the UK, the programmers and designers developed a flow
diagramme of all the parts required. They then worked on the development of the software, both for the visualisation and for the functionality of the prototype.

Based on feedback and discussion with staff from the Alexianer Hospital, the designers and programmers also worked on developing parts of the Good Life Kit. They created the visualisation of the ‘This is me’ game, which allows people to explore their life, starting with reminiscing about the past through to thinking about the future. The design was subsequently presented to a group of people with dementia in the UK, through the Alzheimer’s Society. In the co-design session, people were able to try out the game, and to comment on and help with its design.

**25 June: The ROADMAP project updates on recent progress**

ROADMAP is halfway into its second and final year of the project span and here we give you an outline of recent activities and developments.

The **Management and Coordination** team (WP1), has been providing ongoing support to all partners where necessary. Further, it recently submitted deliverables D1.3 - the initial Knowledge and Management Plan - and D1.4 - the periodic report for the Innovative Medicines Initiative. In addition, it is coordinating the 6th General Assembly Meeting (GAM) which will take place in October.

ROADMAP colleagues from the **Outcome Definition** team (WP2), are preparing a publication on what outcomes are important to people with Mild Cognitive Impairment or Alzheimer’s disease (AD), their carers and healthcare professionals. Further, as an addition to D2.3 the Stakeholder-generated lists of priority real-world evidence (RWE) relevant outcomes for AD, they are working on a supplement entitled: “Priority AD-outcomes from Health Technology Assessment (HTA) and regulatory agencies”. The team is also about to submit a manuscript for publication reporting the findings of their recently completed systematic literature review. Other publications are also in preparation, revolving around outcome prioritisation and meaningful disease progression delay across the AD spectrum. Finally, the team is preparing deliverable D2.4, the Real World Evidence progression marker and outcome classification matrix for AD.

The **Real World Evidence (RWE) identification** team (WP3), have assembled writing teams and started to work on deliverable D3.3: “Update on potential data sources with real-world evidence (RWE) data in Europe”. Also, they are working with the teams from WP4 and WP5 regarding ongoing data requests. Further, they are collaborating with the teams from WP2, WP4, WP5 and WP6 to refine the data cube outcome measure definitions. Fingerprinting of several additional cohort data is ongoing and will contribute to D3.3 and the data cube.

The **Disease Modelling and Simulation** team (WP4), are identifying the people who will be involved in the data analysis for each model validation. Discussions on the challenges in validation are being shared.

The **Health Economics** team (WP5), published a third systematic review protocol in BMJ open:

- Measuring quality of life of people with predementia and dementia and their caregivers
- Resource utilisation and costs in predementia and dementia
- Methodologies and data sources of existing economic models across the full spectrum of Alzheimer’s disease and dementia from apparently healthy through disease progression to end of life care.

The **Regulatory and Health Technology Assessment** (HTA) team (WP6), recently submitted a publication on the main regulatory and HTA considerations for a disease-modifying drug in AD. The next face-to-face Expert Advisory Group (EXAG) meeting will be held on 29th June in Amsterdam (the Netherlands). Lastly, the team also circulated a questionnaire to evaluate the operation and impact of the EXAG, to the ROADMAP Consortium.

The **Communication** team (WP7), circulated the fifth external newsletter. It also added video updates from the GAM to the ROADMAP website’s video section and it is currently working on the sixth external newsletter.

Finally, the **Ethical, Legal, and Social Implications (ELSI)** team (WP8), have recently submitted their paper about the justifications for different kinds of clinical trial data sharing and are collaborating with the Outcome Definition team on a paper about the ethics of outcome prioritisation for Deliverable D8.4. The systematic review on the ethics of predictive modelling for secondary AD prevention is progressing well. The team is also looking forward to meet with the European Working Group for People with Dementia (EWGPWD) on 27 June in Brussels. There, they will discuss concerns raised by sharing health data to create a RWE platform for AD research in an interactive feedback session. Lastly, they are also working on a paper reporting the results of the ELSI focus groups.

Read more about the project.

**25 June: INDUCT project is investigating exergaming in dementia and offered an exceptional opportunity for training at SilverFit**

The Interdisciplinary Network Using Current Technology in Dementia (INDUCT; Marie Skłodowska-Curie project) is a European innovative training network (ITN) aiming to deliver the future leaders in technology and dementia care research
and enterprise. Fifteen Early Stage Researchers (ESRs) are offered

Joeke van der Molen-van Santen (based at the Department of Psychiatry of the Amsterdam University Medical Center, Netherlands), investigates (cost-)effectiveness of exergaming in day care centers for people living with dementia and their (informal) caregivers. The motivation for and the satisfaction with exergaming are also studied and how exergaming can be successfully implemented in dementia day care centers.

Exergaming (exercise & gaming) is an innovative, fun and relatively safe way of exercising in a virtual reality or gaming environment. For instance, bicycling on a home trainer while seeing a route through a village on a big screen (interactive cycling). The faster the person cycles, the faster the movie plays, making it feel as if you’re actually cycling through the village.

Joeke has finished her first secondment at SilverFit, a company developing exergaming equipment for older people with and without dementia. “Being in a different environment (a commercial company) with different colleagues, was an informative and useful experience in itself, learning more about what working in such a company is like. To conclude, the secondment at SilverFit has been enlightening and a great opportunity contributing to one of INDUCT’s most valuable objectives: strengthening the connection between scientific research and enterprise.” said Joeke.

If you are interested to know more, please contact: j.vandermolen@vumc.nl or watch the SilverFit movie about interactive cycling: https://silverfit.com/en/products/silverfit-mile-cycling-with-film

26 June: The EU Joint Act on Dementia project updates on recent progress

The EU Joint Action Act on Dementia has made good progress since the last update for this newsletter. Work packages have all now completed evidence reviews and their reports on diagnosis and post diagnostic support, crisis and care coordination, quality of residential care, and dementia friendly communities can be found at www.actondementia.eu.

The next phase of work is to test best practices in pilot sites across Europe.

The diagnosis and post-diagnostic support work package has published a hierarchised diagnosis strategy, which has been adopted by the French National Authority for Health. The work package is now testing programmes to de-stigmatise dementia in primary care, to trial telemedicine systems, and enhance general practitioner (GP)/nurse cooperation.

On crisis and care coordination, pilot sites are engaged in training GPs and case managers (face to face and by online learning modules) to identify and deal with the signs of stress and distress in patients with dementia. Care co-ordination approaches are being tested in some test site areas to support people before, during and after a diagnosis of dementia, for example through group sessions and one-to-one support.

Testing is also taking place in residential care settings to personalise care, to improve the treatment of stress and distress in people with dementia and to improve care in the last days of life.

Evidence around dementia friendly communities (DFCs) is being tested in a variety of settings - large and small, urban, rural, fledging – as well as mature DFCs with a variety of cultures, economies, and health and social care systems. People with dementia and families as well as caregivers are to be surveyed before during and after testing to measure inclusivity, isolation, stigma amongst others. Further, they will be asked how easy it is to live their daily lives with dementia, including access to travel, shopping, banking, leisure and cultural activity.

The Joint Action has been selected to give an oral presentation at the Alzheimer Europe Conference in Barcelona in October. Meantime, more information can be obtained by accessing the website (see link above) or by e-mailing actondementia@gov.scot.

27-28 June: The PARADIGM project organises a consultation with people with dementia

PARADIGM is a European IMI-funded project, which started in March 2018 and which seeks to improve patient engagement in the medicines lifecycle
Alzheimer Europe is part of this project and its role is to ensure that the voices of people affected by dementia are taken into account in the project. During the meeting of the EWGPWD in June in Brussels, members of the group and their supporters were informed about the project and provided valuable input. Representatives from industry (Sharareh Hosseinzadeh), academia (Suzanne ii) and HTAs bodies (Neil Bertelsen), together with AE representatives, contributed towards this consultation. Participants discussed how to reach out to people with dementia who could be involved in patient engagement, how to address their needs and which outcomes would be important to them when participating at three points of the medicine development lifecycle (i.e. research priority setting, design of clinical trials and early dialogues with HTA bodies). This work is part of the first stage of the project which will help to understand the needs, expectations and aspirations of the different stakeholders involved in patient engagement. The results of the consultation with the EWGPWD will provide meaningful insight into the experiences and perspective of people with dementia in the context of these three areas. Ana, Diianne and Sebastien took part in this consultation.

### Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 126, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

- **Austria**: Heinz K. Becker (EPP); 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 (ALDE); Hilde Vautmans (ALDE).
- **Bulgaria**: Andrey Kovatchev (EPP).
- **Croatia**: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).
- **Cyprus**: Costas Mavrides (S&D); Eleni Theocarous (EPP).
- **Czech Republic**: Olga Sehalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP).
- **Denmark**: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D).
- **Estonia**: Umas Paet (ALDE); **Finland**: Liisa Jaakkonasaari (S&D); Anna Jäättäneenmäki (ALDE); Miepeta Kumpula-Natri (S&D); Merja Kylönen (GUE/NGL); Sirpa Pietikäinen (EPP).
- **France**: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D); **Germany**: Angelika Niebler (EPP); Udo Voigt (NI).
- **Greece**: Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); **Cyprus**: Dimitrios Papadimoulis (GUE/NGL); Ioannis Kousoulis (EPP); Maria Spyridaki (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg-Vrionidi (EPP).
- **Ireland**: Brendan Benfield (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zolfii (S&D).
- **Italy**: Andrey Kovatchev (EPP). **Luxembourg**: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP).
- **Malta**: Roberta Metsola (EPP); Alfred Sant (S&D).
- **Netherlands**: Gerber-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Annie Schreier-Pierik (EPP); Lambert van Nistelrooij (EPP).
- **Poland**: Ewelina Fibak (EPP); Katarzyna Górska (S&D); Tomasz Kołodziej (S&D); Agnieszka Szymon (S&D).
- **Portugal**: Andrey Kovatchev (EPP). **Spain**: Ana Maria Botezatu (S&D); Jordi Girauta (S&D); Juan Manuel López (S&D); **Sweden**: Cecilia Wikström (ALDE).
- **United Kingdom**: Alex Davies-Jones (S&D); Rachel Hinton (S&D); John Mann (S&D); Andrew Dismore (S&D); Catherine Stihler (S&D).
EUROPEAN ALZHEIMER’S ALLIANCE

31 May: MEP Roberta Metsola addresses written question on the use of real-world data for medical research

On 31 May, Roberta Metsola, MEP (Malta) submitted a written parliamentary question on the use of real-world data for medical research. The question can be found here and is reproduced below:

“EU Health Commissioner, Vytenis Andriukaitis, said on 26 January 2018 that ‘big data, in particular, real-world data, holds enormous and obvious potential in the field of medical research’.

The Commissioner also added that ‘regarding the real world data, we will need to further explore the opportunities and limitations of its use for decision making on medicinal products and in the development of new products’. Can the Commission provide more information on what measures will be taken to explore the opportunities and limitations of real-world data for medical research?”

26 June: Members of European Alzheimer’s Alliance attend Alzheimer Europe’s European Parliament lunch debate

Three members of the European Alzheimer’s Alliance, MEPs Sirpa Pietikäinen (Finland), Olga Sehnalová (Czech Republic) and Nessa Childers (Ireland) attended the Alzheimer Europe Lunch debate in the European Parliament on “Dementia Care in the European Union”.

A full report of the event can be read here.

EU DEVELOPMENTS

26 May: European Disability Forum holds its Annual General Assembly

On 26-27 May in Vilnius (Lithuania), the European Disability Forum (EDF) brought together over 150 participants for its Annual General Assembly. The event was co-organised and co-hosted by EDF and the Lithuanian Disability Forum. The event was an opportunity to demand a decent standard of living for all persons with disabilities in Europe. European and national authorities should do more to involve them and the organisations that represent them.

The discussion focused on the implementation of the Web Accessibility Directive, disability assessment, the European Pillar of Social Rights, the future of EU structural funds and the European Accessibility Act. EDF members also met the CRPD Committee rapporteur Stig Langelvad and stressed the need for organisations of persons with disabilities to be fully involved and closely consulted in all spaces of public decision making on an equal basis of others.

A strong call for political participation of persons with disabilities in the European elections was launched. All persons with disabilities should have the right to vote and should be able to vote. EDF President, Yannis Vardakastanis raised the importance for persons with disabilities to have the right to vote and to be able to vote. He stated: “We need to vote. We need to keep the European project in our hands. Persons with disabilities and their families must vote. Candidates with disabilities must stand for election.”

In addition, on 25 May, EDF met Linas Kukuraitis, the Minister for Social Security and Labour, to discuss about the implementation of the UN Convention on the Rights of Persons with Disabilities. “Countries need to ensure proper support for their national disability movement. This is an essential obligation to fully implement of the UN Convention on the Rights of Persons with Disabilities”, said Yannis Vardakastanis.

Alzheimer Europe became a member of the EDF on 1 January 2017.


31 May: MEP Eva Maydell ask written question on EU funding for the translation of scientific findings

On 31 May, Eva Maydell, MEP (Bulgaria) submitted a written parliamentary question on EU funding for the translation of scientific findings. The question can be found here and is reproduced below:

“Many areas of science receive EU funding, from basic scientific research to concrete market-oriented innovation. Increasingly often, these investigations have contributed not only to science, but also to the economy. Many information materials (e.g. Research*EU, European Research Council bulletins and Research Executive Agency bulletins, etc.) are only published in English or in a few other languages.”
What funding possibilities does the Commission provide for the translation into multiple languages (grants for translation, machine translation, etc.) of EU scientific findings, or at least for the most significant such findings?"

6 June: Commissioner Andriukaitis responds to MEP Deirdre Clune’s question about the disbandment of the expert group on dementia

In a Written Question to the Commission, Deirdre Clune, MEP (Ireland) had asked why the Commission had dismantled the Government Expert Group on Dementia and how the Commission would promote the exchange of good practices in the dementia field. In his response of 6 June, EU Health Commissioner Vytenis Andriukaitis highlighted the new role of the Steering Group on Health Promotion, Disease Prevention and Management of non-communicable diseases.

The full answer can be found on http://www.europarl.europa.eu/sides/getAllAnswers.do?reference=E-2018-001919&language=EN and is reproduced below:

“The Commission supports Member States to reach the United Nations’ Sustainable Development Goals including target 3.4 as well as the nine voluntary World Health Organization/United Nations’ voluntary targets on non-communicable diseases. It pursues a horizontal approach to non-communicable diseases instead of addressing individual non-communicable diseases.

The Member States’ Steering Group on Health Promotion, Disease Prevention and Management of non-communicable diseases is a high-level group providing guidance on all non-communicable diseases. It also selects best practices for transfer between countries with the support of the EU Health Programme and other EU instruments. In addition, experts on dementia can continue to exchange information and discuss in a self-coordinated way via the online Health Policy Platform. Member States and other stakeholder can consult and share practices now via the “best practice portal”, launched in April 2018, which will include practices selected under the 2nd joint action on dementia. Practices submitted to the portal which are assessed as “best” will be presented to the Steering Group on Health Promotion, Disease Prevention and Management of non-communicable diseases with the view to transfer between countries.

Following a recommendation from the ALzheimer COoperative Valuation in Europe (ALCOVE) joint action to improve data collection, the Commission is supporting the World Health Organization in preparing a Global Dementia Observatory, a web-based data and knowledge exchange platform of key dementia information.

6 June: AGE Platform Annual Conference takes place in Brussels

On 6 June, the 6th Annual AGE Platform Europe Conference took place in Brussels. The conference was dedicated to the right to self-determination in old age and looked at how, in practice, policies and legislation can better contribute to enabling older people to enjoy their right to live autonomous, independent and dignified lives. The event was attended by AGE members’ representatives and other civil society delegates, researchers and policy makers. Chris Roberts, Vice Chair of the European Working Group of People with Dementia (EWGPWD) was invited to participate in the session “Older people’s rights to autonomy and independence: legal capacity, independent living and participation in the community”. In the session, Chris referred to this important topic from the perspective of people with dementia, and said, “rights have changed my life, but first, we need to be aware of those rights. Ignorance is a barrier. We don’t know what we don’t know, until someone tells us”.

Anne-Sophie Parent, Secretary General of AGE, also affirmed, “we never lose our right to self-determination even if we lose our ability to communicate our will and preferences. Carers and relatives can learn to find out what an older person with severe dementia likes and dislikes. There are interesting initiatives which seek to respect the right to self-determination of persons with severe dementia while limiting risk for their health and safety”. The outcomes of these discussions in this important event will be used to feed the debates in the upcoming 9th session of the United Nations’ Open-Ended Working Group on Ageing that will take place in July. This group is discussing the level of enjoyment of human rights by older persons across the world and the limits of existing international instruments in protecting them. For further information about the event, please visit: http://www.age-platform.eu

14 June: EFPIA hosts Patient Think Tank Meeting

On 14 June, the European Federation of Pharmaceutical Industries and Associations (EFPIA) held a Patient Think Tank (PTT) meeting in Brussels. Nicola Bedlington (EPF) introduced the meeting with a review of the EFPIA anti-trust guidelines. On the agenda was a feedback on the “Working Together with Patients Groups” workshop held in Berlin to report how the document “Working Together with Patients” was received. This paper was drafted by the members of the EFPIA Patient Think Tank and the Ethics & Compliance Committee.

During the meeting, the group discussed about the compensation of patient experts. Myeloma Patients Europe (MPE), along with the Workgroup of European Cancer Patient...
Advocacy Networks (WECAN), a network of 20 pan-European cancer patient organisations, has initiated the project “Reasonable agreements between patient advocacy and the pharmaceutical industry”. They have finalised a first draft of the guiding principles based on comments provided by advocates and company representatives. The template contract and toolbox development will start in September 2018. EFPIA presented then a survey conducted within its members on compensation of patient experts.

On the agenda was also a presentation on the PARADIGM project to inform the group about the project’s developments. EFPIA gave then a presentation entitled “Patient engagement strategy: KPIs on patient engagement for EFPIA staff and working groups”. The objective of this session was to discuss the engagement of the PTT to strengthen EFPIA patient organisation engagement. An update on plans for the next phase of the #WeWontRest campaign was also provided.

Finally, EFPIA gave an update on the health collaboration awards 2018, the future of health conference and the health data platform.

Alzheimer Europe Project Officer Cindy Birck attended the meeting.

18 June: European umbrella organisations are campaigning for the EPSCO Council to adopt a position on the EU Work-Life Balance directive

On 18 June, umbrella organisations representing 3,471 NGOs and 89 trade union confederations sent an open letter to the Employment, Social Policy, Health and Consumer Affairs Council (EPSCO) as part of their campaign.

The call, which is also supported by Alzheimer Europe, urges the EPSCO Council to respect European citizens and their representatives by moving forward and adopting a Council position on the proposal for a Directive on Work-Life Balance for parents and carers at their meeting on 21 June 2018. In the letter, the organisations stress the importance of the Council positioning itself underlining the weight of their decision, which is being taken on behalf of millions of parents and carers.

Until now, the current EU legal and institutional framework still fails to sufficiently address challenges faced by its citizens and does not provide adequate solutions for the needs of modern societies. This proposed directive includes provisions for improving equal sharing of work and care between women and men, by introducing minimum standards for paid paternity leave, paid parental leave, carers leave and flexible working arrangements for parents and carers.

The call is joint with the Presidents and Vice-Presidents of three political groups in the European Parliament, the Rapporteur and shadow Rapporteurs of five political groups, and the Presidents and Vice Presidents of three Intergroups and Coalitions of the European Parliament, together with the Presidents of two groups in the European Economic and Social Committee. You can find more information about the campaign here.

On 20 June, a group of eight non-governmental organisations (NGO) sent a joint letter to EU leaders to strongly welcome the European Commission’s proposal to establish a Rights and Values Programme in the new programming period 2021-2027. The open letter draws EU leaders’ attention to support human rights and democracy across the EU and calls for strong action to defend the core values of non-discrimination and equality, democracy and freedom of expression and respect for fundamental rights and human dignity in the EU.

This joint letter was supported and co-signed by a number of organisations including AGE Platform Europe (AGE), European Disability Forum (EDF), European Network against Racism (ENAR), European Network On Religion and Belief (ENORB), European Roma Information Office (ERIO), European Women’s Lobby (EWL), ILGA Europe and IGLYO. Alzheimer Europe is a member of EDF, an independent NGO that defends the interests of 80 million Europeans with disabilities.

“We hope that the EU institutions and national policy leaders will give their utmost attention to ensuring that this budget line meets the needs of civil society organisations at European level and on the ground, given the threats to democracy and human rights and the momentum for the EU. We also hope that they will ensure that on-going negotiations on the future EU budget will succeed in the establishment of an ambitious Rights and Values Programme 2021-2027.”

25 June: EFPIA PTT launches the Health Collaboration Awards 2018

The European Federation of Pharmaceutical Industries and Associations (EFPIA) Patient Think Tank (PTT) serves as a forum for both EFPIA members and European patients’ organisations. On 25 June, it launched the Health Collaboration Awards to reward collaborative projects that have delivered patient benefit. The Health Collaboration Awards was initiated in 2016 by EFPIA's PTT. The aim of the awards is to share best practice and provide food for thought and inspiration to stakeholders considering developing multi-stakeholder projects that benefit patients. The awards are split in two categories: Prevention & Awareness and Service Delivery. They are open to multi-stakeholder collaborative projects on a local, national or EU level that benefit patients. To be eligible, entrants must include a patient organisation and industry partner. All applicants of the Health Collaboration Awards will be featured in the next year’s Health Collaboration Guide.

The deadline for application is September 21st. Applications should be submitted via the online platform that can be accessed here: https://www.cvent.com/c/abstracts/e0f07bf1-2f5a-47f9-9349-42a21ef1fe71

26 June: IMI plans to launch new call for proposals which includes digital endpoints in neurodegenerative diseases

The Innovative Medicines Initiative (IMI) is planning to launch a new call for proposals in July 2018. Amongst the topics under consideration is also one on neurodegenerative diseases called: “Digital endpoints in neurodegenerative and immune-mediated diseases”.

The key objectives of the programme are:

• to identify appropriate digital devices & platforms for the transformation of the standard clinical and functional endpoints into digital endpoints;
• to experimentally test the validity of the proposed digital endpoints in clinical trials, with the final aim
• to select a few end points and progress them to obtain qualification from regulatory agencies;
• to progress towards the validation of digital procedures to profile activities of daily living (ADL) / disabilities/ health related quality of life (HRQOL) measures whose ecological validity is recognised by patients and payers.

More information is available on IMI’s website: https://www.imi.europa.eu/apply-funding/future-topics

5 June: Executive Director of German Alzheimer Association Sabine Jansen is re-elected as vice-chair of the Centre for Quality in Care

On 5 June, Sabine Jansen (Alzheimer Europe Board member) was re-elected as vice-chair of the Foundation of the Centre for Quality in Care (Germany). Established in 2009, the independent foundation serves as knowledge institute to improve the quality of care. Amongst other activities, the foundation carries out scientific projects and publishes thematic reports as well as practical guides.

You can find the foundation’s website here.

7 June: France Alzheimer launches a petition following the announcement to discontinue reimbursement of treatments for Alzheimer's disease

On 30 May, the French Minister of Health, Agnès Buzyn announced that the four drugs used to treat the symptoms of Alzheimer's disease - donepezil, rivastigmine, galantamine, memantine - will no longer be reimbursed by the French Government from August. This measure followed the government’s assessment of the Haute Autorité de Santé (HAS) (Health Authorities), who reported that these treatments had "medical interest insufficient to justify their costs".

The association France Alzheimer is totally opposed to this decision as it believes such a decision is both intolerable and incomprehensible. The association mentioned the clinical consequences of stopping these treatments and stated that few families will be able to pay the monthly 30 € equivalent to the cost of treatment in addition to their current expenses. This disapproval is also shared by the thousands of families concerned but also by professionals including neurologists, geriatricians, gerontologists and psychiatrists.
To contest this decision, the French association has launched a petition for the maintenance of the reimbursement of treatments for Alzheimer’s disease. Published online on 7 June, the petition has already received more than 6,500 signatures in a day. The association France Alzheimer invites you to sign its petition to show your solidarity with families, to actively participate in improving the quality of care and to alert the Minister of the consequences of such a decision.

You can sign the petition launched by France Alzheimer here.

13 June: Jersey Alzheimer’s Association announces change in management

On 13 June, the Jersey Alzheimer’s Association (JAA) announced that Sean Pontin will take over Mark Blamey’s responsibilities as JAAs manager in July. Mark has been working at JAA for five years and is currently working alongside Sean who started on 1 May ensuring a smooth transition. We’d like to thank Mark for his active collaboration and his representation of JAA as a member of Alzheimer Europe in our meetings and look forward to continuing our partnership.

13 June: Alzheimer’s Society UK reports on its recent events

On 22-23 May, Alzheimer’s Society UK was delighted to welcome over 600 representatives from health and social care, local and national government, policy, research and people affected by dementia to Alzheimer’s Society Annual Conference. The conference was a key part of Dementia Action Week and delegates left feeling inspired to take action against dementia.

On day one, the Three Nations Dementia Working Group who are living with dementia opened the conference with their revised dementia statements and a rallying cry to change people’s experiences and attitudes. Other speakers included Caroline Dinenage, Minister of Health and Social Care, Simon Lovestone, Professor of translational neuroscience at the University of Oxford and ended with a panel of thought leaders discussing how the current system needs to be fixed.

On day two, speakers included Professor Sarah Tabrizi, University College London, who shared her targeted genetic therapies for Huntington’s and how it can inspire similar ways of treating Alzheimer’s disease. In the international plenary, they explored the experience of people affected in different countries and how people are working together for a world united against dementia, including speakers Wendy Weidner, Alzheimer’s Disease International, Minister Takashi Okada, Envoy Extraordinary and Minister Plenipotentiary of Japan and Jayne Goodrick, care supporter and advocate from Wales.

Alzheimer’s Society’s Global Dementia Friends Ambassador Carey Mulligan (pictured) brought the two day conference to a close and urged delegates to take action on dementia. “It feels like we’re on the cusp of change. Real change. And together we can make the difference that people living with dementia want to see, deserve to see and most importantly, have the right to see.”

On 13 June, the second Alzheimer’s Society World Alzheimer’s Ball took place. It was a wonderful black tie gala, consisting of 17 separate dinners hosted by Embassies and High Commissions representing countries from all over the world.

After the dinners, more than 250 of Alzheimer’s Society most influential supporters and its guests congregated at the beautiful Lancaster House for desserts, dancing and plenty of champagne. The evening was brilliantly hosted by Angela Rippon CBE and its guests heard from Dr Avril Staunton, who gave an incredibly inspiring speech about her personal experience of living with young-onset dementia. The guests were obviously moved, and over £65,000 was donated through a pledge moment that followed Avril’s account. Alzheimer’s Society is delighted to announce that through the pledge, ticket sales and a silent auction, the event raised over £200,000 (gross) in total and feedback from all guests has been overwhelmingly positive.

14 June: The Irish southern dementia working group holds a consultation evaluating the Irish national dementia strategy

The Irish dementia working group’s southern branch met in June 2018. They held a consultation with a research team from University College Cork who are evaluating the Irish national dementia strategy.

This regional group is going from strength to strength with three new members at this most recent meeting. The southern group has a varied membership and in particular gives voice to the lived experience of dementia in a rural setting. Long journeys to access services and a lack of awareness in the local community were common themes.

The members range in age from 46 to 75 and this diversity is critical to ensuring the Irish dementia working groups are as representative as possible. The Alzheimer society of Ireland recognises the geographical inequalities in dementia services and supports throughout the country and the varying experience of our advocates is important as we campaign to address this.
18 June: NGO Futura and Ministry of Health of Montenegro sign memorandum of cooperation

On 18 June, the non-government organisation (NGO) Futura and the Ministry of Health of Montenegro signed a Memorandum on cooperation. The Memorandum foresees close co-operation between health care providers and the NGO Futura in respect to the implementation of projects of common interest in improving the quality of health care, especially taking into account the protection of people with dementia. The Ministry will provide support in the professional training of members of this non-governmental organisation as well as persons engaged in projects.

Further, joint cooperation is also planned through the organisation of round tables and other meetings aimed at promoting the quality of life of people living with dementia and their caregivers. It was agreed that NGO Futura will propose project activities that are compatible with the responsibilities of the Ministry of Health and are in the interest of patients and caregivers.

Signatories Mr Kenan Hrapović - Minister of Health and Mrs Alma Orahovac - Director of NGO Futura.

20 June: German Alzheimer Association announces hallmark of 30,000 Dementia Friends in Germany

On 20 June, the German Alzheimer Association announced that they reached the hallmark of 30,000 Dementia Friends (entitled “Demenz Partner” in German). Just two days before, they also informed the public, that the Federal Minister for Family Affairs, Senior Citizens, Women and Youth, Dr. Franziska Giffey has also taken part in one of the 90-minute courses. In addition, she supported the campaign through social media. The courses are held to engage with people that want to learn about dementia itself as well as about interaction with people affected by it. For example, these can be rules that can help with communication and understanding. The courses address both single persons as well as institutions, people working at the police or fire department, banks and many more. You can find their German site here.

21 June: Alzheimer Society UK influences decision makers in Dementia Action Week

This year, Dementia Action Week was held in the UK from 21st to 27th May. As part of Alzheimer’s Society’s activity in this week, Alzheimer’s Society worked to host various events across Parliament and beyond, to make sure the voices of people with dementia were heard by key decision makers.

They hosted a Dementia Friends session for both the Cabinet and Shadow Cabinet, to ensure those at the highest level of Government and the Opposition have an understanding of dementia, and what they can do to help those affected by the condition.

They also held a drop-in event for MPs in Westminster, which was attended by almost 100 MPs. The event was to launch the latest report ‘Dementia – The true cost: Fixing the care crisis’, which discusses the issues that people with dementia have experienced with cost, quality and access to the UK social care system. 50 MPs also signed a letter to Jeremy Hunt, calling on him to consider people with dementia in the Green Paper on social care, due to be published later this year.

The APPG on dementia also launched a new inquiry into dementia and disability. A launch event took place in Westminster, at which the co-chairs of the APPG spoke alongside John O’Doherty, who is a member of the Three Nations Dementia Working Group and living with dementia. John spoke about his experiences of having both epilepsy and dementia, and the difference in how he was treated based on different diagnoses.

Alzheimer’s Society also held the first annual Dementia Friendly London Summit at the GLA. Mayor of London, Sadiq Khan, met people with dementia living at the event and committed to making London the UK’s first dementia-friendly city. To find out more about Alzheimer’s Society’s activity in Dementia Action Week, please visit: https://blog.alzheimers.org.uk/campaigns/dementia-action-week-politicians/

21 June: Ireland’s all-party Oireachtas group on dementia hosts an awareness session on importance of people with dementia eating well

The Alzheimer Society of Ireland supports the all-party group on dementia in the Irish Parliament (the Oireachtas). This
month, the group hosted an awareness session for public representatives on the topic of nutrition and dementia. The session promoted general understanding of the needs of those living with dementia and their carers as well as a specific focus on eating well. It was also an opportunity for the politicians to hear the lived experience. Ray Cregan from the Dementia Carers Campaign Network spoke very movingly about his experience of caring for his father Paddy. Tina Leonard Head of Advocacy and Public Affairs with Communications Manager Cormac Cahill and Research and Policy Manager Dr Bernadette Rock spoke to the public representatives about the issues affecting dementia care in Ireland. The Alzheimer Society of Ireland’s Irish Dementia Working Group collaborated with the researchers on the eating well with dementia. The booklet is available here: http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/ASI-Eating-well-with-Dementia_-_website_2017.pdf?ext=.pdf

25 June: Portugal replicates project “EU no musEU” (I am at the Museum) for people with cognitive impairments and their caregivers in Coimbra and Viseu

In 2007, the Museum of Modern Art in New York (MoMA) created the MoMA Alzheimer’s Project for people who are at an early stage of dementia as well as for their family members and caregivers. Among the many educational programs it offers to people with dementia and their caregivers, the Meet Me at MoMA, a monthly interactive program that takes place in museum galleries and targets people with dementia and their caregivers (informal or formal). It was from this model of cognitive stimulation that the “EU no musEU” project was created in 2011, consubstantiated in a collaboration protocol between the National Museum of Machado de Castro (MNMC) in Coimbra and Alzheimer Portugal Association. The target audience for this project consists of individuals with cognitive impairment with spectrum of change ranging from mild cognitive deficit with maintenance of functional autonomy to moderate dementia. The monthly sessions are led by an interdisciplinary team and aim to promote well-being, social inclusion and stimulate cognition of people with cognitive impairments, dementia and their caregivers, through the enjoyment and (re) interpretation of works of art of the MNMC. Alzheimer Portugal is delighted to acknowledge that the project is being replicated in Viseu, at the Misericórdia Museum and at the National Museum Grão Vasco coinciding with the Association’s 30th birthday.

POLICY WATCH

12 June: OECD launches report on quality of dementia care

On 12 June, the Organisation for Economic Co-operation and Development (OECD) released a comprehensive report on the quality of dementia care in OECD countries. The report gives a comprehensive overview and insight of and into the current status quo of care provided to people living with dementia. This encompasses the access to diagnosis, living in the community and care environments as well as end of life and palliative care. Keys findings include that:

- Dementia will have a growing human and financial cost to society
- Dementia often remains undiagnosed respectively is diagnosed too late
- Primary care doctors play a key role in dementia diagnosis, but lack support and training to do so
- People with dementia struggle to live independently because initiatives to make communities safe, accessible and socially inclusive remain fragmented
- Informal carers are the most important source of support for many people with dementia, but not enough support is available to them
- Care for dementia with advanced dementia lacks dignity and can result in worse health outcomes.

The full report, including conclusions and recommendations on how to tackle these challenges, is available here.

13 June: NHS launches plan to improve patient care by reducing long hospital stays

On 13 June, Simon Stevens and Ian Dalton, the Chief Executives of NHS England and NHS Improvement, announced the launch of a specific plan to reduce long hospital stays at the NHS Confederation’s annual conference in Manchester (UK). The plan is aiming to improve patient care by reducing the length of stay for older patients in hospitals ahead of next winter. NHS Improvement and NHS England will work in close collaboration with local authorities to set up this plan. They expect to reduce the number of long hospital stays by around a quarter, thus freeing up thousands of hospital beds.
“No one wants patients to stay in hospital longer than they have to, or for the health of patients to deteriorate in the very place that is supposed to be making them better. But this is happening all too often and we have to work together to change it. Every day in hospital is a precious day away from normal life” said Ian Dalton.

“For too long people with dementia have been pulled from pillar to post in our not-fit-for-purpose health and social care system. It’s great to see the Government sitting up and taking this issue seriously with an integrated approach, and more support for care home staff is definitely welcome” said Sally Copley, Director of Policy and Campaigns at Alzheimer’s Society.


19 June: The Portuguese Health Ministry launches a National Health Strategy for Dementia

On 19 June, the Portuguese Health Ministry launched the Health Strategy for Dementia (Act of the Minister of Health n° 5988/2018). The launch of the Strategy is the fulfilment of a promise made during the last meeting between the Secretary of State Assistant and of Health, Professor Fernando Araújo and the President of Alzheimer Portugal, José Carreira. During the meeting, Alzheimer Portugal had the opportunity to share a supporting letter from the Executive Director of Alzheimer Europe stressing that: “We would of course be very happy to include information in our Yearbook about the new Portuguese national dementia Strategy.” This Strategy is a result of the recommendations included in the document: “Bases for the Definition of Public Policies in the Field of Dementia”, which Alzheimer Portugal helped to develop. The Strategy states the principles of care for people with dementia, criteria for prevention, early detection, availability of clinical and comprehensive diagnosis, therapeutic intervention at primary, hospital and specialised care, clarifying the care pathway based on ethical principles, proximity, availability, equity and continuity.

The Act of the Minister also includes the creation of the National Health Plan for Dementia Coordination group, led by António Leuschner. It is composed of representatives from several different organisations and experts, including Alzheimer Portugal (Catarina Alvarez Coordinator of the Memory Cafés and of the Dementia Friends Campaign that will be launched on the 30th July, as well as Maria do Rosário Zincke dos Reis, Board member of Alzheimer Europe). The group will be responsible for the accomplishment of the development of the Regional Dementia Plans that will launch measures on dementia adapted to the specificities of each Region within a year. The measures must be prepared in articulation with the National Health Plan and the National Mental Health Plan.

Alzheimer Portugal states that: “The Strategy is a very promising document although it is focused only on the health care system without the inclusion of the social and legal perspectives. It constitutes an initiative of the Ministry for Health and not of the Government as a whole.”

Further they elaborate: “As a clear evidence of the importance of the work that Alzheimer Europe has been doing and how it influences national policies it is to highlight that the Act of the Government includes several references to important Alzheimer Europe’s documents such as: 1) National Dementia Strategies — Policy in Practice — Alzheimer Europe 2009; 2) Alzheimer Europe — Portugal — 2013: The prevalence of dementia in Europe — Country comparisons — Policy in Practice; 3) The prevalence of dementia in Europe/Portugal; Alzheimer Europe. European Dementia Monitor 2017: Comparing and benchmarking national dementia strategies and policies. 2017.”

3 May: Study aims to improve full-time observation of people living with dementia through algorithms

On 3 May, a team of researchers from the University of Surrey in cooperation with the Surrey and Borders Partnership NHS Foundation Trust published a scientific paper on a new technology enabled monitoring system. The system is being developed to enable detection of agitation, irritability as well as aggression (by inference) in people living with dementia. The aspiration of the team is to provide people the possibility to stay independently at home while having the choice to be monitored in order to help healthcare clinicians detect an immediate crisis. By doing so, they hope to provide a system that potentially could help avoid emergency hospital admissions through proactive intervention when required.

The system, which is currently under development, uses different algorithms that analyse data from sensors, monitors, medical devices and trackers to create profile of the users and generate notifications in case of irregularities. For the study, the healthcare practitioners monitored the information and
contacted either the participants or their caregivers (respectively both) to confirm if the notifications generated by the system were correctly reported. Further, the team kept track of hospital admissions, travels and visits the participants received. This information was then used as complementary data to validate the detected irregularities.

So far, the implementation of such systems faces manifold challenges both from a technical and data processing viewpoint but also from an ethical perspective. The team reported although that all participants had given their informed consent and were assessed according to the Mental Capacity Act guidelines.

On 22 May, the biopharmaceutical company Cognition Therapeutics announced that it has received two grants ($6.6 million) from the National Institute on Aging (NIA) to support two clinical trials investigating Elayta (CT812) for the treatment of mild-to-moderate Alzheimer’s disease (AD). This experimental drug is a highly brain-penetrant small molecule protecting synapses. Both trials are currently recruiting participants in US. The SNAP study is a multi-center, randomised, double-blind, placebo-controlled parallel-group Phase 1b trial to evaluate the effect of CT1812 on Aβ oligomer displacement in people with mild-to-moderate AD. The SPARC study is a single-center, randomised, double-blind, placebo-controlled, parallel group Phase 1/2 study to evaluate the effect of CT1812 on synaptic density in people with mild-to-moderate AD.

On 31 May, researchers from The Ohio State University published an article on the association of social networks and preserved memory of mice in the journal Frontiers in Aging Neuroscience. Pervious evidence has shown that there is a correlation between cognitive health and social connections in humans. Yet, the cause and effect of this correlation is still unclear. It is both possible that social ties are protective respectively that circumstances related to declining brain health lead to a loss in social networks.

The team of scientists assigned female mice to either live in pairs of two (ten mice) or to one of two larger groups (seven mice per group). Two of the pairs had to be excluded from the study, because the researcher’s euthanised a respective partner due to overgrooming. After three months in pair or group housing, the mice were put into individual holding cages and the researchers conducted a series of tests. The team reported that the mice living in groups showed greater novel object location memory and stronger preference for a spatial navigation strategy as well as reduced markers of neuroinflammation. However, the mice did not differ in the development of new neurons in the hippocampus. The scientists acknowledged, that there are a variety of possible confounding factors and that the amount of groups was rather small. Future studies could specifically address some of them through cage observations.

On 31 May, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, announced the completion of its two Phase 1 clinical trials of its lead compound COR388 for the treatment of AD. COR388 is a bacterial protease inhibitor targeting a pathogen identified in brain tissue and cerebral spinal fluid of people with AD. The company started its first Phase 1 study in January 2018. It was a randomised, double-blind, placebo-controlled Phase 1
trial to evaluate the safety and tolerability of a single oral dose of COR388 in healthy participants. The second Phase 1 study was a multiple ascending dose trial in healthy participants. The company announced the enrolment of all participants in its two Phase 1 studies. The experimental drug was found to be safe and well tolerated by healthy participants and the company expects to start a Phase 2 study with people with AD next year. In addition, the company announced the completion of $76 million to fund its first Phase 2 proof-of-concept study.


1 June: Recent study suggests that alcohol may contribute to the development of AD

In a recent study published in the journal of Neuroinflammation, US researchers from University of Illinois at Chicago investigated whether alcohol could influence the development of Alzheimer’s disease (AD).

Using rat models, scientists analysed the number of genes affected by alcohol and inflammation in microglia cells, which are cells supporting neural cells and notably playing a role in amyloid degradation in a process known as phagocytosis. They showed changes in microglial genes expression due to alcohol exposure. They also found that alcohol reduced microglial phagocytosis of amyloid beta. Researchers suggested that alcohol consumption may disrupt the process that clear amyloid beta in the brain, representing thus a risk factor for development of AD.


4 June: Eisai and Biogen announce positive results from experimental AD drug Phase II study

On 4 June, the companies Eisai and Biogen announced encouraging results from their Phase II clinical trial of elenbecestat - an oral BACE inhibitor - for the treatment of Alzheimer’s disease (AD).

The 18-months Phase II clinical trial is a double-blind, parallel-group and randomised study to evaluate the safety and tolerability of elenbecestat (E2609) in people with mild cognitive impairment and mild to moderate AD. Three doses of elenbecestat (5, 15 or 50mg) versus placebo were administered orally once per day in a total of 70 participants. First results showed that the experimental drug was generally safe and well tolerated. A statistically significant difference in Aβ levels in the brain was also reported in participants who had taken the experimental oral drug compared to the placebo. In addition, a non-statistically significant decrease in cognitive decline measures was also observed in the treatment group. Both companies expect to present detailed results at a future meeting.


7 June: Study suggests that an asthma drug could restore learning impairments and memory deficits in mouse models

In a study published in the journal of Molecular Neurobiology on 7 June, US researchers from the Temple University in Philadelphia reported that an asthma drug could reduce tau pathology in mouse models.

Previous findings showed that inflammatory molecules called leukotrienes are deregulated in human tauopathy and mouse models with Alzheimer's disease (AD). In the published study, scientists blocked the leukotrienes by using zileuton, a drug used for the maintenance treatment of asthma, to investigate whether or not the inhibition of leukotrienes could result in improvement of behavioural benefits and tau neuropathology. Researchers used transgenic mouse models able to develop a number of tau tangles, a hallmark protein found in the brain of people with AD, and with behaviour deficits. After 16 weeks of treatment, they observed that zileuton could restore behaviour impairments and reduce tau phosphorylation and pathology in aged Tau mice compared to those that had not received the drug. In addition, treated mouse models had an amelioration of synaptic integrity and lower levels of neuroinflammation.


8 June: VUmc, MEETINGDEM network and Meeting Centers 3.0 hold BestCare4Dem congress in Amsterdam

On 7 and 8 June, the international congress BestCare4Dem “sharing effective community-based support for people with dementia”, took place in Amsterdam (the Netherlands).

The congress attracted 280 participants from 13 countries, including professionals, scientists, policy makers, people with dementia as well as carers.

Plenary lectures included topics such as; integrated post-diagnostic care, dementia-friendly cities and a collaborative presentation of the results of the MEETINGDEM project on the adaptive implementation and evaluation of the Meeting Centres Support Program in Europe by the MEETINGDEM consortium.
Ten parallel sessions provided examples of psychosocial interventions for home-dwelling people with dementia and their carers. These varied from art, music, cognitive stimulation and movement activities to DemenTalent, shared decision making, technological tools and e-learning. During lunch, international films on innovative care methods were shown and there was a poetry and art exhibition of work made by people with dementia. During the afternoon, Jacqueline Hoogendam from the Dutch Ministry of Health, Welfare and Sport launched the International MEETINGDEM network.

The network aims to further disseminate the “Meeting Centres Programme” in Europe and beyond and to share effective innovative support methods and strategies via these centres.

The launching event started with an historic film on the development and dissemination of the Meeting Centers from 1993 until 2018 celebrating the 25th anniversary. With representatives from Meeting Centres in the Netherlands, Italy, Poland, United Kingdom, Aruba, Spain, Surinam and Australia present at the congress, this became a very festive event. The congress was closed with a performance ‘Contact by dance’ of people with dementia and members from a Meeting Centre who danced with the Czech ballet dancer and choreographer Petr Veleta.

At the end of the first congress day Prof Dröes, who organised the congress, was awarded with the title Officer in the Order of Oranje-Nassau by the vice-mayor of Amsterdam in name of the King of the Netherlands. This award was given to her in recognition of the national and international scientific as well as societal impact of her research and other activities in the field of dementia care for the past 35 years.

On the second congress day about 45 participants joined the site visits in several Meeting Centres, Odensehuis, care farm or participated in a workshop ‘How to set up a Meeting Centre’. For more information on this congress go to www.meetingdem.eu.

12 June: Eli Lilly and AstraZeneca halt the AMARANTH and DAYBREAK-ALZ Phase 3 studies for the treatment of AD

On 12 June, the pharmaceutical companies Eli Lilly and AstraZeneca announced the end of two global Phase 3 trials of the experimental drug lanabecestat, which is an oral beta secretase cleaving enzyme (BACE) inhibitor, for the treatment of Alzheimer’s disease (AD).

The studies weren’t discontinued due to safety concerns. An independent data monitoring committee reported that lanabecestat was unlikely to meet its primary endpoints in both the AMARANTH trial, in early AD disease, and the DAYBREAK-ALZ trial, in mild AD dementia. The primary endpoint for both studies was change from baseline on the 13-item Alzheimer’s disease assessment scale - cognitive subscale (ADAS-Cog13), which is a test widely used for cognitive measures in clinical trials of AD.

Both trials recruited participants in many European countries. The AMARANTH study was a multicenter, randomised, double-blind and placebo-controlled Phase 3 study to evaluate the efficacy, safety and tolerability of lanabecestat in people with early AD. The AMARANTH extension trial for the participants who completed the AMARANTH study will also be discontinued. The DAYBREAK-ALZ study was a randomised, double-blind and placebo-controlled Phase 3 study to evaluate the efficacy of lanabecestat in people with mild AD dementia.

For more information on this congress go to www.meetingdem.eu.

12 June: Study shows potential of detecting early signatures of neurological damage using MRI in people with high blood pressure

On 12 June, a team of scientists from the University of Rome published an article on an approach that may help to identify people at the initial stages of brain damage in the Journal Cardiovascular Research. Chronic high blood pressure has been linked to neurological damage and is one of the risk factors that contribute to the probability of developing dementia.

In order to tackle this, scientists are working on ways to identify changes in the brain due to hypertension before brain damage leads to cognitive impairments. This may provide a way to target the right patients with medication limiting neurodegeneration.

While changes would have otherwise been undetectable by conventional neuroimaging. The team was able to show that using MRI scans and neuropsychological tests, they were able to detect very early signatures of brain damage in people with high blood pressure, before any symptoms of dementia occurred. The publication will be available here.

12 June: Second part of vTv Therapeutics’s phase 3 study for azeliragon fails to meet its co-primary efficacy endpoints

vTv Therapeutics, a clinical-stage pharmaceutical company focused on the discovery and development of human therapeutics to fill unmet medical needs, revealed in April that its experimental drug azeliragon failed to meet its co-primary endpoints in the part A of the STEADFAST phase 3 study. Azeliragon is an active small molecule inhibiting the RAGE receptor, which may contribute to the pathogenesis of Alzheimer’s disease (AD).

On 12 June, the company announced that results from part B of the STEADFAST study did not meet its co-primary efficacy endpoints in participants with maximal azeliragon plasma concentrations of less than 7.5 ng/mL, which were cognitive or functional outcomes as measured by the Alzheimer’s Disease Assessment Scale-cognitive subscale (ADAS-Cog) and the Clinical Dementia Rating Scale Sum of Boxes (CDR-sb). However, the lower maximal plasma concentrations of
azeliragon showed improvements in efficacy relative to placebo.

The STEADFAST study included two independent and identical randomised, double-blind and placebo-controlled phase 3 trials investigating the safety and efficacy of azeliragon in people with mild AD. Part A enrolled participants in the United States and Canada and part B also enrolled participants at additional study sites in the United Kingdom, Ireland, Australia, New Zealand and South Africa.


13 June: Study investigates the mechanisms of resilience against neurodegeneration through resveratrol in mice

On 13 June, a group of scientists from Spain published an article on the mechanisms involved leading to brain resilience in Alzheimer’s disease (AD) neurodegeneration of mice through a natural compound (resveratrol) in the journal Molecular Neurobiology. Previous evidence has suggested neuroprotective effects of resveratrol in mouse models of AD and possible improved cognitive performance in older adults. Yet, so far, underlying mechanisms strengthening the hypothesis remain under-investigated.

The small study included four groups of mice:
- 14 non-transgenic mice as control, not receiving resveratrol
- 12 non-transgenic mice receiving resveratrol
- 10 AD-mouse models as control, not receiving resveratrol
- 10 AD-mouse models receiving resveratrol.

Two groups of mice were fed with a daily supplement of 100 mg/kg of resveratrol for a duration of 10 months. Results suggested a resveratrol-induced amelioration of cognition as well as a protection against amyloid and tau pathologies (which are hallmarks of AD). Further investigation proposed that this was caused due to an improvement of “proteostasis” in both groups, which is a mechanism controlling the actions of proteins in cells.

While the scientists’ results showed a protection against cognitive loss in the AD-mouse models, and better memory in post-tests for the 12 control mice, these findings cannot be directly translated to humans. Future research is needed in order to assess whether or not resveratrol may have a comparable effect in humans. The publication is available here.

DEMENTIA IN SOCIETY

28 May: Conference in Galway shares good practice models from Europe on supporting persons living with dementia

The Living Well with Dementia in Rural Ireland Conference took place in Glenlo Abbey Hotel, Galway, Ireland on 28 May 2018. This conference was seeking to highlight and share good practice models from other European countries on supporting persons living with dementia. It explored the experiences of those living with dementia across Europe and examined existing strategies and approaches to meeting their needs and living with the diagnosis. The conference facilitated reflection on the nature of living with dementia today through the lens of other European countries’ experiences, created opportunities for sharing of learning, profiled models of good practice and highlighted the need for joined up responses, both in policy making and practice.

Ms Carmel Geoghegan from Dementia Ireland, a voluntary organisation highlighting the needs of persons living with dementia and their supporters, described the event as “an opportunity for those living in the west of Ireland to hear the experience of other European countries especially through the direct voice of those living with dementia and interact with experts in the field who are passionate about what they do and want to make a real difference.”

Speakers from Alzheimer Europe included Dianne Gove, Director for Projects, as well as Helen Rochford Brennan and Chris Roberts, Chair & Vice Chair of the European Working Group of People with Dementia. From Scotland, there was Agnes Houston and Nancy McAdams, as well as speakers from Wales, England, Northern Ireland and Ireland. The conference presented the direct voice of those living with a dementia diagnosis who delivered personal accounts of the impact of living with dementia. Other perspectives were also delivered on the day by family members, carers and healthcare professionals working with people with dementia.

4 June: France holds ceremony for its first village for people living with dementia

On 4 June, the village in Dax (France) held a ceremony for France’s first village for people living with dementia. The village will provide accommodation for 120 people living with dementia and costs about EUR 29
million with additional running costs of EUR 7 million per year. Daily costs for the residents are expected to be at approximately EUR 60.

The village design will be oriented on a medieval-style citadel with small shared-houses and a big space of 7 hectares with vegetation. A wide space will include a small supermarket, hairdressers, local brasseries, a library, a gym and a little farm. Although there will be no visible fence, residents will be confined in the cordoned off area.

Contrasting from other similar models in the Netherlands, it is planned that at the same time of becoming residents, the new inhabitants will also become research subjects. Researchers (who will cohabitate in the village) will conduct a comparative study contrasting traditional nursing homes. The aim of the study will be to assess the impact of new therapeutic approaches on patients, carers and medical staff.


12 June: Publication calls to action for a better understanding of the impact of sex and gender in Alzheimer’s disease

On 12 June, the Society for Women’s Health Research Interdisciplinary Network on Alzheimer’s Disease published an article on a review of ongoing and published research in the context of sex and gender differences in Alzheimer’s disease (AD) in the journal Alzheimer’s & Dementia.

In their non-systematic review, the international and multidisciplinary team highlights a variety of undertakings, which stress the significance of acknowledging both sex and gender influences. These encompass the examination of epidemiology, clinical presentation, disease progression as well as neurobiological manifestations.

The work, supported by a programmatic grant from Eli Lilly & Co, concludes with a list of recommended priority research areas that warrant future attention from the perspective of the authors:

- Potential risk factors that affect only one sex, like menopause and pregnancy disorders, and the influence of sex hormones like estrogen on brain function
- Differences between women and men in risk factors that affect both sexes, like cardiovascular disease, diabetes, exercise, and depression
- Sex differences in genetic risk factors like APOE ε4
- Sex and gender differences in racial and ethnic subgroups
- Gender differences in caregiving and how the burden of caregiving influences AD risk for the caregiver
- Differences between women and men in response to current AD therapeutics and those in development
- Differences between women and men in the detection, diagnosis, progression, management, and treatment of AD

You can find the publication here.

21 June: Idalina, member of the EWGPWD, advocates for recognition of carers in Portugal

A few years ago I was diagnosed with Alzheimer’s. This changed my life since I needed to be supported and cared for. My daughters and sister are providing the care and support that I need. Becoming a carer and caring for someone can be difficult. I know about this as about 35 years ago I had to become a carer myself. My husband and father of my daughters had an accident which caused severe brain damage. After a period in deep coma and long hospitalization, and against all medical expectations, he began to recover, but he needed a lot help and family support to relearn everything. Then, despite a limited quality of life he lived for two decades. As his carer, I learned how to fight against setbacks and to face obstacles in life. We (myself and my daughter) have recently joined a group of citizens in Portugal that intends to create a statute for informal carers. This is something very close to my heart as I was a carer and now I am receiving care from my family. Like me, there are many other people in Madeira who provide or receive care from their families and friends. I therefore completely endorse this cause and think that it is urgent to create this Statute, which recognises the importance of the dedication and work of all informal carers in Portugal and guarantees their rights. Idalina is supported by her daughter Nelida, to whom we are grateful for her help in translating Idalina’s words to English.
25 June: Helen Rochford-Brennan shares her experience of the Galway conference

For me there were many common threads running through the Living Well with Dementia in Rural Ireland Conference. It is not just an Irish issue which in a way was surprising. It was an enlightening day of listening to the difficulties, how change is possible and about the need to advocate and lobby our government. Timely diagnosis, infrastructure and person-centred quality care were the main issues. The lack of broadband service, transport services, isolation, good health and social care services, poverty and no sense of community were also important issues that were raised.

It was also interesting to hear about palliative care and the support offered to people with dementia to die in their own homes. This will be of great assistance to families in rural Ireland who want their loved ones to have dignity to the end of life. Another interesting discussion was on the abuse of anti-psychotic medication of patients in long-term care. Finally, this abuse is being challenged thanks to Kieran Walsh from the University College of Cork.

All the presentations were excellent. So many great topics beginning with Dianne Gove’s presentation on the European Working Group of People with Dementia and Alzheimer Europe, followed by pathways of care in acute hospitals to re-framing dementia as a disability, care home person-centred approach, to the voice of the carers and people with dementia. It was a very diverse day and we all realised the importance of many voices... there is no one expert. The Alzheimer Society of Ireland CEO Pat McLoughlin talked about looking at services county by county which is a welcome development for people with dementia in Ireland as then families can lobby politicians for adequate services.

The greatest joy was having my friends, Agnes and Nancy from Scotland together with Chris and Jayne from Wales, visit my home. We had lots of laughter and I can still cook an Irish breakfast!!! Thanks to Carmel Geoghegan, it was so heartening to have my Scottish and Welsh friends join me on Irish Television discussing rural dementia.

NEW PUBLICATIONS & RESOURCES

12 June: CORBEL organises webinar about the BBMRI-ERIC Helpdesk for Ethical Legal and Social Implications

The BBMRI-ERIC ELSI Helpdesk is a personalised support service assisting researchers with ethical, legal and societal questions in the context of research projects related to biobanking.

On 10 July, CORBEL will organise a webinar with Jasjote Grewal from BBMRI-ERIC (ELSI Helpdesk Coordinator) for interested people, providing information on how the helpdesk works, including a future trajectory of service and a questions and answers session. You can find more information here.

JOB OPPORTUNITIES

1 June: Karolinska Institutet is recruiting two postdoctoral scientists

The Department of Neurobiology, Care Sciences and Society at the Karolinska Institutet is recruiting two postdoctoral scientists in Huddinge, Sweden. The lab will move to Bioclinicum at Karolinska Solna during 2018.

- Postdoc position on biomarkers related to risk factors and prevention strategies for Alzheimer disease. The purpose of the project is to understand the longitudinal effects of multimodal intervention strategies and to lay ground for deeper phenotyping of AD as well as establishing prognostic tools. The project will be focused on biomarker identification and quantification of human samples from the Memory Clinic database Gedok and the multimodal intervention studies FINGER and MIND-AD led by Prof Kivipelto.

- Postdoc position in biostatistics in late-life cognitive disorders and Alzheimer’s disease. The purpose is to work on developing and improving prediction models for dementia/Alzheimer’s disease, and investigate in detail the effects of preventive strategies in clinical trials. The position involves statistical design and data analysis, data management, preparation of manuscripts, grants, and ethical and other data-related permit applications.

The deadline for applications is 13 August 2018. You can find more information about the entry requirements and the recruitment process here.

5 June: The University of Worcester is recruiting a Professor of Family Care

On 5 June, the University of Worcester announced an opening for a Professor of Family Care at the Institute of Health and Society: Association for Dementia Studies.

The Association for Dementia Studies and Dementia Carers Count (DCC) have worked in partnership since 2012 to develop a service offer to support families caring for a person living with dementia. Both parties have agreed to part fund a professorship to increase research centred on family carers.

The DCC Professor of Family Care will focus wholly on the development of a research and knowledge transfer portfolio...
around family care and dementia. They will provide a high profile role for the charity as the service develops and augment the senior leadership capacity within the Association for Dementia Studies.

For the job description and person specification as well as to apply, please go to this link. Applications need to be made online through the University of Worcester website. The closing date for applications is 5 July 2018. The interview date will be 31 July 2018.

8 June: The Warneford Hospital in Oxford is recruiting for the EPAD project

The European Prevention of Alzheimer’s Dementia Consortium (EPAD) seeks a Communications and Events Officer (part-time: 18.75 hours/50% FTE). The post is for a fixed-term of 1 year based at the Department of Psychiatry, Warneford Hospital in Oxford (UK).

The post holder will support the delivery of EPAD’s communications strategy, disseminate high quality communications through a range of channels and take the lead in organising the delivery. He/she will be responsible for monitoring the impact of communications activities to help improve future performance.

They are looking for someone with:

- Educated to degree level or equivalent
- Excellent communication skills
- Experience in event design, management and delivery
- Excellent writing, editing and proof-reading skills, with the ability to adapt editorial style to a wide range of audiences.

The deadline for applications is 4 July 2018. You can find more information about the entry requirements and the recruitment process here.

AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 July</td>
<td>Field visit for 28th AE Conference #28AEC (Barcelona, Spain)</td>
<td>Jean and Gwladys</td>
</tr>
<tr>
<td>5-6 July</td>
<td>AETIONOMY Meeting (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
<tr>
<td>11 July</td>
<td>European Medicines Agency Scientific Advice Meeting (London, UK)</td>
<td>Dianne</td>
</tr>
<tr>
<td>13 July</td>
<td>ADDIA Project Meeting (Strasbourg, France)</td>
<td>Jean</td>
</tr>
<tr>
<td>16 July</td>
<td>Meeting with Luxinnovation (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
<tr>
<td>18 July</td>
<td>PARADIGM WP3 meeting (Brussels, Belgium)</td>
<td>Ana and Dianne</td>
</tr>
<tr>
<td>18 July</td>
<td>Field visit for 29th AE Conference #29AEC (The Hague, Netherlands)</td>
<td>Jean and Gwladys</td>
</tr>
<tr>
<td>21 July</td>
<td>Biogen Global Alzheimer’s Advocacy (Chicago, USA)</td>
<td>Jean</td>
</tr>
<tr>
<td>22-29 July</td>
<td>Alzheimer’s Association International Conference (Chicago, USA)</td>
<td>Jean</td>
</tr>
<tr>
<td>22 August</td>
<td>Second Alzheimer Europe ethics working group (Amsterdam, Netherlands)</td>
<td>Dianne and Jean</td>
</tr>
</tbody>
</table>

CONFERENCES 2018

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>4-6 July</td>
<td>British Society of Gerontology Annual Conference, <a href="http://www.britishgerontology.org">www.britishgerontology.org</a></td>
<td>Manchester, UK</td>
</tr>
<tr>
<td>22-26 July</td>
<td>Alzheimer’s Association International Conference, <a href="https://www.alz.org">https://www.alz.org</a></td>
<td>Chicago, USA</td>
</tr>
<tr>
<td>26-29 July</td>
<td>International Conference of Alzheimer’s Disease International (ADI), <a href="https://www.adi2018.org/">https://www.adi2018.org/</a></td>
<td>Chicago, USA</td>
</tr>
<tr>
<td>3-6 October</td>
<td>Croatian Congress on Alzheimer’s disease (CROCAD), <a href="http://btravel.pro/en/crocad-18/">http://btravel.pro/en/crocad-18/</a></td>
<td>Novigrad, Croatia</td>
</tr>
<tr>
<td>18-19 October</td>
<td>2nd MINC Symposium, <a href="http://mmni.de/minc-2018/">http://mmni.de/minc-2018/</a></td>
<td>Cologne, Germany</td>
</tr>
<tr>
<td>24-27 October</td>
<td>11th Clinical Trials on Alzheimer Conference (CTAD), <a href="http://www.ctad-alzheimer.com">www.ctad-alzheimer.com</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>22-25 October 2019</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague, Netherlands</td>
</tr>
</tbody>
</table>