WELCOME

Firstly, a warm welcome to yet another new member of our European Alzheimer’s Alliance (EAA), MEP Annie Schreijer-Pierik. It is great to see so many MEPs (126 from 27 Member States and from all 7 political groups) joining the effort to make dementia a European priority. I am hopeful we will have as many EAA members and more after the 2019 EP elections, despite the long shadow being cast by Brexit. I would also like to thank the five MEPs, all members of the EAA, who were able to join our successful lunch debate in Parliament at the end of February: Heinz K. Becker (Austria), Deirdre Clune, (Ireland) Marian Harkin (Ireland), Rory Palmer (UK) and Keith Taylor (UK). You can read about this event in the Alzheimer Europe section of this newsletter. For more information about this alliance of MEPs and about how to join, see the Policy in Practice section of our website.

I would also like to congratulate our colleagues in Ireland on a historic day this 7 March, which saw the country ratifying the UN Convention on the rights of persons with disabilities (UN CRPD), 11 years after signing it. This makes Ireland the final country in the EU to pass the UN CRPD. We welcome this long-awaited ratification as it will help improve the lives of persons with disabilities, including people with dementia. The Chair of our European Working Group of People with Dementia (EWGPWD), Helen Rochford Brennan welcomed the news, saying the convention “can keep the will and preference of people with dementia at the centre of all decisions.”

On the subject of the EWGPWD, the first meeting of the group for 2018 was held in Luxembourg this month. It was a pleasure to be able to join the group on the second day and to welcome a new member to the fold, Geert Van Laer from Flanders, Belgium. It was also a pleasure to meet Kathy Ryan from Ireland, who was standing in for Helen Rochford Brennan on this occasion.

Our Public Affairs meeting at the end of February in Brussels was also a success, and I would like to take the opportunity to thank all our members who attended and a special thank you also to Katrin Seeher and Anne Magriet Pot from the WHO, who presented the Global Dementia Observatory and introduced the new e-programme for carers of persons with dementia, “WHO iSupport”.

On the EU Project front this month, the new PARADIGM project, in which AE is heavily involved, has officially kicked off. You can find out more about this important IMI-funded project on patient engagement in the EU Projects section of this newsletter.

Finally, I invite you all to submit abstracts for the 28th Alzheimer Europe Conference (28AEC) and to register also. Abstracts are welcomed until end of April and our Early Bird registration fee is available until the end of June.

Jean Georges
Executive Director
ALZHEIMER EUROPE

26-27 February: Alzheimer Europe Board reviews 2017 activities and discusses plans and finances for 2018

The Alzheimer Europe Board held its first 2018 meeting on 26 and 27 February in Brussels.

The Board approved the organisation’s 2017 Annual Report and Financial Accounts and discussed various other financial and operational matters including the preparations for the 28th Alzheimer Europe Conference, to be held this year in Barcelona, Spain from 29 to 31 October.

The Board also addressed the 2018 financial situation and possible repercussions of the delays encountered with the signature of the association’s operating grant by the European Commission services. Finally, the Board endorsed a campaign by a number of health NGOs calling for greater support of health at EU level #EU4Health. The next Board meeting will take place in Brussels on 25 and 26 June 2018.

27 February: Alzheimer Europe’s European Parliament lunch debate focuses on the potential for interventions in the earlier stages of dementia and dementia prevention

On 27 February Alzheimer Europe (AE) held a successful lunch debate in the European Parliament which focused on the prevention of Alzheimer’s disease (AD) and dementia. The lunch debate gathered over 50 people including MEPs Heinz K. Becker (Austria), Deirdre Clune, (Ireland) Marian Harkin (Ireland), Rory Palmer (UK) and Keith Taylor (UK). The audience included representatives from 20 AE member associations, as well as several pharmaceutical companies.

Iva Holmerová, AE Chairperson opened the debate and welcomed all participants. The lunch debate looked at the potential for interventions in the earlier stages of dementia and dementia prevention. Europe is already financing several key research initiatives in this area illustrating the importance of EU research programmes to address this promising field of dementia prevention. During the discussion the speakers looked at social innovation, modifiable risk factors through nutrition, physical exercise, blood pressure and cholesterol control etc. as well as the development of pharmacological interventions working on the underlying brain processes.

The first speaker, Prof. Kate Irving, Professor of Clinical Nursing at Dublin City University, Ireland spoke about reducing dementia risk by targeting modifiable risk factors in mid-life and the lessons of the In-MINDD project which promotes long term brain health and prevention to at least delay the onset of dementia.

The second speaker was Dr Edo Richard, Neurologist at the Academic Medical Centre, Amsterdam and Radboud University Medical Centre, Nijmegen, Netherlands from the European Dementia Prevention Initiative (EDPI) a project connecting European researchers and dementia projects.

The final speaker was Prof. Craig Ritchie from the European Prevention of Alzheimer’s Disease (EPAD) IMI project who looked at what the project can offer in terms of research into prevention. EPAD is about creating a novel environment for testing numerous interventions (drugs and non-pharmacological interventions) targeted at the prevention of Alzheimer’s dementia.

Photo highlights from the lunch debate

 MEP Heinz K Becker (Austria)  
 MEP Rory Palmer (UK)  
 MEP Keith Taylor (UK)  
 Iva Holmerová, AE Chairperson  
 MEP Marian Harkin (Ireland)  
 Speaker Prof. Kate Irving
All speakers agreed that more could and should be done in the area of prevention. Currently there is a much higher focus on basic research and clinical research but research should start to focus more on prevention. Just defining dementia as a medical disease is too limiting because if it is defined as more than just the neurological impairment then maybe there are things everyone can do to prevent it.

Dr Holmerová then announced the publication of AE’s two new publications, the 2017 Yearbook on “Care standards for residential care facilities in Europe” and the Ethics report on “Dementia as a disability?” She closed the meeting, thanking everybody for coming and the AE corporate sponsors of the event, Lilly, MSD and Roche.

A full report can be downloaded here: [https://goo.gl/rAvBwn](https://goo.gl/rAvBwn)

The next AE European Parliament lunch debate will be on 26 June 2018 and will be entitled “Dementia Care in the European Union”.

**28 February: WHO participates in Alzheimer Europe Public Affairs meeting**

On 28 February, Alzheimer Europe (AE) hosted a Public Affairs meeting in Brussels, Belgium. 27 representatives from AE member organisations, 8 AE staff members and 2 representatives of the World Health Organisation (WHO) were in attendance. AE Chairperson Iva Holmerová led the meeting.

The agenda focused on:

- The Global Dementia Observatory of the WHO – “Benchmarking and indicators for comparing dementia responses”, and “Opportunities for interaction for national Alzheimer’s associations” (both sections presented by Katrin Seeher, WHO)
- WHO iSupport: E-programme for Carers of People Living with Dementia (presented by Anne Magriet Pot, WHO)
- Making dementia a European priority – Updating the AE campaign and preparing for EP elections in 2019 (presented by Vanessa Challinor, AE Policy Officer)
- AE’s 2018 Yearbook on national dementia strategies (presented by Ana Diaz, AE Project Officer)
- AE’s 2018 Ethics report on needs and services for people with dementia, carers and care professionals from ethnic, cultural and religious minorities (presented by Dianne Gove, AE Director for Projects)
- Representatives from each member organisation attending the meeting also had the opportunity to present recent policy development in their countries (with a particular emphasis on whether a national dementia strategy was in place and if so, how the implementation of this plan was unfolding); recent campaigning / lobbying activities; and ethnic, cultural and religious minorities and what initiatives, if any, exist in their countries to support these groups.

The next Public Affairs meeting will take place in Brussels on 27 June 2018.

**5 March: Call for abstracts and registrations opens for 28th Alzheimer Europe Conference**

Alzheimer Europe, Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA) and Fundación Alzheimer España (FAE) are pleased to announce that registrations and the call for abstracts are both open for the 28th Alzheimer Europe Conference (#28AEC). The conference will take place in Barcelona, Spain from 29 to 31 October 2018.

Abstracts for oral and poster presentations are welcome in the following categories:

**Policies and strategies**

- Dementia strategies
- Awareness campaigns
- Cost/funding of dementia research and care
- Global and European collaborations on dementia
15 March 2018: Race Equality Foundation organises workshop for professionals on dementia and black and minority ethnic communities

On 15 March 2018, Dianne attended a workshop in Bristol (UK) on “Dementia and black and minority ethnic communities” for professionals working in the field of dementia services and support. The workshop was organised by the Race Equality Foundation.

The meeting started with a presentation on the impact of dementia on Black, Asian and Minority Ethnic communities in the UK by David Truswell, Chair of the Dementia Alliance for Culture & Ethnicity. David described the national demographics of migrant and minority ethnic groups in the UK, highlighted certain myths and stereotypes and drew attention to cultural issues in accessing services and common service challenges.

Trish Caverly, Community Development Coordinator at the Dementia Wellbeing Service (DWS) then presented the work of the DWS, which is a partnership between the Alzheimer’s Society and Devon Partnership NHS, responsible for delivering dementia services in Bristol. The DWS has produced films and leaflets and carried out consultations with members of minority ethnic groups. Trish highlighted certain examples of good practice which had been achieved such as every GP practice in Bristol having a named Dementia Practitioner and Dementia Navigator.

Next, Subitha Baghirathan from the University of the West of England, presented her work on dementia experiences of Caribbean, Chinese and South Asian people in Bristol. She described her work within minority ethnic communities and how she had made initial contacts and consulted relevant members of those groups (e.g. by spending time talking to older Sikh men at Gurdwara and in barber shops, building trust before broaching the topic). She drew attention to the fact that minority ethnic groups are not homogenous in that there are distinct differences between and within BME communities (e.g. with regard to religion, gender, class and language), pointing out that almost 100 languages are spoken in Bristol alone.

Finally, Shahid Mohammed, a former carer and current consultant, gave a presentation on the topic of cultural awareness. He emphasised the need to develop a better understanding of dementia within the South Asian community, to develop culturally appropriate assessments, to increase diagnosis rates and to promote ‘dementia-friendly’ mosques, shops and communities. He also highlighted challenges linked to the use of interpreters for people from minority ethnic groups (especially the use of relatives for this task) and the need to employ people from minority ethnic groups in the field of service development and provision.

The four presentations provided valuable insight into the issues faced by people with dementia and their carers or supporters from minority ethnic groups. Throughout the afternoon, there were also small group discussions amongst the participants. These provided an opportunity for participants to discuss various issues further and to think about how the issues raised related to their own work and experience and what they could do to improve the experiences of people with dementia from minority ethnic groups in their area. The speakers shared materials such as DVDs, leaflets and links to websites and reports which will hopefully all be referenced in the European database which Alzheimer Europe aims to develop as part of its work this year on intercultural care and support for people with dementia from minority ethnic groups (which is jointly funded by the European Commission and the Robert Bosch Stiftung).
Members of the EWGPWD and their supporters met in Luxembourg on 19-20 March. During the meeting, members welcomed a new member from Belgium, Geert van Laer, who joined the EWGPWD at this meeting. Geert was accompanied and supported by his wife Ikuko van Laer. It was a pleasure to have Kathy Ryan at the meeting representing Ireland in Helen’s absence. Kathy was accompanied by Clodagh Whelan (The Alzheimer Society of Ireland). The meeting kicked off with a consultation on transport. Members of the group spoke about their experiences whilst using different kinds of transport locally, nationally and internationally. They referred to the different challenges that they had experienced whilst travelling, challenges that they felt people at more advanced stages of dementia may experience and examples of how such challenges could be overcome and their experiences improved. A summary of this consultation will be shared with the European Disability Forum so that the perspectives of people with dementia can be also included in their work related to the specific requirements of people with hidden disabilities in travel.

In the afternoon, Kate Boor Ellis, AE Communications Officer, provided an update on the communication tools used by AE and the involvement of the group in each of them (i.e. newsletter, Dementia in Europe magazine, Facebook and Twitter, and website). The rest of the afternoon was dedicated to providing feedback on the accessible version of the AE 2017 "Discussion paper on the possible implications for ethics, policy and practice of recognising dementia as a disability’.

The following morning, the group started the meeting with a lively discussion on possible topics and approach for the EWGPWD Special Symposium at the next AE Conference in Barcelona (Spain). Dianne then provided an overview of this year’s ethics work on the topic of minority ethnic groups. Members of the EWGPWD shared information about possible experts for the working group. During the last session of the meeting, the group welcomed Jurn Verschraegen, Olivier Constant (Flanders Centre of Expertise on Dementia) and Hilde Lamers (Flemish Alzheimer League). The session focussed on existing working groups of people with dementia in Europe and the main challenges for setting up these groups in some countries. The group had the opportunity to hear about the plans for setting up a similar group in Flanders. The colleagues from Flanders thanked the group for the wealth of information, experiences and suggestions that members of the group shared with them. Dianne Gove, Ana Diaz and Sebastien Libert participated in the meeting.

EU PROJECTS

20 February: EPAD publishes a paper in the Journal of Alzheimer’s Disease

The EPAD project is proud to present its new paper, " Perspectives on Communicating Biomarker-Based Assessments of Alzheimer’s Disease to Cognitively Healthy Individuals ", published online in the Journal of Alzheimer’s Disease on 20 February.

The review article was led by Richard Milne from the University of Cambridge (UK). Alzheimer Europe is happy to have contributed to this paper, with Project Officer Ana Diaz, Director for Projects Dianne Gove and Executive Director Jean Georges being among the authors.

“This paper presents the results of a qualitative focus group study of attitudes and concerns toward learning information about biomarker-based risk status among healthy research participants in the United Kingdom and Spain and people with dementia and their supporters/caregivers from countries represented in the European Working Group of People with Dementia of Alzheimer Europe.”

https://goo.gl/CaJ71b
1 March: PARADIGM project officially begins

PARADIGM - Patients Active in Research and Dialogues for an Improved Generation of Medicines - is an IMI-funded European project with a mission to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) and demonstrates the “return on the engagement” for all players.

The objective is to develop much needed processes and tools for three key decision-making points: research priority setting, design of clinical trials and early dialogue. Building on advances at international level, PARADIGM will integrate the needs, perspectives and expectations of all actors (including vulnerable populations) involved and will also produce a set of metrics to measure the impact of patient engagement.

PARADIGM was launched on 1 March 2018 and will run for 30 months. Alzheimer Europe is a partner and is involved in all work packages of this project.

http://imi-paradigm.eu/

5 March: PRODEMOS project launches its website

The PRODEMOS – Prevention of Dementia using Mobile phone Applications- project is proud to announce the official launch of its website.

The project website has been established to promote the PRODEMOS project, which aims to make an evidence-based dementia prevention strategy using mobile Health accessible to those at increased risk of dementia, who are usually not reached by preventive medicine. The website includes a public section for dissemination to scientists and communication to the general public (i.e. project objectives, partners, impact and publications).

http://www.prodemos-project.eu/

7 March: Call is open for projects to contribute to IMI’s first Scientific Symposium

IMI was launched in 2008 as a public-private partnership (PPP) between the European Union and the European Federation of Pharmaceutical Industries and Associations (EFPIA). Since then, the initiative has launched almost 100 projects, all of which take a collaborative, open innovation approach to some of the biggest challenges in medical research and drug development today, including Alzheimer’s disease and dementia.

As IMI approaches its 10th anniversary, it has decided to organise a special Symposium, reflecting on 10 years of impressive activity, by bringing IMI project partners together to share their high-quality research with the wider scientific community, and to provide a space for projects to learn from one another. The hope is that these discussions will trigger new ideas, bringing the research funded by IMI a step further.

IMI’s first Scientific Symposium will be organised on 22 and 23 October 2018 in Brussels.

For more information and to submit abstracts (the closing date for which is 7 April) visit: https://goo.gl/5hjmXe.

8 March: People with dementia, carers and MinD project members take a design journey together

The MinD project has hosted a further secondment in March 2018, jointly by the University of Wolverhampton and Nottinghamshire Healthcare NHS Foundation Trust, UK. A key task of this secondment was the consultation with people with dementia and carers from the Nottinghamshire Public and Patient Involvement Group about the “Social Engagement Map”, one of the project’s proposed designs.

The Social Engagement Map aims to support people with dementia to stay socially connected and engaged, and in control of their social life. The design concept had been selected in October 2017 from a shortlist with the help of people with dementia, caregivers and healthcare experts in a number of public and patient involvement (PPI) sessions in Germany, Spain and the UK.

The consultation in this secondment had two purposes: to help with the development of the design, and to improve the project’s understanding of how to conduct co-creation processes with people with lived experience of dementia in order to develop the design idea in a way that is relevant and desirable to the people it is intended for. MinD therefore organised a PPI-co-design session on Thursday 8 March at the Institute of Mental Health, Nottingham with 20 participants, including 14 experts in lived experience of dementia and memory loss as well as MinD researchers, including psychologists, psychiatrists and designers.

The day was conceived of as a journey together for all participants to enable sharing knowledge and experiences of lived experience and of designing. The morning started with sharing experiences, success and difficulties and gave voice to hopes and suggestions around socialising, recognising them as shared human issues. This was followed by a lecture about co-research with people with dementia, which all participants elected to attend.

The afternoon commenced with picture slides of the project’s journey and a brief introduction to the nature and purpose of design. Groups brought familiar objects to consider how useful these were as memory aids and guides; what they liked about them, what was difficult, and what improvements were wished for. People with lived experience began to think like designers; designers began to see more clearly the lived-in world of memory loss. The afternoon finished with an
introduction to the proposed Social Engagement Map with participants offering suggestions on improvements or variations that might be useful. A large amount of material was gathered, which is fed back to designers for further development now.

http://designingfordementia.eu/

9 March: 2nd PACE User Forum is held in Brussels

PACE is an FP7-funded project looking at palliative care for older people in care and nursing homes in Europe. As part of this 5-year project, two different studies have been carried out looking at the quality of palliative care provided in long-term care facilities in Europe. In addition, the project is developing policy recommendations to inform and assist policy and decision-makers. The 2nd User Forum was organised by AGE platform Europe and was attended by members of the AGE’s Task Force on Dignified Ageing, AE representatives and members of the PACE consortium. The forum built on other past similar events held in 2015 and 2016, where some of the key challenges for the provision of good quality palliative care in nursing homes were identified. The 2nd User Forum focused on the policy actions needed to overcome these key challenges and which would enable better access. The input provided in the user forums, together with the conclusions of similar events organised by AE on dementia, and the results of the different studies carried out by the PACE consortium, will form the basis of the PACE Policy Recommendations which will be published before the end of 2018. Project Officer Ana Díaz, Policy Officer Vanessa Challinor and AE Board member Sabine Henry participated in the event.

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

http://www.eupace.eu/

20 March: INDUCT project announces advances on the study of complex health technologies for people living with dementia

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http://www.eupace.eu/

20 March: INDUCT project announces advances on the study of complex health technologies for people living with dementia

INDUCT Early Stage Researchers Rose Miranda (ESR 11) and Annelien van Dael (ESR 12) are both delighted to announce the progress they have made in their studies on complex health technologies for people living with dementia. Rose and Annelien are currently based at the End-of-Life Care Research Group at the VUB in Brussels, Belgium. Both of them are conducting studies on how complex health technologies, such as palliative care and advance care planning interventions, can improve the care for people with dementia. Their study findings will be presented at the 10th World Research Congress of the European Association for Palliative Care (EAPC) from 24-26 May 2018 in Bern, Switzerland.

Rose (pictured, left) aims to contribute evidence to how a palliative care intervention can improve the quality of life of people with dementia and their families. As a step in this exciting research trajectory, she explored the attitudes towards palliative care in dementia of caregivers of nursing home residents with dementia in Belgium, the Netherlands, Italy, Poland, Finland, United Kingdom, and Switzerland. Assessing such attitudes is important as these can influence the decision-making process concerning end-of-life care and the delivery of this care. She found that, although the EAPC strongly recommends palliative care for this population, the attitudes of those caregivers towards palliative care in dementia differ between countries. Rose will share these and other insights of the study during her oral presentation on 24 May at 14:00-14.15h.

Annelien (pictured, right) is investigating trends in end-of-life decision making in individuals dying of dementia. Using a mortality follow-back survey, she examined the trends in Flanders (Belgium) in 1998, 2007 and 2013. The research shows that for end-of-life decision making, physicians consult regularly with family, nurses and colleague-physicians. However, the wishes of people dying of dementia are rarely part of the decision-making process at the end-of-life. Annelien will share these and other insights of the study during her oral presentation on 24 May at 16.30-16.45 hours.

Another project Annelien is working on concerns advance care planning (ACP) for people living with dementia in nursing homes. ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. An important topic for qualitative care. Together with the research team, she developed an extensive training program for nursing home (care) staff to have ACP conversations with residents and their families. The new ACP program was assessed for feasibility and acceptability in nursing homes in Flanders. This study found that, to facilitate implementation of the ACP program, three elements are essential: 1) tailoring, 2) engagement of management, and 3) having an experienced ACP trainer. If you are keen to learn more about the results of the feasibility of this training program, please come see Annelien at her poster (ongoing display 24-26 May).

If you have any questions, please contact:
Rose Miranda, rosemiranda@vub.be
Annelien van Dael, annelien.van.dael@vub.be
End-of-Life Care Research Group, Vrije Universiteit Brussel, Laarbeeklaan 103, 1090 Jette, Belgium

http://www.dementiainduct.eu/
22 March: ROADMAP outcomes definition team meets for data synthesis meeting and publishes deliverable on systematic literature review

On 22 March 2018 (Edinburgh, Scotland), Alzheimer Europe joined a data synthesis meeting with colleagues from Edinburgh working on the Outcome Definition team for the real world outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data access platform (ROADMAP) project.

The meeting was attended by various Work Package 2 (WP2) partners from the public-private sectors either in person or via telephone. The meeting, chaired by Claire Tochel, aimed to develop a consensual plan in order to integrate the information from the various activities carried out by the WP including; systematic literature reviews, surveys, workshops and interviews. These activities will lead to the development of the next upcoming deliverables “D2.3 Stakeholder generated lists of priority real-world evidence (RWE) relevant outcomes for AD” and “D2.4 RWE progression marker and outcome classification matrix for AD” and provide the basis for a summary of gaps between data requirements and currently available data. The latter constitutes the last deliverable for the Outcome Definition team during ROADMAP phase 1. In advance of the meeting, the WP recently submitted the findings of their systematic literature review entitled “D2.2 Report of systematic review of published and unpublished data identifying important and relevant outcomes in AD and criteria for disease progression” to the Innovative Medicines Initiative.

After that, Amanda Ly introduced the current state of the quantitative surveys; the online version has been closed on 5 March and yielded more than 425 engagements from professionals (333), carers (80) and people with either mild cognitive impairment (MCI) or dementia (12) with an average completion rate of 51%. Additional paper survey collections in Edinburgh and Oxford memory clinics are currently ongoing to gather the responses of more people with MCI respectively dementia and carers until the end of April.

Following this, Mia Nelson gave an overview of the qualitative work that has been going on. She is currently analysing transcripts from a 2-day workshop with the European Working Group of People with Dementia (EWGPWD) and their carers, as well as from a series of individual interviews with professionals such as ethicists, health economics, representatives of Alzheimer’s associations, industry representatives and clinicians.

During the final session, Annette Bauer presented work that has been conducted by the London School of Economics on the perspective of Health Technology Assessment and regulatory agencies through an additional systematic literature review. The aim is to understand whether the processes employed by these agencies (in form of technology assessments) lead to prioritisation in outcomes and outcome measures that might vary between European countries. In addition to this, potential publications were discussed with an emphasis on publishing the SLR (D2.2) on outcome priorities along with findings from the EWGPWD and their supporters/carers consultations in a white paper format, giving an insight into what constitutes a meaningful delay in disease progression and when a delay in onset of dementia is considered meaningful.

www.roadmap-alzheimer.org

26 March: AMYPAD project team discusses diagnostic study protocol in Barcelona

During a full-day meeting in Barcelona, the AMYPAD project team discussed the implementation of the diagnostic and patient management study (DPMS) within the AMYPAD project.

WP lead Giovanni Frisoni from University of Geneva introduced the overall protocol whilst representatives from IXICO and Clintec provided practical updates on the use and integration of electronic case report forms (eCRF). The monitoring plan, the disclosure of amyloid status to research participants and the overall recruitment strategy were additional points which were discussed with the representatives of the eight clinical centres involved in the project: Amstermad, Barcelona, Cologne, Edinburgh, Geneva, London, Stockholm and Toulouse.

https://amypad.eu/

27 March: The MOPEAD project publishes new infographic on normal ageing versus dementia as part of a series of educational materials

On 27 March, the Models of Patient engagement for Alzheimer’s Disease (MOPEAD) project’s communication team released its third educational leaflet. The leaflet is part of a series of materials developed to support awareness of memory problems and the importance of early diagnosis.

The infographic illustrates changes that may occur as a result of normal ageing compared with those that could be associated with dementia. Its aim is to raise awareness of these potentially important differences and encourage people that are uncertain about their mental health to seek help at an early stage. Additionally, it intends to motivate people that are interested in cognitive problems to learn more about Alzheimer’s disease and its symptoms.

You can find the infographic here: https://goo.gl/qYW7TN

www.mopead.eu
EU project acknowledgement

A number of the projects in which Alzheimer Europe is a project partner receive funding from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter with IMI and IMI2 funding are:

- AMYPAD - grant agreement 115952
- EPAD - grant agreement 115736
- MOPEAD - grant agreement 115985
- PARADIGM
- PRODEMONS - grant agreement 779238
- ROADMAP - grant agreement 116020

Alzheimer Europe Networking

On 26 February (Brussels, Belgium), the Board of the Alzheimer Europe Foundation met.

On 26 and 27 February (Brussels, Belgium), the Alzheimer Europe Board met.

On 27 February (Brussels, Belgium), Alzheimer Europe held a Lunch Debate “Will we be able to prevent Alzheimer’s dementia?” in the European Parliament.

On 27 February (Brussels, Belgium), Alzheimer Europe organised a Company Round Table with its sponsors and members organisations.

On 28 February (Brussels, Belgium), Alzheimer Europe organised a Public Affairs meeting with its member organisations.

On 9 March (Brussels, Belgium), Vanessa and Ana participated in the 2nd PACE User Forum.

On 13 March (Brussels, Belgium), Vanessa attended a meeting at the European Disability Forum.

On 13 March (Brussels, Belgium), Vanessa attended a meeting with COFACE Families Europe.

On 13 and 14 March (Turin, Italy), Jean participated in the meeting of the European Alzheimer’s Disease Consortium.

On 15 March (Bristol, UK), Dianne attended a workshop for professionals on dementia and black and minority ethnic communities organised by the Race Equality Foundation.

On 15 and 16 March (Turin, Italy) Jean presented the findings of the 2017 Carers’ Survey at a Roche-sponsored symposium at the AAT-AD/PD Conference.

On 19 and 20 March (Münsbach, Luxembourg), Dianne and Ana participated in the meeting of the European Working Group of People with Dementia.

On 26 March 2018 (Esch/Belval, Luxembourg), Cindy and Chris attended the “Forum Demenz”, a follow-up on the National Dementia Plan for Luxembourg.

On 27 March 2018 (Barcelona, Spain), Jean attended a F2F meeting of the AMYPAD project.

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 (S&D); Hilde Vautmans (ALDE).

**Bulgaria**: Andrey Kovatchev (EPP).

**Croatia**: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).

**Cyprus**: Costas Mavrides (S&D); Eleni Theocharous (EPP).

**Czech Republic**: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP).

**Denmark**: Ole Christensen (NI); Jens Rohde (ALDE); Christel Schaldemose (S&D).

**Estonia**: Urmas Paet (ALDE).

**Finland**: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Merja Kyllönen (GUE/NGL); Sirpa Piletikäinen (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); Kyrrkos Miltiadis (S&D); Dimitrios
EUROPEAN ALZHEIMER’S ALLIANCE

26 February: MEP Annie Schreijer-Pierik joins the European Alzheimer’s Alliance

On 26 February 2018, Annie Schreijer-Pierik, MEP (EPP, Netherlands) joined the European Alzheimer’s Alliance.

Ms Schreijer-Pierik sits on the Committee on the Environment, Public Health and Food Safety. She is a substitute on the Agriculture and Rural Development Committee.

Alzheimer Europe extends a warm welcome to Ms Schreijer-Pierik and thanks her for helping make dementia a European priority.

https://goo.gl/e1UqVc

27 February: Members of European Alzheimer’s Alliance attend Alzheimer Europe’s European Parliament lunch debate

Five members of the European Alzheimer’s Alliance, MEPs Heinz K Becker (Austria), Deirdre Clune, (Ireland) Marian Harkin (Ireland), Rory Palmer (UK) and Keith Taylor (UK) all attended the Alzheimer Europe Lunch debate in the European Parliament on the prevention of Alzheimer’s disease and dementia.

A full report of the event can be read here:

https://goo.gl/aNq5Sd

21 March: Six European Alzheimer’s Alliance members win MEP awards

Winners of the 14th annual MEPs awards (2018), hosted by the Parliament Magazine were announced at an awards ceremony on 21 March in Brussels.

Six of the winners are members of our European Alzheimer’s Alliance:

- Jan Olbyrcht (Poland) won the Economic and Monetary Affairs award
- Brando Benifei (Italy) won the Employment and Social Affairs award
- Soledad Cabezón Ruiz (Spain) won the Public Health award
- Franc Bogović (Slovenia) won the Research & Innovation award
- Biljana Borzan (Croatia) won the Women’s Rights and Gender Equality award
- Andrey Kovatchev (Bulgaria) won the Outstanding Achievement award

The awards are voted for by MEPs only.

www.mepawards.eu

EU DEVELOPMENTS

21 February: Experts warn health risks are being forgotten in Brexit negotiations

Every month, 45 million packs of medicine move from the UK and the EU and 37 million travel from the EU to the UK. It is clear that all experts agree that the UK

https://goo.gl/e1UqVc
needs to be in close cooperation with the EU and that medicines should remain accessible to all patients. There should continue to be seamless trade between the EU. However Brexit risks access to medicines and treatment. This is only one part of the health conundrum of Brexit.

At a meeting of experts in Brussels on “Prioritising patient safety and health across Europe post-Brexit” according to Fiona Godfrey the highly integrated supply chains could be disrupted and thus the UK could receive medicines later and at a higher price.

There are still many unanswered questions said Fiona Godfrey “How will the UK ensure there is no race to the bottom on public health protections? How will the EU and the UK ensure their citizens continue to have consistent access to affordable and necessary medicines and treatments? How will the UK minimise Brexit impact for patients?”

Mark Lloyd Davies from Johnson and Johnson, said that “many Pharmaceutical companies face multibillion contingency costs” and he emphasised that “there must be transition until at least December 2020.”

At the same time some clinical trials on new medicines will be put on hold until they have greater certainty on what the UK’s relationship with the EU is likely to look like.

“Patients need to be able to continue to access appropriate healthcare across the EU and UK and healthcare professionals to be able to practise safely across the EU and the UK with the minimum of bureaucratic obstacles.” said Pascal Garel from HOPE SG

The European health community has issued a joint statement with a list of key unanswered questions that must be answered by the EU and the UK in order to put patients first in phase 2 of the Brexit negotiations.

Both Nicola Bedlington from European Patients’ Forum (EPF) and Heather Clark from European Federation Neurological Associations (EFNA), representing the voice of patients across the UK and Europe at the meeting, highlighted the fact that the UK leaving the EU is not just a UK issue and will impact EU patients too and the number one Brexit concern for patients is again uncertainty.

28 February: EMA adopts a revised guideline on clinical studies for AD medicines

On 28 February, the European Medicines Agency (EMA) announced that it has revised its guidelines on clinical trials for the treatment of Alzheimer’s disease (AD). The document aims to provide guidance to facilitate developments of medicines across all AD stages.

The EMA highlighted that the revision of these guidelines were discussed at several meetings. EMA organised first a workshop for patients, academia, regulators, representatives from the pharmaceutical industry and independent experts to ensure that it was informed of the most up-to-date scientific developments in understanding and treating AD. Several further meetings between EMA and developers of medicines complemented this workshop.

The new guidelines will become effective on September 2018 and will address the impact of new diagnostic criteria for AD such as asymptomatic disease stages and factors to be considered when selecting parameters to measure trial outcomes. Another new section was added on the potential use of biomarkers in the various stages of medicine development.

https://goo.gl/ItUvEmS

19 March: Françoise Grossetête, MEP raises concerns about the future of the Health Programme

The debate around the future EU budget, post-2020 Multiannual Financial Framework (MFF) is hotting up. After the five scenarios laid out by Jean Claude Junker in a European Commission White Paper in March 2017, it is now questionable as to whether health will be a priority of the EU and there are concerns about the future of the EU Health Programme.

Françoise Grossetête, MEP (France), Chairperson of the EAA and member of European Parliament’s ENVI committees spoke out in a debate on the EU budget and raised concerns with DG SANTE representative John F. Ryan about the future of the EU Health Programme:

“We need to ensure that the necessary funding is made available… when I hear about financial restrictions, I get alarm bells in my head,” said Ms Grossetête. She said she was adamantly opposed to putting health funding together with plant and animal health, an idea the Commission floated in a leaked document recently.


MEMBERS’ NEWS

19 February: Alzheimer Sweden completes project on “Persons with Down Syndrome & Alzheimer’s disease in the Swedish care context”

Alzheimer Sverige (Alzheimer Sweden) has finalised a three-year project (2014-2017) on “Persons with Down Syndrome & Alzheimer’s disease in the
Swedish care context”. Alzheimer Sweden was given the opportunity to investigate this area thanks to the foundation Arvsfonden in 2014. They worked together with co-partner the Swedish Down Association.

The mission became to estimate how raising awareness on caregiving-issues surrounding the AD-testing process would benefit the memory testing procedures for this patient group. Alzheimer Sweden knew that genetic drivers result in a high frequency of AD pathology in persons with Down Syndrome (DS); approximately 7 in 10.

Through experience of working with persons with AD (and all types of dementia) for many years, we suspected that the Swedish health system had very little knowledge to support this group in a proper manner and to sustain their quality-of life.

As Alzheimer Sweden promotes early testing and have established a substantial scientific contact-network in Swedish Dementia-society since before the millennium, a pilot study started out 2015 in the three largest health care-regions in Sweden.

In societal terms; the project concludes with a desire to:

- Increase the understanding for all persons about “cognitive decline” and the specific disease progression of AD in persons with DS.
- To strengthen the care-giver perspective – Psycho-social and socioeconomic expectations and attitudes about caregiving when testing for AD, time after diagnosis and disease progression.
- Society – inclusion (key value for the IDD & Down -society) & Dignity (Key value for AD-society). Discussion about how persons with DS & AD get treated by other citizens where they live and what quality-of-life really means in the broader sense.

Alzheimer Sweden is now contemplating whether to go forward and find funding to continue the project in a suitable and innovative form. Intrinsic actions that are outlined in a possible plan would be:

- To carry on with the pilot study of random testing procedures of persons with DS and AS in the three largest health care-regions in Sweden
- and in parallel to that, conduct an analysis of the caregiver perspective.
- To continue with the well-renowned education programme for staff at care homes in the south of Sweden.
- Finally, to carry on with the dialogue that has started out in IASSID that brings attention to persons with DS & AD.

There are many caregivers of persons with DS interested, if the project were to continue.

To hear more about the learnings, book a Skype session, a meeting, or even a presentation/workshop or similar, please email Karin@alzheimersverige.se

25 February: Spominčica – Alzheimer Slovenia tells us about its involvement in new IONIS project

IONIS Spominčica – Alzheimer Slovenia has started its involvement in IONIS project.

IONIS (Indoor and outdoor NITICS plus solution for dementia challenges) will integrate technologies and services to provide new solutions to problems and difficulties of people with dementia. The IONIS solution can compensate in an adaptive way for mild to moderate dementia associated challenges such as memory problems and cognitive decline.

The integrated technologies and services will offer support to both care users and caregivers. By providing new technologies and services it will support the autonomy of people with dementia and significantly improve the quality of life of people with dementia and their care partners.

There are 10 partners from 5 European countries involved in the project, which began in October 2017 and will end in March 2020. The IONIS project is co-funded by AAL - ACTIVE AND ASSISTED LIVING PROGRAMME - ICT for ageing well.

26 February: France Alzheimer introduces a new app for carers

A new French language app has been launched for family carers, announced France Alzheimer on 26 February. The app, Familicare, was developed by nurses from Caen in the Normandy region of France. It aims to help family carers to manage their day-to-day role and allow them to support their loved one in staying at home for as long as possible. It includes a profile of the dependent person, medical treatment and background, tabs with numbers to call in case of emergency, appointments, geo-location and in the longer term, it will also be possible to find nearby healthcare professionals using the app.

The Familicare app is freely available via GooglePlay. 

https://www.francealzheimer.org/application-dediee-aux-aidants/

28 February: Alzheimer’s Society launches the first ever dementia-friendly utilities guide

On 28 February 2018, the Alzheimer’s Society launched its dementia-friendly utilities guide, asking businesses to unite against dementia and commit to better supporting customers affected by the condition.

Utilities like gas, water and a phone line play an essential part of a person’s home life – but the Alzheimer’s Society has found that sadly many utilities companies are failing vulnerable people with dementia. Dealing with bills, booking appointments and having unexpected disruption to your
energy, water or communications can be dangerous, confusing and extremely difficult to navigate when you have dementia.

The guide was launched at an industry-wide event. Sector representatives heard from the Secretary of State for Business, Energy and Industrial Strategy, The Rt Hon Greg Clark MP, CEO of Ofgem Dermot Nolan and Alzheimer’s CEO Jeremy Hughes about the current situation, which sees many utilities businesses failing vulnerable people with dementia and their carers.

The Alzheimer’s Society developed the guidance with input from people with dementia and their carers, and also with utilities businesses who are already taking active steps to becoming more dementia friendly.

The guide itself includes key information on dementia, anecdotes of the difficulties utilities can cause for people living with the condition and examples of best practice already being implemented by some leading utilities companies in an effort to address these issues.

In the guide, practical advice on protecting vulnerable people with dementia is offered to utilities companies of all sizes - such as ensuring processes like comparing tariffs are straightforward, and encouraging staff to become Dementia Friends.

“We hear too often from people with dementia and their families who are struggling with their Utilities providers - from the woman in her 90s, living alone, who had her phone line cut off just before Christmas to the man paying hundreds of pounds for TV services he didn’t even realise he had...too many vulnerable customers are being failed and urgent action is needed to change this” - Jeremy Hughes, CEO at the Alzheimer’s Society.

For more information on the campaign, and to download the guide, please visit: www.alzheimers.org/uk/utilities

12-18 March: Finland marks Brain Awareness Week with a number of events

The Alzheimer Society of Finland and its member associations held many events and were active on social media during Brain Awareness Week 2018, from 12-18 March. Memory associations held “Brain Parlours” together with other Finnish associations for persons with neurological disorders and diseases.

This year, the theme was to “cherish our brain”, and it especially emphasised the importance of taking things easy - chill and rest – because our brains “need some easy-living” to function properly.

12-18 March: Alzheimer Croatia celebrates Brain Awareness Week 2018

“Open doors” events organised by Alzheimer Croatia to mark World Brain Awareness Week 2018 featured two public speeches about Alzheimer’s disease and the safety of people who live with dementia in their private homes. This was an opportunity for numerous people who visited the offices of Alzheimer Croatia for the first time to speak about their caregiving problems and to receive expert advice.

These events were also a good opportunity for promoting the Dementia Friends initiative and to gain new supporters.

Pictured: Brain Awareness Week 2018 in Alzheimer Croatia

15 March: Alzheimer’s Society reports back from UK-Japan meeting “Forging partnerships for a world without dementia”

On 15 March 15 2018 Jeremy Hughes, Alzheimer’s Society’s CEO, attended a UK-Japan Dementia Conference in Tokyo. The conference was hosted by Nikkei Inc and the Financial Times and in collaboration with the World Dementia Council (WDC). The conference aimed to raise awareness of the importance of international collaboration in combatting dementia and pioneering sustainable initiatives. Following the conference, a seminar on care research was hosted by the British Embassy.

The events marked the unique partnership on dementia forged between the UK and Japan. There have been many learning exchanges between both nations; most notably Japan’s development of the inspiring Dementia Supporter programme and now Alzheimer’s Society’s growing Global Dementia Friends Network. In 2016, both countries partnered on dementia and age friendly communities and established Global Dementia Friends Ambassadors to help raise awareness of the condition. UK actress Carey Mulligan and the Japanese alpinist Yuichiro Miura have since brought international attention to the benefits of making communities’ dementia friendly. The collaboration doesn’t stop there. Future collaboration was reinforced in a video statement from the UK Secretary of State Jeremy Hunt and via a speech by Minister Katsunobu Kato. In a recent blog Jeremy Hunt reaffirms this commitment saying:

“We cannot achieve our ambitions for dementia alone. Our partnership with Japan, which shares so many similar challenges associated with an ageing population, has demonstrated that we are far stronger when we collaborate beyond our borders.”

During the conference there was recognition of progress made, but also of how far we still have to go. Every drug development failure actually embodies learnings that can contribute to a future success, but researchers need to share data with one another to ensure this happens. Governments worldwide must commit to develop national dementia plans to realise the WHO Global Action Plan on Dementia goals. Across both events, researchers from UK universities presented alongside Japanese counterparts and leading
companies such as Eisai (developers of Aricept) and Sony. Hilary Doxford, from the newly formed Three Nations Working Group of People with Dementia proved a powerful advocate for people affected by dementia.

Our partnership with Japan shows how valuable cross-border collaboration is when it comes to answering one of the biggest global health challenges of our times. Whether it’s in Japan, the UK or anywhere on the planet, we must unite together to ensure that the rights of people affected by dementia are never forgotten.

17 March: Hugely successful 10th annual Caregivers Day held in Greece

On 17 March 2018, the Alzheimer Athens organised, for the 10th year in a row, a full-day event dedicated to caregivers of people with dementia. The motto for this year’s event, known as “Caregiver’s Day” was “Caring Does Not Mean Falling to Pieces”. The event consisted of workshops in which dementia caregivers had the chance to get informed about dementia-related issues such as: memory loss, symptoms and stages of Alzheimer’s, heredity of the disease. They also were taught pharmacological and non-pharmacological ways to handle troubling behavior of people with dementia and how to deal with practical issues of daily care. Overall caregivers had the chance to share their concerns and thoughts.

Dr Paraskevi Sakka’s introductory speech about Dementia Friendly Communities in Greece and the implementation of the Greek Dementia Strategy was followed by neuropsychologist Areti Efthimiou’s speech about online educational opportunities and tools for dementia caregivers. The last speech was by Dr. Kostis Prouskas, psychologist/gerontologist, who presented concrete directions and advice on interacting with people with dementia. Later on, caregivers were divided into groups and participated in workshops coordinated by experienced health professionals. These workshops provided caregivers with a deeper understanding of dementia, caregiving skills and the ability to manage their feelings and cope with the losses they may experience.

A total of 400 caregivers from all over Greece participated in the event and 200 more were given printed material, along with Alzheimer Athens’ invitation to visit its daycare centres and benefit from a wide range of provided services. During the event, 60 new members joined the organisation.

The speeches were broadcast live, via Alzheimer Athens’ Facebook page and website, and more than 750 people watched the live streaming from their homes. Audience engagement was extremely high on social media as well. Many comments and messages were received and the organisation was able to reach more caregivers than in any previous year.

22 March: People with early-onset Alzheimer’s aren’t listened to enough, concludes Alzheimer Society of Finland survey

When the memory-related disease is diagnosed while still working (under 65 years), success depends on three things:

- the person with memory problems is taken seriously
- the symptoms are investigated thoroughly
- and action is taken immediately.

These were the main conclusions of a survey, carried out by the Alzheimer Society of Finland, of people with early-onset Alzheimer’s disease or other memory-related diseases. Over half of the respondents said that they were not heard enough in working life or health care after they noticed problems with their memory or after they received a diagnosis.

In some cases, it took a long time to get a diagnosis and that is why respondents felt uncertain before getting the right diagnosis. Some of the respondents felt that their opinions and views were underestimated or they had to visit way too many authorities.

Two thirds of respondents said that they did not continue working after their diagnosis and almost half did not continue working after symptoms appeared.

Many employers had a positive attitude for finding solutions, but in practice the employment relationships were not continued or the rehabilitation was not supported in any way. Colleagues were usually amongst the first ones to notice that something isn’t “right”.

19 March: City of Umag becomes second Croatian Dementia Friendly Community

Umag, a North Adriatic Croatian city well known for the tennis ATP tournament, is the second city to have signed an agreement with Alzheimer Croatia on becoming a Dementia Friendly Community.

This is a natural extension of the results achieved in the European Interreg project Demenca aCROsSLO in which, among others, Umag takes its place with Alzheimer Croatia, stated City Mayor Vili Bassanese.

It is expected that among the first goals of City of Umag will be further improvements to support provided for people with dementia in their private homes.

Pictured: Vili Bassanese, Mayor of City of Umag (right) and Tomislav Huić, director of Croatian Dementia Friends Initiative, with signed pledges.

https://goo.gl/BBwPu8
Given that public authorities do not currently offer any similar programme that can provide a solution in the midterm, before institutionalisation, FAE considers this to be quite innovative in nature, as it favorably affects the quality of life of the person with dementia and their families, and is an effective alternative for maintaining their capacities and favouring more respite for caregivers.

Finally, FAE, in collaboration with CEAFA - Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias, is still working conscientiously on the upcoming 28th Alzheimer Europe Conference (#28AEC), which will take place in Barcelona from 29 to 31 October 2018.

23 March: Alzheimer Society of Ireland launches new regional group of its Dementia Carers Campaign Network

The Alzheimer Society of Ireland (ASI) is delighted to announce the launch of a new regional group of its Dementia Carers Campaign Network (DCCN).

The DCCN is a national campaigning group which was established in 2013. It is made up of people who have experience caring for a loved one with dementia and aims to raise awareness of issues affecting families living with dementia. To date members have been involved in monitoring the implementation of Ireland’s first National Dementia Strategy, taken part in national and local media work, contributed to research programmes and spoken at conferences and events across Ireland. The new regional group known as the Southern DCCN will focus on highlighting issues affecting dementia carers in the south of Ireland.

Pictured: Carers at the first meeting of the Southern DCCN in Co. Limerick on Friday, 23rd March 2018

26 March: Members of the Panhellenic Federation of Alzheimer’s Disease and Relative Disorders participate in RECage project

RECage tries to tackle one of the most challenging symptoms of the clinical course of dementia: the so called Behavioural and Psychological Symptoms of Dementia (BPSD). The major objective of REspectful Caring for AGitated Elderly (RECAGE) will be to adapt and upscale the implementation of a particular intervention aimed at controlling BPSD, the special medical care unit for persons with dementia and BPSD (SCU-B), an intervention that has already been implemented in some European countries.

The mission of the SCU-B is to improve patients’ behaviour and its goal is to allow, when possible, their return home. The therapeutic approach in most existing SCU-Bs is a mix of cautious pharmacologic treatment and non-pharmacologic...
therapies (such as occupational therapy, physiotherapy, doll therapy, sensory room and so on).

The specific objectives of RECAGE are:

- To start a prospective cohort study, comparing the activity of the centres endowed with a SCU-B of both types, with that of the other centres lacking this structure.
- To adapt the model in accordance with the results of the cohort study, not only regarding the main endpoints, but also comparing the experience and the different working methods of participating centres and the different socio-political context in which they act.
- To scale up the intervention in the countries taking part in the study, but where SCU-Bs are absent, or sporadic, such as Italy and Greece.

Regarding the observational study, 12 clinical centres, distributed across 7 European countries (Italy, France, Germany, Belgium, Greece, Switzerland and Norway), will follow up over time – during 3 years – the persons who have moderate dementia and behavioural problems, with visits every six months. Six centres are able to admit patients to a SCU-B, during a short time, should they have a behavioural crisis, which is difficult to control using normal medication. The other six centres don’t have this facility and can do only outpatient visits. The total number of persons enrolled in the study will be 500. Half of these (250) will be cared for by centres with a SCU-B and the other half (250) by centres without a SCU-B.

POLLICY WATCH

7 March: Ireland ratifies the UN Convention on the rights of persons with disabilities (CRPD)

Alzheimer Europe shares Ireland’s delight and welcomes the news on the ratification by Ireland of the UN Convention on the rights of persons with disabilities (CRPD). This is a big day for persons with disabilities including people living with dementia in Ireland. Congratulations to all those that campaigned tirelessly to make this happen.

On 8 March, the Dáil (House of Parliament) passed a resolution that enables Ireland to ratify the CRPD. Ireland is the last of the 28 European Union Member States to ratify this international human rights treaty. Ireland signed the CRPD in March 2007, and waited more than 10 years to ratify.

The approval of the resolution by the Dáil will be followed by the depositing of the instrument of ratification with the United Nations. The CRPD then enters into force 30 days after being deposited.

The ultimate goal of the UN CRPD is to set out the rights of people with disabilities, and provide a path to achieving those rights. By becoming a party to the CRPD, a state affirms these rights. It also commits to working towards achieving these rights within its laws, policies, and culture.

The CRPD does not create any new human rights. Instead, it states that all existing human rights apply equally to people with disabilities. States must take all necessary actions to ensure that people with disabilities are able to enjoy and exercise the full range of human rights.

Member of the Irish Dementia Working Group and Chair of the European Working Group of People with Dementia, Helen Rochford Brennan is delighted that the UNCRPD has been ratified:

“This convention can keep the will and preference of people with dementia at the centre of all decisions. There are specific articles in relation to people with dementia: article 12 deals with rights to equal treatment before the law; article 13 deals with having access to justice on an equal basis with others; article 19 deals with being included in your community, and article 27 is about no discrimination in employment. This is all about personhood. The Convention ensures that we can participate in society on an equal basis with others and I am delighted to see that it has finally been ratified.”

12 March: Further investment announced for UK Dementia Research Institute

On 12 March, a GBP 40 million (EUR 45 million) investment in the UK Dementia Research Institute (DRI) was announced by the UK Government. This now gives the DRI a total budget of GBP 290 million - 190m from the Medical Research Council, 50m from the Alzheimer’s Society and 50m from Alzheimer’s Research UK.

The new funding from the Department for Business, Energy and Industrial Strategy will help build a new DRI Hub at University College London, which is due to open in 2023.

https://ukdri.ac.uk/

13-14 March: World Dementia Council welcomes new Chair and launches translations of its Global Care Statement in Tokyo

During the 12th meeting of the World Dementia Council (WDC) in Tokyo, Japan on 13 and 14 March 2018, a number of translations of the WDC's Global Care Statement were announced. The Statement, launched in May 2017, stresses the importance of care and support for those affected by dementia and their families. It has now been translated into eleven other languages with the help of Council members and associate members. The hope is that the availability of the Global Care Statement in numerous languages will help increase the reach of the Global Care Statement and its Calls to Action.
The Global Care Statement stresses that everyone affected by dementia has a human right to receive the highest quality care and support possible; to be treated with dignity; and to be entitled to full and effective participation and inclusion in society. The Global Care Statement includes two Calls to Action designed to help ensure these rights, calling on all the world’s governments and governing bodies to adopt, implement, and ensure high-quality, person-centered care and support for people living with dementia; and for all health and social care systems to fund and provide access to high-quality, person-centered dementia care and support services.

Also during the meeting, the WDC welcomed Care Global Team lead and incoming Chair, Harry Johns. Mr Johns said, on the subject of the translations of the Statement: “We hope that governments, governing bodies, health and social care systems, care providers and communities in all parts of the world will adopt these urgent priorities and calls to action, to ensure that those living with dementia and their families are given the highest quality care and support possible to meet their needs.”

Departing WDC Chair, Dr Yves Joanette said:

“WDC’s Global Care Statement is critically important in specifying what needs to be done to offer person-centered, high-quality care and support to everyone affected by dementia world-wide. We wish to acknowledge the support from our members, the World Young Leaders in Dementia (WYLD) and Alzheimer’s Disease International (ADI) for their help and support in translating these important Calls to Action and Principles of High Quality Care and Support.”

The English Global Care Statement and other available languages (Chinese, Dutch, French, German, Icelandic, Italian, Japanese, Portuguese, Romanian, Spanish and Swedish) can be downloaded from the WDC Website: https://www.worlddementiacouncil.org/news/wdc-publishes-translations-global-care-statement

21 March: Luxembourg Ministry of Health and local institutions give update on implementation of National Dementia Plan

On 21 March 2018 (Esch/Belval, Luxembourg) the “Forum Demenz”, a follow-up on the National Dementia Plan for Luxembourg took place. The aim of the meeting was to provide a follow-up on the implementation of actions derived from the National Dementia Plan for Luxembourg five years into the project.

The meeting was chaired by Dr Carine Federspiel, President of the Luxembourgish Association of Gerontology and Geriatrics. The first session focussed on the recently finalised guideline “People with dementia in hospitals”. This guideline constitutes a multidisciplinary effort for use at the heart of the healthcare system with recommendations for adoption in hospitals. It will be released in French and German. After an introduction by Dr Françoise Berhet, Luxembourgish Ministry of Health, Lydie Diederich, Association Luxembourg Alzheimer (ALA), provided an overview of the rationale behind its development and gave an overview of its pillars. Topics revolved around meeting knowledge gaps, a need for a better exchange of information between the ALA and hospitals, specific needs of patients with dementia as well as the potential of systematic screenings.

The next session, held by Jennifer Kemp, Ministry of Health and University of Luxembourg, focussed on the personalised prevention of dementia through the dementia prevention programme. She introduced the second stage of this project, led by Prof. Reiko Krüger. The aim of the programme is to positively influence the progression of memory deficits through the combination of diverse interventions that focus on prevention. The new target groups for the second phase of the project are people with mild cognitive impairment (MCI) and people with mild dementia that are still able to carry out their activities of daily living.

Next, Jean-Marie Desbordes, Info-Zenter Demenz, gave an overview of the activities of the Centre for Dementia Information as well as impact measures of their communication activities. In order to provide public information on dementia and support people affected by dementia and their relatives, the Centre for Dementia Information launched a website as well as a Facebook page. In addition to that, they provide a helpline, informational events and have an office at which they also provide further informational materials and videos in French, German, English and Portuguese.

The last session comprised three presentations on the basic module “dementia”, which is part of the psycho-geriatric education programme. First, Murielle Weydert, Ministry of Health, gave a general introduction of the programme. After that, Simon Groß, RBS – Center vir Altersfroen, provided a first-hand insight into the educational video sequences they developed to support discussions as part of the programme. Topics include amongst others challenging behaviours. Finally, Denis Mancini, ALA, gave a comprehensive explanation of the content discussed within the different sessions of the course.

AE Project Officers Cindy and Chris attended the meeting.

22 March: Voices of people with dementia and carers crucial in informing policy on safeguarding vulnerable adults in Ireland

The Alzheimer Society of Ireland (ASI) was recently invited to prepare a submission on current policy, Safeguarding Vulnerable Persons at Risk. The submission concentrated on how safeguarding policy is experienced and how it is working in practice for current users of the policy. In developing ASI’s submission, Dr Bernadette Rock, Policy and Research Manager, sought the views and experiences of both internal and external stakeholders. Crucially, the voices of people with
dementia and their carers also were highlighted and emphasised as part of this Submission.

To this end, three members of the Irish Dementia Working Group took part in a focus group, all of whom have young onset dementia. A further focus group was carried out with six residents of a day care centre whose dementia is at a progressive stage. In addition, nine members of the Dementia Carers Campaign Network took part in a focus group. Participants with dementia were asked questions including:

- What does being safe/unsafe mean to you?
- What would make it difficult for a person with dementia to report abuse?

This was the first policy submission that sought to include the views and experiences of people with dementia at various stages of the condition. The voices of people with dementia were crucial in informing ASI’s submission on the safeguarding of vulnerable adults. It is anticipated that future ASI policy submissions will continue to give people with dementia the opportunity to participate and have their voices heard.

26 March: A draft National Dementia Plan is on the horizon for Turkey

Regrettfully, there is no structured National Dementia Plan in Turkey to date, however the Turkish Alzheimer Association (Alzheimer Derneği) is currently working on a Draft Plan, anticipating presentation to the Ministry by the end of 2018.

Nevertheless, there are certain initiatives taken by the Ministry of Health and the Ministry of Family and Social Policies, to define and describe the position and rights of the elderly.

The first initiative “The Strategic Plan 2013-2017” was delivered by the Ministry of Family and Social Policies, where the gradually increasing elderly population was defined as a “risk group” in terms of social service and aid, along with children, family, disabled people and women for the first time and the need for the design of new social models for them due to the insufficiency of financial resources was addressed with emphasis. The Strategic Plan aims to improve the quality of life for elderly people and provide active aging, through projects and activities like research and analysis, workshops, cooperation and collaboration and design of a National Elderly Action Plan. The Plan also recommends taking precautions to avoid problems in elderly care and develop policies and models that serve this field, such as an Elderly Care Assurance Model and Elderly Care Insurance.

The second action was the “Turkish Healthy Aging Action Plan and Implementation Program 2015-2020” (ISBN 978-975-590-520-4) published by the Ministry of Health. This Plan was prepared to better address the needs in providing accessible, proper, effective and efficient health services to individuals, the public and physically or mentally disabled people or to those who have special needs due to their social or economic conditions. The target and priority of the strategies are defining the fundamental framework of the supportive work to be performed together with shareholders, institutions and organisations.


The most recent publication in the domain is the book by the Ministry of Health, named “Elderly Health” which describes all the possible diseases that may challenge the elderly and which accommodates the initial mention of dementia.

The Turkish Alzheimer Association has assembled a National Dementia Action Plan Working Committee, made up of five medical doctors who are Board members of different branches of the association. The first draft is expected to be ready by the end of May.

26 March: One year on from launch of Global plan on dementia, ADI invites governments to share knowledge and best practices

Alzheimer’s Disease International (ADI) is preparing to celebrate the one-year anniversary of the adoption of the Global plan on dementia, by hosting a side event at the World Health Assembly in May, 21-26 May 2018.

The event will mark the landmark opportunity the global plan provides for all countries to develop tailored responses to dementia and will bring together representatives of several governments to discuss best practise and share knowledge.

The Global plan contains a target for 146 governments to discuss best practice and share knowledge. The event will mark the landmark opportunity the global plan provides for all countries to develop tailored responses to dementia and will bring together representatives of several governments to discuss best practise and share knowledge.

We are actively looking to engage ministers in your country to attend the event, and to especially engage representatives of those countries that do not have an existing response to dementia. More details will be shared soon.

If you believe this would be interest to your government, we would love to hear from you. Please contact James Smith, Communications and Policy Officer, at: jsmith@alz.co.uk
We hope to see many of you in Geneva in May.
SCIENCE WATCH

12 February: NIH-funded study looks at associated risk of congenital heart defect and dementia

On 12 February, scientists from Aarhus University Hospital, Denmark, published their investigation of the association between congenital heart defect and dementia in the journal Circulation. The congenital heart defect (CHD), often also referred to as disease, is an abnormality that manifests when the heart or blood vessels near the heart don’t develop normally before birth.

According to previous evidence, research showed that children born with heart problems such as CHD are at an elevated risk of developing neurological issues. Although it should be noted that over the last decades medical and surgical interventions have improved exponentially.

The team used medical registries and a records review to cover all Danish hospitals in order to identify adults that were diagnosed with CHD between 1963 and 2012. From these, the researchers were able to study information from 10,632 adults born between 1890 and 1982.

For their analysis, the researchers matched 10 members of the general population by sex and birth year to each individual identified with CHD. The calculations showed that the people developed dementia in more cases depending on the severity of their CHD than the general population. Interestingly, the team also found that the probability of developing dementia with early onset (under the age of 65) was particularly higher in their sample set.

Noting that these results cannot be directly applied to young adults diagnosed with CHD in the present eras, the scientists concluded nevertheless that it is pivotal to recognise healthcare needs and risk factors affecting the larger number of middle aged and older adults currently living with CHD.

https://goo.gl/jI27hL5

21 February: Mark Zuckerberg to fund early career scientists in the field of neurodegenerative disease research

In 2016, Facebook co-founder Mark Zuckerberg and his wife, Priscilla Chan, launched the Chan Zuckerberg Initiative with the ambitious goal of curing all diseases before the end of the century.

Now, the Chan Zuckerberg Initiative is setting its sights on neurodegenerative diseases such as Alzheimer’s and Parkinson’s. Over the next five years, it plans to hand out USD 2.5 million (EUR 2.03 million) in funding to early career scientists in the field of neurodegenerative disease research, with the aim of jumpstarting their work. In addition, it plans to give USD 1 million (EUR 813,000) over three years to scientists in different fields that want to apply their work to neurodegeneration.

Much of the Chan Zuckerberg Initiative’s funding efforts have focused on basic research, which can often have trouble getting funding despite the critical importance of such research in solving problems of disease further down the road. The same goes for the new neurodegenerative research grants, for which applications are now open.

https://goo.gl/KvrxzZ

27 February: Brain amyloidosis alone did not predict progression to prodromal Alzheimer’s disease within 30 months in INSIGHT-preAD study

THE LANCET Neurology

On 27 February, a team of French scientists, led by Prof. Bruno Dubois, published an investigation into the progression of cognitive decline in people with preclinical Alzheimer’s disease (AD) to prodromal AD, in The Lancet Neurology journal.

Data from the observational INSIGHT-preAD study provided information on 318 participants aged 70-85 years with subjective memory complaints (SMC) but unimpaired scores in memory and cognition tests. These were allocated to two groups, either with or without the AD-associated brain amyloid β deposition. The researchers identified amyloid β deposition using medical imaging of the brain (18F-fluorodeoxyglucose (18F-FDG) PET) in 88 cases. All participants also underwent clinical and neuropsychological assessments as well as other noninvasive methods to monitor the brain and its activity during a span of 30 months (EEG, MRI & PET).

Surprisingly, only 4 of the 88 subjects with amyloid β deposition progressed from preclinical to prodromal AD over these 30 months. In addition to this, the cognitively healthy participants with SMC didn’t diverge from those with depositions regarding their cognition both at the initial testing as well as at a follow-up 24 months later.

The team explained that this low number might be due to (amongst other factors) the high level of education in their study sample.

Regarding the implications of their findings, the authors concluded that future clinical trials on interventions in people with preclinical AD should incorporate large numbers of participants and last longer than 30 months in order to be able to assess clinical efficacy.

https://goo.gl/HwbwA3

28 February: Scientific Advisory Committee on Nutrition publishes independent report on diet, cognitive impairment and dementia

On 28 February, the Scientific Advisory Committee on Nutrition (SACN) published an independent position statement with a
comprehensive overview of available evidence that might be considered relevant to the prevention of cognitive impairment and dementia.

The report of evidence which focuses on the prevention rather than treatment, encompasses publications that assessed or evaluated the effects of nutrients such as vitamins and fatty acids, but also other components like flavonoids and caffeine. The overview includes the review methodology as well as limitations of the evidence base, an overall summary and research recommendations.

Overall, the position statement concluded that:

- the evidence base in this area is very limited
- there is no evidence that specific nutrients or food supplements affect the risk of cognitive impairment or dementia
- there is some observational evidence that greater adherence to a Mediterranean dietary pattern may be associated with reduced risk of mild cognitive impairment and dementia.

While a variety of Mediterranean diets exists, they tend to share features such as a higher consumption of vegetables, fruits, cereals, legumes, fish and monounsaturated fatty acids along with less saturated fat, dairy products as well as meat, and a moderate consumption of alcohol.

The UK government concluded that Mediterranean type diets broadly align with current UK healthy eating recommendations as depicted in the Eatwell Guide (PHE, 2016).

Looking to future assessments, the SACN recommended the development of evidence through large randomised controlled trials (RCTs) that take into account long-term effects of early nutrition on risk of later life cognitive impairments also considering different ethnic groups and examining effects on separate dementia types.

1 March: Researchers publish pimavanserin trial results for AD psychosis

Pimavanserin is a selective serotonin inverse agonist and antagonist approved by the US Food and Drug Administration (FDA) to treat Parkinson’s disease psychosis.

The company Acadia Pharmaceuticals, which develops innovative therapies in the nervous system area, conducted a Phase II clinical trial in the UK to evaluate the safety, tolerability, and efficacy of pimavanserin in people with Alzheimer’s disease (AD) psychosis. The randomised, placebo-controlled and double-blind phase II study included 181 participants (50 years or older) assigned to receive pimavanserin (two 17 mg tablets daily) or placebo.

The full data analysis of the Phase II study has been detailed in the March issue of the journal Lancet Neurology. The research study led by the University of Exeter Medical School (Exeter, UK) reported that pimavanserin could significantly reduce psychosis, after 6 weeks of treatment, in participants with AD compared to placebo. In addition, the drug was well tolerated, with no negative effects on cognition or motor function. However, after 12 weeks of treatment, no significant decrease in psychosis was observed compared to the placebo group.

https://goo.gl/sc43Hx

1 March: Study suggests that stabilising the endosomal network could reduce amyloid beta and tau levels in human neurons

On 1 March, US researchers from University of Washington published an article in the journal Stem Cell Reports, suggesting that an experimental compound can reduce the amount of toxic proteins implicated in brain-cell death in Alzheimer’s disease (AD). Both amyloid beta peptides and tau proteins are known to be implicated in AD.

In the published study, scientists used stem cells from healthy people and people with AD. They tested a compound to stabilise the retromer, a highly conserved multiprotein assembly that plays a pivotal role in the elimination and trafficking of proteins through the endosomal network. Previous research suggested that the defect of this system leads to an accumulation of amyloid beta and tau in AD brains.

The team, led by Jessica Young, found that the experimental compound R33 could enhance the function of the endosomal network and reduce the production of amyloid beta and tau as well.

http://www.cell.com/stem-cell-reports/fulltext/S2213-6711(18)30057-2

5 March: Scientists report epigenetic changes during normal aging are negatively correlated with changes in AD

In a study published online on 5 March in the journal Nature Neurosciences, US researchers from the Perelman School of Medicine at the University of Pennsylvania studied how ageing could affect the epigenetic profile of Alzheimer’s disease (AD).

Epigenetics is the study of heritable changes in gene expression that do not involve changes in the actual DNA sequence itself. Previous studies showed that epigenetic factors that integrate environmental stimuli into structural changes are major determinants of whole organism aging.

In the published study, researchers reported the first genome-wide profile of the histone modification H4K16ac in AD human brains. They compared the epigenetic changes in the lateral temporal lobe area, one of the regions affected early in AD, of AD individuals as well as younger and elderly cognitively normal controls.

Scientists found that normal aging led to increased H4K16ac, while AD caused losses of H4K16ac in the proximity of genes linked to aging and AD. In addition, results described an
association between the genomic locations of H4K16ac changes and genetic variants identified in prior AD genome-wide association studies.

http://www.nature.com/articles/s41593-018-0101-9

6 March: Bart De Strooper, Michel Goedert, Christian Haass, and John Hardy win 2018 Brain Prize for their ground-breaking Alzheimer’s disease research

On 6 March, the Lundbeck Foundation announced the prize-winners of this year’s annual Brain Prize at the spring meeting of the Danish Society for Neuroscience. The most valuable prize for brain research was awarded to Bart De Strooper (Belgium), Michel Goedert (Luxembourg), Christian Haass (Germany), and John Hardy (UK).

It recognises the pivotal work of the world’s best neuroscientists and has been awarded since 2011. The prize acknowledges the researchers “for their ground-breaking research on the genetic and molecular basis of Alzheimer’s disease (AD), with far-reaching implications for the development of new therapeutic interventions as well as for the understanding of other neurodegenerative diseases of the brain”.

The Lundbeck Foundation stated in its press release that; “these four internationally respected neuroscientists have revolutionised our understanding of the harmful changes in the brain that lead to AD. Their research achievements form the basis for development of the drugs that are currently tested as therapies for the disease”.

So far, there is no disease modifying treatment for AD and due to the demographic change, its societal impact is on the rise, giving even more importance to the development of new medicines and a better understanding of the development of AD.

Christian Haas contributed to today’s knowledge that the gathering of beta-amyloid between brain cells is the result of an imbalance in production and removal of amyloid. Bart de Strooper’s specific description of how secretases work and how they are built led to the development of medicines that can either lower the production or increase removal of beta-amyloid. Michel Goedert proved that tau is the most important part of tangles and showed with his experiments that it is likely that tau plays an important role in the development in AD. John Hardy’s research focuses on genetic mutations that can cause AD. Based on his genetic studies, John Hardy and his co-workers were the driving force behind the hypothesis that accumulation of beta-amyloid is the cause of AD.

On 9 May, the Brain Prize will be presented at a ceremony in the Royal Danish Library Black Diamonds Building in Copenhagen. Around half of the EUR 1 million is donated to brain research.

http://www.thebrainprize.org

7 March: eHealth is falling short of its potential in the EU, study finds

A study has concluded that health apps are failing to reach their potential in the EU. The report, written by health policy and communications agency Incisive Health, examines findings from exclusive polling undertaken in seven EU countries: Austria, Bulgaria, Estonia, France, Germany, Italy, and the UK. It shows that public attitudes towards eHealth are mixed and while some healthcare systems are embracing new technologies, others are well behind.

The full report is here: https://goo.gl/6QViHX

7 March: EIP Pharma publishes positive Phase Ila AD findings with neflamapimod

On 7 March, the private company EIP Pharma LLC, which advances CNS-focused therapeutics for improved patient benefit, announced the publication of positive results of its Phase Ila Alzheimer’s Disease (AD) study with neflamapimod. Neflamapimod is a brain-penetrant oral small molecule that inhibits the intra-cellular enzyme p38 MAP kinase alpha, a kinase suggested to lead to the dysfunction of synapses that underlies memory deficits in AD. The 3-month phase Ila trial investigated the efficacy and safety of neflamapimod in 16 participants with early AD.

Findings, published in the journal of Annals of Clinical and Translational Neurology, showed that neflamapimod was well tolerated in participants as well as a significant improvement in tests of episodic memory and learning in people with AD.

Based on these data, the company has started a 6-month randomised double-blind placebo-controlled phase Ib study, REVERSE-SD, to confirm the preliminary findings by evaluating neflamapimod in reversing memory deficits in people with early AD.

http://www.jpreventionalzheimer.com/all-issues.html?article=348

7 March: Researchers identify panel of microRNA biomarkers potentially able to help differentiate between prodromal Alzheimer’s disease and Mild Cognitive Impairment

On 7 March, scientists from the Royal College of Surgeons in Ireland (RCSI) presented 5-year study results on the identification of unique changes within microRNA in high-risk patients with Alzheimer’s disease (AD) at RCSI’s Research Day 2018. MicroRNA is a new class of small molecule that can be found in the cells of plants and animals.

The scientists reported that the changes identified within the microRNA “transcriptome” correlated with the development
of AD and a reduction in neuropsychological measures. The team also compared microRNA in confirmed cases of AD and other dementias and identified biomarkers capable of differentiating the disorders.

The team is currently working with clinical colleagues to translate these insights into a test for patients. Looking to future research, the authors wrote that their panel of distinct microRNA biomarkers could play an essential role for clinical and research applications for prodromal diagnosis.

http://www.rcsi.ie/index.jsp?p=100&n=110&a=11333

15 March: International team of scientists explores possible way to restore cognition in AD mouse model through neuron transplants

On 15 March, researchers from the US, Spain and France published an article on the investigation of a potential new path towards an Alzheimer’s disease (AD) treatment, in the journal Neuron. The scientists wanted to elucidate if it could be possible to restore brain rhythms and cognition using improved neurons in an AD mouse model.

Their investigation is based on evidence showing that damage to specific neurons can change brainwave rhythms and cause a loss of cognitive functions. In particular, the so-called “inhibitory interneuron” seems to be a key player in the management of brain rhythms. These interneurons allow other neurons to send signals throughout the brain in a harmonised way.

The team used genetically improved interneurons and implanted them into the brains of the AD mouse models. Their findings showed that the altered interneurons were then able to control the activity of other cells, which helped to re-establish brain rhythms and improve cognitive functions.

While these results may open up new ways to tackle the pursuit for a cure in future, the plain findings cannot be adapted to humans and remain at a fundamental stage. The scientists are therefore currently examining if the cell therapy is translatable to humans. At the same time, the findings encouraged the researchers to focus on new drug treatments to enhance the function of inhibitory interneurons to improve cognition in AD.

http://www.neuronjournal.org/

17 March: Otsuka and Lundbeck report positive results for the treatment of agitation related to AD

Brexpiprazole is currently indicated for the treatment of schizophrenia and major depressive disorder. Global pharmaceutical companies Otsuka and Lundbeck set up two Phase 3 trials to evaluate the safety and efficacy of brexpiprazole in the treatment of people who have agitation related to Alzheimer’s disease (AD).

Studies were 12-week, double-blind and randomised trials enrolling approximately 700 participants between 55 and 90 years of age with a diagnosis of probable AD and symptoms of agitation. One trial studied fixed doses of brexpiprazole (1 or 2 mg) and the second evaluated a flexible-dose range (0.25, 0.5, 1 and 2 mg).
Top line results released last year announced that brexipiprazole may reduce agitation in people with AD. On 17 March 2018, findings were presented for the first time at the American Association for Geriatric Psychiatry (AAGP) in Honolulu, Hawaii, US. The drug was well tolerated. Both studies showed a significant improvement in symptoms of agitation compared to placebo in people receiving the drug only at its highest dose 2mg/day.


DEMENTIA IN SOCIETY

5 March: Queen Sofia of Spain becomes ADI Ambassador

Queen Sofia of Spain has become an Honorary Ambassador of Alzheimer’s Disease International (ADI), in recognition of her significant personal dedication to dementia research and care globally.

Queen Sofia is also Executive President of Fundacion Reina Sofia and Honorary President of Confederación Española de Familiares de Enfermos de Alzheimer (CEAFA).

https://goo.gl/hzGh8U

9 March: People with dementia involved in all stages and aspects of new UK theatre festival “Every Third Minute”

At the West Yorkshire Playhouse (UK) “Every Third Minute” - a festival curated by people living with dementia - began on 9 February 2018. The festival’s title refers to the fact that every three minutes, someone in the UK is diagnosed with dementia. The first of its kind, the series features a range of performances, discussions and workshops, as well as a new stage adaptation of Lisa Genova’s best-selling novel, “Still Alice”, starring UK television actress Sharon Small (pictured).

The project originated from the theatre’s successful community programme, Every Third Minute Festival Director and Theatre & Dementia Research Associate Nicky Taylor explains:

“It developed organically from our work with older people. Some wouldn’t engage with our regular programme as much. With their guidance to show us what was possible, we eventually began dementia-friendly performances.

“After seeing everything the participants had to offer, it was the natural next step to ask them what stories they wanted to hear and give creative control. Some of the stories out there about people living with dementia weren’t doing justice to the complexity of the experience. It’s so multi-layered.

Loneliness is a big problem for many people with dementia, as friendship circles fall away and people become more isolated. Ms Taylor commented that the group had got “a huge amount from just being listened to and asked questions...They’ve also all really bonded and there’s been a great sense of teamwork. Ownership of the project has been really important too: “Our key curators have also been part of the design process. They’ve been handing the leaflets out with huge pride, sharing what they’ve done and the decisions they’ve made.”

“Every Third Minute” is billed as “a festival of theatre, dementia and hope”. Challenging perceptions of people living with dementia is significant to Ms Taylor and the curators:

“The language we use is very important. It’s living with dementia, not retreating or suffering from it. It’s supporting the notion that it is possible to live well with dementia. People can live a long life with the right support and understanding. It’s also great being able to highlight those moments of triumph when people find a coping strategy that works for them. They are still capable of so much.”

In a festival of many highlights, Ms Taylor is particularly excited about one ground-breaking part of the programme, a trio of new plays, commissioned by West Yorkshire Playhouse, called “Three” The pieces have been co-written by people living with dementia and professional writers.

You can find more information about this festival and the methodology behind it here:

http://www.northernsoul.me.uk/every-third-minute-nicky-taylor-interview/

LIVING WITH DEMENTIA

13 March: Wendy Mitchell blogs about a new Design School for people with dementia

Wendy Mitchell, author of Sunday Times Bestseller book “Somebody I Used to Know” (2018), was diagnosed with Early-onset Alzheimer’s dementia in 2014, at age 58. She has kindly shared this blog post with us, about attending a Design School for People with Dementia in Birmingham, UK on 13 March 2018:

So yesterday saw me heading to Birmingham for an overnight stay. I’d actually snuck this one in as Tuesday was supposed to be a day of snuggling but I couldn’t resist the opportunity, and why? Well I would be seeing my dear friend Agnes Houston.
Agnes was the first person with dementia I remember meeting when I was first diagnosed. It was at my very first event in York. I was in awe of Agnes and it was she who showed me how there was still so much living to be done. It had such an impact on me that I recount the meeting in my book. I saw her quite a few times after that but don’t think I’ve seen her for ages, so when she emailed me about this event in Birmingham I had to fit it in somehow...

I was heading to Birmingham International for a Dementia Design school organised by Dr Julie Christie, from Dementia Centre, Hammond Care. They’d sorted out my travel and someone was going to meet me at the station.

Dawn was meeting me at Birmingham International but in the meantime I had to fight my way out of the train at Birmingham onto a platform that was heaving...then heard someone say it was Cheltenham races today...but luckily there was a nice guard who told me where to get my final train and showed me to the lift.

Dawn was there ready and waiting for me and we made our way to the hotel to be met by the sight of Nigel, followed by Agnes who had brought me Yorkshire tea!, Tommy and Joyce and Paul from Liverpool soon joined the party. Mary Marshall was also there (social worker) along with a new playmate, Kath from Ireland. Dr Julie Christie and Colm Cunningham, Director of Hammonds Care Dementia Centre had flown over from Australia...

Once everyone had arrived and after a cuppa Agnes started off by welcoming us.

Mary then went onto the main aim of the day – Introduction to design and why it matters...[she] showed slides of what she teaches professionals for us to chip in – it focuses on older people – most of the time we don’t think about the design of buildings until things go wrong...confusion between ageing impairments and good design for people with dementia. Most people with dementia are old and dementia adds to the physical and sensory challenges that come with age.

The biggest revelation was around the use of air fresheners! Don’t use air fresheners as they contain harmful agents for people with breathing difficulties – open windows. The automatic air fresheners provide lung problems. Often windows won’t open in hospitals and care home but if the rooms in care homes and hospital are continually hot, which they often are, it can lead to dehydration...Gardens are the most underused area of care homes – as it’s too much hassle. Research has shown the main reasons care staff for not allowing people with dementia to go out is the weather...

Mary talked about design of everyday areas – as the hours passed some key themes kept emerging...

Firstly, we need to join forces with the other disability groups to make places accessible to many. British standards Institute are being re-written in the next 4 years and we must make it include cognitive issues as it currently deals with wheelchair access and visual impairment. The British standard is built into regulations so now is prime time to influence for building regulations. We don’t want new building that still aren’t right when built.

Most cities have ‘disability access panels’ – it’s mainly about wheelchairs and vision impairment – we have to get cognitive and perceptual issues considered. They are a powerful group. Many disabilities rights group are wary of people with dementia.....so we have to get ourselves on those panels, as they believe we don’t have the ability. It’s joining forces with other disability rights groups...many disability groups are established and may not want to see us piggybacking onto their organisation. But our role is to show them the benefit of having us connected.

Secondly, we need to get Architectural schools to allow us to speak at their conferences. We need disability not to be seen as a burden but celebrating what we can do and be enabled to do that and design can be the starting point. A new bunch of students to influence...

The third action could be to focus on one major hotel change that we frequently use for conferences. If we change one hotel group in design that holds conferences...

“A group of like-minded people can change the world” – said Nigel...

Many people said to the Dementia Centre: “You can’t have a design school for people with dementia”

Well we had it today. We’ve redefined what we thought we were here for today as we’ve taken it into the Political and Rights arena.

NB: Ms Mitchell’s original blog post is longer than the text shown here, as we have cut some sections out, purely in the interest of space, but you can read the full blog post here: https://goo.gl/SijgdB

To find out more about Ms Mitchell: https://whichmeamitoday.wordpress.com/

Read more in this article and visit DementiaCentre's homepage from April 2018 to find out about future dementia Design Schools.

Pictured: “Cuppa tea time...Nigel, Tommy, Agnes, Paul, Kathy, me and Joyce....”
23 March: Geert Van Laer gives us his thoughts on joining the EWGPWD

It was the first time I attended a meeting of the European Working Group of People with Dementia. I met a lot of interesting persons over there, from many different nationalities. I also met people from Flanders, my own country (they were from the Expertise centre and the Alzheimer’s association). They are thinking about making a working group of people with dementia in Flanders now. So I would like to join them.

Geert Van Laer (pictured, front right) is a new member of the EWGPWD. He joined during the group’s Luxembourg meeting on 19 and 20 March 2018. You can read more about this meeting in the “Alzheimer Europe” news section.

28 March: Idalina Aguiar tells us about her EWGPWD colleague Petri Lampinen’s visit to Madeira Island

It was with great pleasure that I hosted our dear EWGPWD colleague, Mr Petri Lampinen from Finland, who visited my island, along with Nina, his wife.

I gave them a guided tour, and took them to visit the Alzheimer Portugal delegation, where we had the company of all the technical team that showed everything they do, and what kind of activities are offered to all the people with dementia that go there. The Madeira delegation of Alzheimer Portugal offers a lot of services to people with dementia. We also visited the new day care centre I frequent, called “place of memories”, which is the only such centre on the island, aimed at people with dementia. There, I had the opportunity to show him the “snoezelen room” - the cognitive stimulation room - and all the activities available to the users who attend this day care centre every day.

It was an excellent trip, during which ideas were exchanged and new friendships created.

Idalina is supported by her daughter Nelida, to whom we are grateful for her help in translating Idalina's words to English.

NEW PUBLICATIONS & RESOURCES

21 February: “Young Onset Dementia” book published

“Young Onset Dementia” - written by Dr Hilda Hayo, Chief Admiral Nurse and CEO of Dementia UK, and contributed to by University of Northampton Researcher Alison Ward and Professor Jacqueline Parkes of the Dementia Research & Innovation Centre at the University of Northampton - provides key information and insight into the experiences of people living with a diagnosis of young onset dementia.

To find out more or to purchase the book visit https://goo.gl/9uoPds

3 March: New EDF human rights report looks at SDGs and the UNCRPD in Europe

On 3 March, the European Disability Forum (EDF) presented its second human rights report entitled “2030 Agenda and Sustainable Development Goals (SDGs) report: A European perspective to respect, protect and fulfil the United Convention on the Rights of Persons with Disabilities”.

The report provides an overview of the strong link between the Convention and the SDGs and presents recommendations on how to ensure Europe takes a human rights based approach to the Sustainable Development agenda, fully including persons with disabilities.

This report, presented during EDF’s SDGs conference, has been designed as a resource for organisations of persons with disabilities and decision-makers in Europe to learn more about the 2030 Agenda and what opportunities exist for advocacy around the SDGs in order to respect, protect and fulfil the CRPD, in Europe and in international cooperation.

Read more here: https://goo.gl/USJrpb

Find the full report here: https://goo.gl/8kJEY1

7 March: WHO launches e-programme for carers of people living with dementia

The World Health Organisation (WHO) recently developed “iSupport”, an online training programme for carers of people with dementia, to help carers to:

- understand the impact of dementia;
- deal with “challenging behaviours”;
- provide good care;
- and take care of themselves.
Carers can tailor the programme to their personal needs and select as many lessons as they want. All lessons consist of several exercises and carers receive immediate feedback as they work through them. At the end of each lesson there is a relaxation exercise.

This generic online programme is now being adapted and tested in countries worldwide.

https://www.isupportfordementia.org/en

8 March: Eurocarers launches publication “The gender dimension of informal care” on International Women’s Day

Across the EU, 80% of care is provided by informal carers. A majority of them are women, as informal carers are typically spouses, middle-aged daughters or daughters-in-law, aged 45 to 75.

The European Institute for Gender Equality: EIGE’s Gender Equality Index shows that the unequal distribution of care and domestic responsibilities between women and men remains the most problematic area in the EU in terms of gender equality.

Long-term care responsibilities tend to aggravate the gender pay and pension gaps already present because of childcare responsibilities. Overall, because of the unequal distribution of domestic and care work between women and men at household level, women experience income drops, loss of economic autonomy, increase dependency on men and/or the state (social benefits) and a greater risk of poverty than men (including in-work poverty related to involuntary part-time).

Eurocarers – the European Association working with and for informal carers - believes that “care has to be considered a central activity for the well-being of our societies and it should be redistributed between men and women, as well as between the family and the State.”

Eurocarers is therefore calling on governments to improve the quality, affordability and access to long-term care systems, as well as to improve the design and gender-balanced take-up of family-related leaves and flexible working arrangements. This is necessary both to increase gender equality and to meet challenges such as an ageing population and labour shortages, the association emphasises.

Eurocarers has brought out a new publication on the topic of “The gender dimension of informal care”, underlining the causes, the consequences, the reasons why action is needed and some possible solutions: https://goo.gl/nXGZ6y

8 March: Publication on dementia and sexuality launched in Scotland

On 8 March, Scottish Care launched a new publication on the issues of sexuality and dementia. Written by Clive King, Terrence Higgins Trust and Jennifer Hall, Alzheimer Scotland, the publication challenges some of the popular preconceptions and taboos around the issues of sexual health, sexual identity and sexuality for older people in Scotland.

The event aimed to address misconceptions around sexuality and older individuals from the perspective that sexuality and the ability to express oneself sexually is a basic human right.

Dr Donald Macaskill, CEO of Scottish Care said:

“All too often the discussions on sexuality and dementia focus on the need to manage behaviour, issues of risk, capacity and consent.

“As a society we need to get much better at supporting people who live with dementia, at whatever age, to be able to be full human beings – that crucially includes their ability to be sexual beings. We have to get off our prurient moral high horses and let people be fully who they are. We have to call out discrimination especially of the LGBT community and help people live well with dementia.”

Scottish Care is the representative body for independent social care services in Scotland.

https://goo.gl/RNhCcM

13 March: Journal of Prevention of Alzheimer’s Disease 1/2018 published

The Journal of Prevention of Alzheimer’s Disease (JPAD) Volume 5, Number 1, 2018 is now available.

JPAD publishes reviews, original research articles and short reports to help improve knowledge in the field of AD prevention including neurosciences, biomarkers, imaging, epidemiology, public health, physical cognitive exercise, nutrition, risk and protective factors, drug development, trials design and heath economic outcomes.

http://www.jpreventionalzheimer.com/current-issue.html

19 March: UK Dementia Researcher website goes live

Launched on 19 March, the new Dementia Researcher website is a network for Early Career Researchers (ECRs), bringing together the latest jobs, events and funding opportunities delivered by the National Institutes for Health Research (NIHR), UK.

You can view a video about the new website and what it is for here: https://www.youtube.com/watch?v=81Rxf9VcB6g

And the website itself is:

https://www.dementiaresearcher.nihr.ac.uk/

28 March: Professor Suzanne Cahill introduces her new book on Dementia and Human Rights

These days, we hear a lot about human rights in the context of dementia. In fact, ‘personhood’ and ‘rights’ have become the new buzz-words in the dominant discourse on dementia. Yet what
13 March: Together in dementia everyday (tide) is recruiting for its Learning and Development Team

Created by carers for carers, tide – together in dementia every day - is a national (UK) involvement network for carers and former carers of people with dementia hosted by Life Story Network CIC. Using lived experience, tide enables a diverse range of carers to have a powerful collective voice, which raises awareness of their unique needs and rights, ensuring that these influence practice, policy and research at all levels.

Tide is recruiting for permanent two roles in its Learning and Development Team, based in Scotland: a Learning and Development Lead and a Learning and Development Coordinator. The closing date for applications for both positions is 13 April 2018 and interviews will be held in the week commencing 30 April 2018.

https://goo.gl/CyMBQG

21 March: Conference of INGOs of Council of Europe opens call for candidates for Expert Council on NGO Law

In 2008, the Conference of INGOs created the Expert Council on NGO Law (Terms of Reference) to ensure the best possible articulation between Council of Europe norms and NGO Law. Through its opinions, the Expert Council advises the Conference of INGOs, NGOs and national authorities, while ensuring a democratic oversight when the national legal framework or legal regulations compromise the rights of NGOs.

If you have a legal background and knowledge of the NGO sector in one or several countries and wish to contribute to the creation of an enabling environment for NGOs throughout Europe, by examining national legislation relating to NGOs and its implementation, and by promoting the respect of Council of Europe norms and good practice in this area; if you wish to work with eminent experts specialised in human rights, democracy and the rule of law, the Expert Council is the place for you.

The mandate of the experts within the Council is three years. It will start in July 2018 and will end in July 2021.

The deadline for applications is 15 April 2018. For more information about the mandate and how to apply: https://goo.gl/pPCvgh

22 March: Young Dementia UK is looking for a new Chair of Trustees

On 22 March, Young Dementia UK announced an opening for a new Chair of Trustees as of July 2018,
when the current Chair will step down. “This presents an exciting opportunity to join the charity at a pivotal moment of national development and growth” said the charity. The Chair of Trustees will provide strategic leadership to the Board and the Management Group to enable a range of national projects to be piloted, developed and evaluated. They will also help fulfil Young Dementia UK’s intention to offer support, information and connection to people with young onset dementia across the UK.

To apply please submit your CV to: alisonkenny@youngdementiauk.org

The deadline for applications is 12 April 2018. Or for an informal conversation about the role, contact the Director: tessagutteridge@youngdementiauk.org

You can find the role description here: https://goo.gl/wrwJ2D

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

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

** Alzheimer Europe Staff:**
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** AE CALENDAR**

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>11 April</td>
<td>Nordic network of senior officials and experts on dementia (Stockholm, Sweden)</td>
<td>Jean</td>
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<tr>
<td>18 April</td>
<td>IMI consultative workshop on disease interception (Brussels, Belgium)</td>
<td>Cindy</td>
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<tr>
<td>23 April</td>
<td>DPUK conference (London, UK)</td>
<td>Chris</td>
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<tr>
<td>25-26 April</td>
<td>ROADMAP 5th General Assembly Meeting (Barcelona, Spain)</td>
<td>Jean, Dianne, Chris</td>
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** CONFERENCES 2018**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>2-4 May</td>
<td>24th Nordic Congress of Gerontology (24NKG), <a href="http://www.24kg.no">www.24kg.no</a></td>
<td>Oslo, Norway</td>
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<td>6-8 June</td>
<td>8th Kuopio Alzheimer Symposium, <a href="https://www.uef.fi/fi/web/kuopioalzsymposium">https://www.uef.fi/fi/web/kuopioalzsymposium</a></td>
<td>Kuopio, Finland</td>
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<td>7-8 June</td>
<td>HammondCare International Dementia Conference - Mission Impossible? Truth and Lies in the Age of Choice, <a href="http://www.dementiaconference.com">www.dementiaconference.com</a></td>
<td>Sydney, Australia</td>
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<td>7-8 June</td>
<td>BestCare4Dem - Sharing effective community-based support in dementia, <a href="https://www.meetingdem.eu/">https://www.meetingdem.eu/</a></td>
<td>Amsterdam, Netherlands</td>
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<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>
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<td>26-29 July</td>
<td>International Conference of Alzheimer’s Disease International (ADI), <a href="http://www.alz2018.org/">https://www.alz2018.org/</a></td>
<td>Chicago, USA</td>
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<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>
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<td>29-31 October</td>
<td>28AEC &quot;Making dementia a European priority&quot; <a href="http://www.alzheimer-europe.org/Conferences/barcelona-2018">www.alzheimer-europe.org/Conferences/barcelona-2018</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>22-25 October</td>
<td>29th Alzheimer Europe Conference &quot; Making valuable connections”</td>
<td>The Hague, Netherlands</td>
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This conference presents an overview of the latest insights in the field of effective care and support for home-dwelling people with dementia and their informal carers.

There are many new types of interventions and services that are available in different countries and at all levels of care. An increasing number of initiatives are also being developed by national or regional governments. However, an important question is whether these interventions are cost-effective and provide substantial benefit to the people who need support. How can we measure the impact of these interventions on people’s lives and their informal carers? What can we do to improve the quality of care and support for people with dementia and their informal carers?

All the centres function as knowledge centres in the community. Adapting new effective care options requires a high level of professional training and the development of new knowledge in the field. The conference will provide an opportunity to meet the experts in the field of dementia care and support and to exchange ideas with colleagues from other countries.

This conference is organized by the Department of Psychological Health and Care, University Medical Centre Utrecht. For further information please go to www.emif.eu

SAVE THE DATE! 7-8 June 2018
We are looking forward to meeting you in AMSTERDAM

International conference

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

International conference

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

The conference is intended for care providers, scientists and policymakers in the field of dementia care as well as for people with dementia and their informal carers.
The UK Dementia Research Institute wishes to recruit an Associate Director with an exciting vision for how patient focussed research can lead to a significantly improved quality of life for people affected by dementia.

With a £20 million budget and the world-class environment and infrastructure of the UK DRI, the Associate Director is expected to lead an innovative care research programme exploring how science and technology can be used to further our understanding of causes and consequences of dementia by working with people affected by dementia in daily life situations.

The successful candidate will:

- Set out a bold vision for patient-centred research that may lead to significantly improved quality of life for people affected by dementia.
- Develop a research programme that is fully integrated into the UK DRI and will benefit from being part of the UK DRI’s considerable infrastructure and resources.
- Mobilise current dementia researchers and clinicians and attract new non-dementia experts with relevant expertise.
- Engage and involve public, patients and other key stakeholder groups in the programme.
- Exploit opportunities for partnerships, commercialisation and further funding to enhance the programme.

This call is open to any investigator with a vision for improved quality of life for people affected by dementia today. We particularly encourage unexpected and creative applications that will combine novel technology with assessment, monitoring and improving quality of life in the everyday environment. Proposed programmes should ideally meet the dual challenge of advancing our understanding of patient care and contributing to our understanding of the aetiology of dementia, and demonstrate the added value of being fully integrated in the UK DRI environment.

Want to join us?

Further details of the position and how to apply can be found at [www.ukdri.ac.uk/joinus](http://www.ukdri.ac.uk/joinus). The closing date for letters of intent is 17 April 2018.
The Alzheimer Europe newsletter received funding under an operating grant from the European Union’s Health Programme (2014-2020). The content of this newsletter represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.