WELCOME

First of all, I would like to extend our most sincere condolences to Dermod Slevin’s family and friends. Dermod passed away on 29 January. He was a founder member of both the European Working Group of People with Dementia (EWGPWD) and the Irish Dementia Working Group. He was passionate about his European work and in particular engaging with European policy makers.

On a happier note, we would like to warmly congratulate our colleagues in Wales on the long-awaited launch of the new Dementia Action Plan 2018-2022 in mid-February, which sees a dedicated annual budget of GBP 10 million to help with its implementation. We are glad to see that this new Action Plan is taking a rights-based approach to services and that it includes the “Dementia Statements”, which were developed by people affected by dementia including EWGPWD Vice-Chair Chris Roberts. You can find more information about the Action Plan in the Policy section of this newsletter, and you can also learn more about the Dementia Statements in the Members’ news section.

Still on the policy front, I am delighted to welcome two new MEPs to the European Alzheimer’s Alliance (EAA) this month. We look forward to collaborating with MEPs Gerben-Jan Gerbrandy (Netherlands) and Rory Palmer (United Kingdom) and hope to see them at future Alzheimer Europe (AE) lunch debates in the European Parliament in Brussels, including tomorrow’s edition: “Will we be able to prevent Alzheimer’s disease?”

As well as this lunch debate, we are holding our usual series of meetings in Brussels this week including a Board meeting today and tomorrow, a Company Round Table tomorrow afternoon and a Public Affairs meeting on Wednesday, all of which I am looking forward to immensely; most particularly to the opportunities for networking and collaboration they present and to the updates we will hear from AE’s national member organisations, who never fail to surprise us with their boundless energy and excellent initiatives. I am also pleased to announce that we will officially launch our 26th Dementia in Europe magazine during the lunch debate.

Finally, also on the topic of collaboration, I am excited to inform you that AE has signed a Memorandum of Understanding with the European Academy of Neurology (EAN), with the aim of our two organisations working together more closely. As ever, collaboration is key.

On that note, I wish all of you continued success in your endeavours to support and strengthen the European dementia movement.

Jean Georges
Executive Director
In Memoriam Dermod Slevin, 1940-2018

It is with great sadness that we share the news that Dermod Slevin passed away on 29 January. He would have turned 78 in March this year. Dermod was a founder member of the Irish Dementia Working Group and a former member of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD). He was the first person with dementia in Ireland to speak to the media and give voice to the lived experience of dementia. This voice began a shift in perception in Ireland, from patient to person.

As the Irish representative on the first European Working Group of People with Dementia (EWGPWD), he was passionate about his European work and in particular meeting European policy makers. Dermod commented that the exchange of ideas with his European colleagues brought great opportunities.

When the government of Ireland called for submissions to Ireland’s first National Dementia Strategy Dermod contributed his views on diagnosis, information and services, maintaining yourself in your home and in your community, living well with dementia and residential care to the Alzheimer Society of Ireland submission. Those views formed an important part of the Alzheimer Society of Ireland’s submission to the National Dementia Strategy.

A highlight for Dermod was in December 2012, when he met with the President of Ireland Michael D. Higgins. Dermod said about the visit that “meeting the President was one of the greatest honours of my life and it brought tears to my eyes”.

We are deeply saddened by the news of Dermod’s passing and would like to extend our heartfelt condolences to those close to him, in particular his family.

Pictured: Dermod Slevin at the first ever meeting of the EWGPWD in Vienna, Austria, October 2012.

ALZHEIMER EUROPE

9 February: Video of Jean Georges speaking at 2017 IMI event on AD projects is online

As of 9 February, you can watch videos of the various speakers at last year’s “Collaboration in Alzheimer’s disease & beyond: the present and the future of IMI initiatives in neurodegeneration”, including one of our ED Jean Georges:

https://www.youtube.com/watch?v=Qa8HLz3KjbM

12 February: Alzheimer Europe joins other European organisations in call to support swift progress on Work-Life Balance Directive

Alzheimer Europe (AE) has joined a European network of NGOs led by COFACE Families Europe, who are working together to raise awareness about the daily challenges faced by women and men across the EU in reconciling their work, family and private life including caring for family members. Families struggle to cope with their multiple responsibilities, so helping them reconcile their work, family, care and private lives is fundamental.

On 26 April 2017, the European Commission proposed a Directive to “support work-life balance for parents and carers.”

The following new rights are proposed:

- an entitlement to 5 days of leave paid at sick pay level, per year, per worker to take care of seriously ill or dependent relatives;
- the possibility for flexible uptake (piecemeal and part-time) of the 4 months entitlement to parental leave paid at sick pay level; the 4 months entitlement can be taken up until the child reaches the age of 12 and cannot be transferred between parents;
- an entitlement to 10 working days of paternity leave when a child is born, paid at sick pay level;
- a right to request flexible working arrangements for parents of children up to 12 years old and workers with caring responsibilities.

The #IwantWorkLifeBalance social media campaign was launched to shore up citizen support for the EU Work Life Balance Directive and it will end with the adoption of the Work Life Balance Directive.

13 February: Alzheimer Europe signs Memorandum of Understanding with European Academy of Neurology

Alzheimer Europe (AE) is delighted to have signed a Memorandum of Understanding with the European Academy of Neurology
(EAN), the principal goal of which is to strengthen the collaboration between AE and EAN.

The cooperation between the two organisations aims to achieve the following objectives:

- Promoting AE and EAN as leading societies for the representation of people with Alzheimer’s disease and other forms of dementia patients as well as their carers and neurologists in Europe.
- Working towards timely and optimal diagnosis and care for people with dementia in Europe.
- Improving the availability and quality of educational and scientific endeavours and attracting, forming and retaining talents.
- Working towards co-operation between healthcare professional associations with patient/carers associations whenever possible.
- Lobbying at the EU level for increased availability and standards of neurological care in Europe.

Find out more about the EAN here:

https://www.ean.org/

20 February: Alzheimer Europe continues to comply with EMA’s strict eligibility criteria

We are delighted to have received confirmation from the European Medicines Agency (EMA) that Alzheimer Europe continues to meet its strict criteria for transparency and accountability and that we will be able to continue our involvement in EMA activities during 2018. The list of all the patients’ and consumers’ organisations that are involved in EMA activities can be viewed here:

https://goo.gl/e7sVLS

21 February: Alzheimer Europe publishes new Dementia in Europe magazine


In this issue, AE presents its two new publications - the 2017 Yearbook on care standards in Europe and a discussion paper on the possible implications for ethics, policy and practice of recognising dementia as a disability. We also present our most recent lunch debate at the European Parliament, on improving the early diagnosis of Alzheimer’s disease thanks to European research collaboration, and we present our position paper on involving people with dementia in research through patient and public involvement (PPI). We also introduce our new national member organisation from Montenegro.

Nationally, Portugal’s Health Minister Adalberto Campos Fernandes talks about the first dementia strategy for Portugal. Globally, we look at the launch of the world Health Organisation (WHO)’s Global Dementia Observatory and at European level we look at the #Health4EU Campaign, the European Working Group of People with Dementia (EWGPWD)’s activities at the 4th European Disability Parliament of Persons with Disabilities and we present the 20th anniversary of the Council of Europe’s Oviedo Convention on Human Rights and Biomedicine.

For the first time in this magazine, we are pleased to present a “Europe in Brief” section highlighting key EU news, such as the newly-signed European Pillar of Social Rights, the relocation of the European Medicines Agency, the mid-term evaluation of the Health Programme and the State of Health in the EU report.

We also present the work young researchers are doing in dementia through the WYLD, SyDAD and EPAD projects and take a look “behind the headlines” with Dr James Pickett at recent reports in several newspapers discussing a “vampire” therapy as a potential way to treat Alzheimer’s disease.

Finally, there is also a special “spotlight” section of the magazine dedicated to Alzheimer Europe’s 27th Annual Conference held in Berlin in October 2017.

The Dementia in Europe magazine appears in print twice per year with a circulation of around 3,000-3,500. It is distributed to all the Members of the European Parliament (MEPs) and many high-level decision makers in the European Commission, among others. For further information about this edition please contact Policy Officer Vanessa Challinor on Vanessa.Challinor@alzheimer-europe.org

You can buy the magazine via our E-shop:

The PredictND team held its final meeting and preparations for the final audit of the project in Saariskelä, Finland on 29 to 31 January. The researchers discussed progress on each work package, the various presentations for the final review, articles which have been published and articles which are pending completion or publication. There was also a management board meeting and the final audit will take place soon. Director for Projects Dianne Gove represented Alzheimer Europe at this meeting.

The project has been a tremendous success and has produced some very interesting findings which will be valuable to clinicians, patients and researchers alike. Please see the PredictND website for details and to keep track of any further developments:

https://www.predictnd.eu/

29 January-2 February: INDUCT has its 3rd successful School including the Mid-Term Review

From 29 January to 2 February, members of the INDUCT (Interdisciplinary Network for Dementia Using Current Technology) project got together for the 3rd INDUCT School, which took place in Witten, Germany. This school was organised by the German Center for Neurodegenerative Diseases (DZNE), the Karolinska Institutet, the University of Maastricht, and the INTERDEM Academy Network (Early detection and timely INTERvention in DEmentia).

This School was marked by several highlights, one of which was the Mid-Term Review, as the INDUCT project had reached its half-way point. The INDUCT project and all consortium members were evaluated by an external reviewer on the activities and work carried out so far. The day proved to be quite a success as the external reviewer shared positive feedback and was very impressed with the complex and in-depth work on dementia and technology. The INDUCT fellows had all made a great amount of progress within their individual projects as well.

The remainder of the school was attended by members of the INTERDEM Academy and included an interactive workshop on “Qualitative methods and how to get access to the experiences of people with dementia” amongst others. This session was led by Prof. Louise Nygård and Ms Helga Rohra from Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD). This workshop was extremely informative as both Prof Nygård & Ms Rohra shared their unique experiences and discussed how we could all optimally ensure that the voices of people living with dementia are heard while we conduct our research activities.

The positive Mid-Term Review in addition to all the interesting sessions during the week contributed to the immense success of the 3rd INDUCT School.

Find out more about INDUCT here: http://www.dementiainduct.eu/

8 February: The EPAD project congratulates its Trial Delivery Centre of the Month

The European Prevention of Alzheimer’s Dementia (EPAD) consortium is delighted that the team of CITA Foundation (pictured) screened 16 research participants in January 2018 for their inclusion in the EPAD Longitudinal Cohort Study, making it the most successful Trial Delivery Centre that month.

The CITA Foundation (San Sebastian, Spain) opened as a new EPAD Trial Delivery Centre in June 2017. It is a private, non-profit foundation, whose vision is to be an international benchmark institution in research on Alzheimer’s disease and to contribute to the wellbeing of society through the transfer of knowledge generated and the creation of economic value.

For more information visit http://www.cita-alzheimer.org/.

The CITA Foundation is an active partner of EPAD, which currently has 11 participating sites. Several sites have been opened in England, France, The Netherlands, Scotland, Spain, Sweden and the latest site to enrol research participants is Oxford, England, UK. 453 research participants have already been screened, of which 417 are currently enrolled. EPAD is poised to open further sites in Europe in the coming weeks.

Pictured: (Ltr) Standing: Montse Clerigue, Jon Saldias, Ane Iriondo, Maria Arribas, Maite Garcia, Pablo Martinez Láge, Ainara Estanga, Amaya Garcia Eizaga, Fernando Boada. Seated: Mikel Tainta, Maite Murillo, Zigor Diaz, Mirian Ecay

8 February: The ROADMAP project updates us on recent and ongoing activities

On 15 January, an international group of 18 ROADMAP collaborators from academia and industry including Alzheimer Europe
joined a workshop convened by Edinburgh University for the outcome definition team – Work Package 2 (WP2). They discussed data synthesis for the Systematic Literature Review (SLR) under Deliverable 2.2. The group explored the evidence base, looking at the findings identified in response to the SLR’s two research questions. The relative importance of patient-reported outcomes was emphasised, as was the synergy with the universe of outcomes published in ROADMAP Deliverable 2.1 and the need to carefully report on the robustness of included studies. The group developed a draft structure and approach to interpreting and synthesising the evidence, which is taken forward to create the final report at the end of February.

WP3, responsible for identifying, mapping and integrating real world evidence (RWE) for ROADMAP has been involved in several activities. They have added fields in the European Medical Information Framework-Alzheimer’s Disease (EMIF-AD) catalogue to the data cube to adapt it to ROADMAP needs and refine the current outcomes fingerprinted. They also developed a working document with potential Alzheimer’s disease (AD) cohorts for the validation studies being carried out under WP4. In addition to this, the team gained access to Memento and Gothenburg cohorts for the WP4 validation studies, and efforts to identify and gain access to other data cohorts are ongoing. Finally, they are working towards making Lilly clinical trial (CT) placebo data available through hosting at EMC’s database.

The disease modelling and simulation team from WP4 have selected three models for validation. The first is a Mini Mental State Examination model (Handels model), the results of which are available for the Integrated Primary Care Information database (IPCI). Data extraction is ongoing from SIDIAP (Information Systems for Research in Primary Care), Dementia Platforms UK (DPUK), Memento, and discussions are ongoing regarding the inclusion of University of Gothenburg cohorts. The second model is the pre-symptomatic model (Novartis), for which the Memento, Amsterdam, and Gothenburg cohorts have been identified. The Transparent Reporting of a multivariable Prediction model for individual Prognosis or Diagnosis (TRIPOD) checklist has been completed for use with the NOVARTIS model. The third model is the PENTAG institutionalisation model (Lilly), for which the TRIPOD model development checklist has also been completed.

The health economics team at WP5 have organised a workshop on 14 February in Paris, with external advisors. This will be back-to-back with the International Pharmaeconomic Conference on Alzheimer’s Disease (IPECAD) conference the day after: “Modelling the economic value of Alzheimer’s Disease interventions: How far have we come, and what next“. Members of the ROADMAP team attend the conference to give three presentations:

- “Real-world evidence in Alzheimer’s disease: the ROADMAP collaboration” from Pieter Jelle Visser (WP3 co-lead),
- “Swedish registry data (Svedem, Gothenburg biomarker registry)” from Ron Handels (WP3), and

In WP6, the regulatory and Health Technology Assessment (HTA) engagement team completed the first draft of a manuscript reflecting on main regulatory and HTA considerations for a disease-modifying drug in AD, under Deliverable 6.3, and have organised the third Expert Advisory Group teleconference (26 February).

The communications team from WP7 produced the fourth external newsletter, circulated on 11 January, and added a new video section on the ROADMAP website. They had face-to-face discussions with Big Data for Better Outcomes (BD4BO) colleagues from BD4BO’s Work Package 3 and other disease specific project representatives (Harmony & BigData@Heart) on 16 January in Brussels at the offices of the European Federation of Pharmaceutical Industries and Associations (EFPIA). In addition, as part of our internal communication on ROADMAP goals and milestones, WP7 shared the second ‘EFPIA partners Newsletter’ with representatives of partner companies for internal sharing with their leaders and team members. The EFPIA partners Newsletter is intended to give a high-level update on where we are with ROADMAP and next steps.

Finally, the Ethical, Legal, and Social Implications team from WP8 held a consultation on 7 December 2017 with the European Working Group for People with Dementia (EWGPWD) to explore concerns raised by sharing health data to create a RWE platform for AD research, and have completed a first draft of the protocol for the systematic literature review on the ethics of predictive modelling for secondary prevention of AD, under Deliverable 8.5.

9 February: Want to know more about the SoCaTel project? Check out this new video

Recently-launched H2020 project SoCaTel aims to improve the accessibility, responsiveness, efficiency, transparency and transferability of social and care services by developing a multi-stakeholder platform for the co-creation, and later deployment, of long-term care services.

Want to know more about SoCaTel? Check out the project’s new promotional video here:

https://goo.gl/SiZz3o
9 February: MOPEAD publishes educational leaflet

On 9 February, the communication team of the MOPEAD project released an educational leaflet on Alzheimer’s disease (AD) and other dementias.

The informative leaflet gives an insight into dementia and commonly used terminology, as well as risk factors and prevention. In addition, there is a dedicated section on the value of early diagnosis, highlighting individual benefits. The leaflet is currently being translated into different languages. Hard copies of the leaflet aim to support the project’s launch of screening procedures and patient recruitment, which are soon going to start in Germany, Sweden, Slovenia, Spain and the Netherlands. You can find the leaflet here: https://goo.gl/44TuVZ

16 February: The MinD project team prepares design concepts for consultation with people with dementia

The MinD project hosted secondments in January and February 2018, at the University of Wolverhampton, UK, and in the Netherlands with Partners Panton Healthcare Design, University of Twente and Zorggroep Sint Maarten. In both sites, secondments were dedicated to a number of tasks, most importantly to preparing design information on the two designs for consultation with people with dementia and caregivers in March, in the UK and Germany.

The initial design concepts had been selected in October 2017 from a shortlist, with the help of people with dementia, caregivers and healthcare experts through a number of public and patient involvement (PPI) sessions: The “Good Life Kit” aims at helping people with dementia to deal with their condition constructively and openly, especially at the point of the diagnosis, where there can be a feeling of loss and uncertainty about the future. The “Social Engagement Map” aims to support people with dementia to stay socially connected and engaged. It responds to findings that elderly people in general have fewer social connections, and that people with dementia in particular may find it difficult to maintain or establish social connections.

In November and December 2017, the MinD team had worked on developing the design concepts into tangible ideas. With much progress being made then, it is now important to involve people with dementia and carers in the design process. We will involve people through co-design sessions, where we will work together to decide which features to include in the designs, as well as how the designs should look and work to suit them. It is very important to have the views and experiences of people with dementia guiding the design process to make our design fit for purpose.

The work in January and February 2018 focused on preparing the design ideas for presentation in the co-design sessions, which included preparing visuals, translation of English texts into German for the German participants, and determining relevant areas and questions for the discussion in the co-design sessions.

http://designingfordementia.eu/

20 February: PredictND publishes paper in Alzheimer’s Research & Therapy journal

The PredictND project is proud to present its new paper, “Disease related determinants are associated with mortality in dementia due to Alzheimer’s disease”, published online in Alzheimer’s Research & Therapy journal on 20 February.

“Survival after dementia diagnosis varies considerably. Previous studies were focused mainly on factors related to demographics and comorbidity rather than on Alzheimer’s disease (AD)-related determinants. We set out to answer the question whether markers with proven diagnostic value also have prognostic value. We aimed to identify disease-related determinants associated with mortality in patients with AD.”

http://rdcu.be/H04i

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

26 February: AMYPAD DPMS protocol is approved by Geneva Ethical Committee

On 26 February, the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project released its fourth external newsletter and reported the development and the submission of a research protocol for its multicentre clinical study. The development of the AMYPAD Diagnostic and Patient Management Study (DPMS) protocol was led by WP3. The submitted protocol is the result of a year-long intense collaboration between academia, industry, Alzheimer Europe, and the European Medicines Agency.

The drafting of the protocol posed great challenges due to the diversity within its participating centres, and it required a team effort to be able to account for important differences across European healthcare systems in the final study design. The final research protocol is the result of true teamwork, with all Principal Investigators and clinicians within the different memory clinics having been involved in the protocol preparation to ensure a seamless integration between the study and the diagnostic routine of the different centres. Finally, the AMYPAD DPMS protocol was agreed upon and the study design was locked.
As a result, the AMYPAD DPMS became a multicentre, open-label, Phase 4, randomised study that, in the context of the AMYPAD project, will explore the impact of β-amyloid Positron Emission Tomography (PET) imaging on diagnostic thinking and management of patients with subjective cognitive decline, mild cognitive impairment, or dementia where Alzheimer’s disease is in the differential diagnosis.

In August 2017, the study Chief Investigator submitted the first Research Ethics Committee application for the AMYPAD DPMS to the Commission Cantonale d’Éthique de la Recherche Genève (CCER) in Geneva, Switzerland. The DPMS protocol was approved in Switzerland at the beginning of January 2018. Final practical and logistical details are being finalised and Geneva will be ready to recruit its first participant very soon, which will be a long-awaited milestone for AMYPAD.

**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
- ROADMAP - grant agreement 116020

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**Alzheimer Europe Networking**

From 29 to 31 January (Saariselkä, Finland), Dianne attended the final meeting and preparation of the final audit for the PredictND project.

On 2 February (Brussels, Belgium), Vanessa attended an EPF Educational Workshop on Pharmaceutical Incentives.

On 6 February (via Skype), Jean and Ana participated in a meeting for the carers’ experiences of diagnosis survey.

On 8 February (Brussels, Belgium), Dianne attended an INTERDEM meeting.

On 8 and 9 February (The Hague, Netherlands), Ana attended a meeting of the Joint Action on Dementia on residential care.

On 12 and 13 February (Barcelona, Spain), Gwladys met with the hotel, the AV team and various potential suppliers for 2BAEC.

On 13 February (via teleconference), Kate participated in a meeting of the EPF Patient Comms Network.

On 20 February (London, UK), Jean met with Paola Barbarino and Chris Lynch from Alzheimer’s Disease International.


On 21 February (Brussels, Belgium), Vanessa attended a meeting in the European Parliament on Barriers to preventing frailty: “Why pharma policy has not aged well and what it needs”.

On 21 February (Brussels, Belgium), Vanessa attended a meeting on “Brexit: prioritising patient safety and public health across Europe”.

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**Members of the European Alzheimer’s Alliance**

Currently, the total number of MEPs in the Alliance stands at 125, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

**Austria:** Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (EPP). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleftherios Sofokleous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); Liisa Jaakonsaari (S&D); Anneli Jääteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Kostas Chartier. **Ireland:** Mary Lou McDonald (S&D); Bríd Quaile (GUE/NGL). **Italy:** Emma Bonino (EPP); Elke Angel (S&D); Fortunata Donzelli (S&D). **Latvia:** Roberts Zile (EPP). **Lithuania:** Algirdas Ramonavičius (S&D). **Malta:** Cassandra Galizia Cuschieri (S&D); Miriam Dalli (GUE/NGL). **Netherlands:** Annemariester Hennis-Plasschaert (S&D); Karin van Soust (NI); Jasmijn van der Laan (EPP). **Poland:** Janusz Cichoń (S&D); Krzysztof Tusk (PIS). **Portugal:** Silvia Mesquita (S&D); Teresa Gaspar (S&D). **Romania:** Elena Udrea (EPP). **Slovakia:** Gabriela Šišková (S&D); Robert Hradil (EPP). **Slovenia:** Povlenko (S&D); Neža Šroer (EPP). **Spain:** María Jara Cortés (S&D); Doña Margarita (S&D); María Del Carmen Martín Álvarez (EPP). **Sweden:** Mats Odell (S&D); Maria Johansson (S&D); Sven GåCompat (NI). **Switzerland:** Angelika Bihler (EPP); Udo Voigt (NI). **UK:** Steve Fosdick (S&D); Mark Durkan (SDLP); John Finucane (S&D). **Other countries:** Andrey Kovatchev (EPP); Marielle Gallo (EPP).
On 31 January, Gerben-Jan Gerbrandy, MEP, (ALDE, Netherlands) joined the European Alzheimer’s Alliance (EAA).

Mr. Gerbrandy sits on the Committee on the Environment, Public Health and Food Safety and is a substitute on the Committee on Industry, Research and Energy.

On joining the Alliance Mr Gerbrandy said that, “Alzheimer’s disease is the most common cause of dementia. Dementia has a major impact, not only on those who have the syndrome, but also on their relatives.

We should do much more to create awareness and give Alzheimer’s disease the priority it deserves, also in European policymaking.”

On 7 February, Rory Palmer, MEP (S&D, United Kingdom) joined the European Alzheimer’s Alliance.

Mr Palmer sits on the Committee on the Environment, Public Health and Food Safety. He is a substitute on the Employment and Social Affairs Committee.

On joining the EAA Mr Palmer said, “I am pleased to join Alzheimer Europe’s Alliance and I look forward to building on my previous work with the Alzheimer’s Society in the East Midlands area to secure better support for people with Alzheimer’s and their carers, to raise awareness and to support more research.”

Alzheimer Europe extends a warm welcome to Mr Gerbrandy and Mr Palmer and thanks them both for helping make dementia a European priority.

http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance/Members/Gerbrandy-Gerben-Jan

EU DEVELOPMENTS

12 February: Expert Panel on Health publishes 3 opinions to help guide policy makers

The Expert Panel on effective ways of investing in health - which is an interdisciplinary and independent group established by the European Commission, providing advice in the form of opinions in response to questions submitted by the Commission - has recently published three opinions:

- Opinion on Innovative payment models for high-cost innovative medicines
- Opinion on Benchmarking access to healthcare in the EU
- Opinion on Tools and methodologies for assessing the performance of primary care

The Panel aims to analyse evidence that could support EU countries in delivering high quality care and making their health systems more effective, accessible and resilient. In addition, these Opinions are produced to generate debate and provoke thinking amongst stakeholders, national authorities and other relevant bodies. Should you be interested in discussing these topics further with the Panel members athttp://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance/Members/Gerbrandy-Gerben-Jan

EUROPEAN ALZHEIMER’S ALLIANCE

7 February: MEPs Gerben-Jan Gerbrandy and Rory Palmer join the EAA

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suitable events, you can explore this possibility by contacting the Panel’s secretariat: SANTE-EXPERT-PANEL@ec.europa.eu. Please note that the opinions of the Expert Panel present the views of the independent scientists who are members of the Expert Panel. They do not necessarily reflect the views of the European Commission.

https://ec.europa.eu/health/expert_panel/home_en

12 February: #EU4HEALTH campaign sets out its vision for 2018

The #EU4HEALTH campaign led by the European Patients Foundation (EPF) and European Public Health Alliance (EPHA) is calling for reassurances from the European Commission (EC) that in the future, health will continue to be a priority in the European Union (EU) and that the European Commission’s DG SANTE will not be closed and a Health in All Policies (HiAP) approach taken by the EC. Alzheimer Europe fully supports this campaign and to date is amongst over 230 organisations who have signed the petition calling on the EC to step up coordinated EU action to tackle cross-border health challenges.

On 18 January, EC President Jean-Claude Juncker appointed six members to the Task Force on subsidiarity, proportionality and "Doing less more efficiently" to explore and identify which policy areas should be addressed at a different level (national, regional, local).

Despite the clear European added value, there is a growing concern that EU Health policy action and health collaboration might be one of the areas this Task Force decides to de-prioritise at European level.

Based on the work developed under the #EU4HEALTH Campaign since last year, the group of public health NGOs has developed some key asks to forward to the Task Force headed by Frans Timmermans.

The message the campaign wants to get across is clear: “European health collaboration has a lot of added value. We want continued EU policy action on health with a strong political leadership from the European Commission on health, including a Commissioner and Directorate General on Health.”

The group is also expanding the campaign activities for 2018.

20 February: You can register as patient expert at the European Medicines Agency

As part of the European Medicines Agency’s endeavours to involve patients in all aspects of medicines evaluation and regulatory processes, it is looking for any patients interested in working as a patient expert.


The European Parliament has adopted a draft report, on the EU’s next long-term post 2020 budget, also known as the Multiannual Financial Framework (MFF).

The #EU4HEALTH Campaign made suggestions to the rapporteurs with amendments to the text for the budget concerning health. This advocacy work has been successful and the amendments on health championed by the health community, especially the work done by EPF and supported by AE, were included.

Here is the paragraph from the report, as adopted:

“Recognises the European added value of collaboration in addressing common public health threats; notes that no single Member State can tackle cross-border health challenges alone, and calls for the next MFF to reflect the EU’s responsibility to implement the SDG on public health, health systems and environment-related health problems, and to support Member States in eliminating growing health inequalities; considers that, on the basis of the positive outcome of the ongoing actions in this field, the next MFF should include a robust next-generation health programme that addresses these issues on a cross-border basis, e.g. by achieving innovative solutions for healthcare delivery including digital health, such as the European Reference Networks, and provides support to Member States in the form of expertise and exchange of data, evidence and good practice; recalls that good health is a prerequisite for achieving other goals set by the EU and that policies in such fields as agriculture, environment, employment, social issues or inclusion also have an impact on the health of Europeans; calls, therefore, for the strengthening of health impact assessments and for cross-sectoral cooperation in the next MFF in this field.”

MEMBERS’ NEWS

22-23 January: Foundation Compassion Alzheimer Bulgaria receives European award for project on inclusive society

On 22 and 23 January, in Sofia, Bulgaria, 12 awards were given to organisations for projects that empower people living with dementia. The winners include the Bulgarian organisation Foundation Compassion Alzheimer Bulgaria. The awards 2017, with the title “Valuing the expertise of people living with dementia” represent a mark of recognition for these exemplary practices and acknowledge the work of the 12
organisations in respecting the autonomy, dignity and right to self-determination of people living with dementia.

These awards are given by the “European Foundations’ Initiative on Dementia” (EFID), a collaboration between The Atlantic Philanthropies (IE), Fondation Médéric Alzheimer (FR), Robert Bosch Stiftung (DE), Genio Trust (IE) and the King Baudouin Foundation (BE), in the context of the Network of European Foundations (NEF). Foundation Compassion Alzheimer Bulgaria won the award for the second time, in this 2017 edition. The project “Together we respect, promote and act - Inclusive society for all ages and all stages of dementia” aimed to study, promote respect for the needs of people with dementia and enhance a model for inclusion through a series of activities in Sofia and Varna.

The award ceremony took place at the University of Sofia on 23 January, under the auspices of the Bulgarian Presidency of the European Union. The ceremony was preceded by a conference on 22 and 23 January that offered a stimulating networking and learning space for the EFID network of practitioners and stakeholders on the topic “Valuing the expertise of people living with dementia”.

During the opening speech at the ceremony, Rositsa Dimitrova, Vice-Minister of Labour and Social Policy announced the foreseen measures for improving the lives of people living with dementia in Bulgaria:

"According to the Implementation Plan of the National Strategy for long-term care, 100 new social services for more than 2,000 users are planned, including 6 day care centres for people with different forms of dementia and their families, 16 day care centres for people with disabilities, including with severe multiple disabilities, 10 centres for social rehabilitation and integration for persons with mental disorders, 68 care centres for people with disabilities and elderly people who need care."

www.edif.info

29 January: Gea Broekema steps down as Executive Director of Alzheimer Nederland

On 29 January, Alzheimer Nederland announced that Gea Broekema-Procházka has stepped down from her position as Executive Director at Alzheimer Nederland - a position she held since 2007 – for health reasons. Ms Broekema-Procházka said:

“This step back is best for my health. But it is also a step forward, a step into a new phase of my life. I can look back on a wonderful time with Alzheimer Nederland, in which I worked alongside staff, volunteers, donors, ambassadors, companies, researchers, funds, grant providers and partners to build an organisation for people with dementia and those close to them. Although I will miss my work with Alzheimer Nederland, I shall continue to follow its progress. My departure has done nothing to affect my commitment.”

The Supervisory Board of Alzheimer Nederland expressed its respect and appreciation for the way in which Ms Broekema-Procházka led the organisation, stating:

“Because of her professionalism, dedication and hard work, Alzheimer Nederland has grown into a leading organisation in the field of dementia and in the circle of national and international charities.”

To mark her departure, Alzheimer Nederland is setting up a fund to support the Caribbean islands of Aruba, Bonaire, Curacao, Eustatius, Saba and Sint-Maarten in their efforts to help people with dementia and their families.

1 February: Chairman of Alzheimer Sverige presents 2018 Nordic Medicine Prize

Researchers Gunhild Waldemar and Kaj Blennow were awarded the 2018 edition of the Nordic Medicine Prize, for creating a comprehensive and important scientific basis for the presence, causes and treatment possibilities of dementia diseases. The Chairman of Alzheimer Sverige (Alzheimer Sweden), Krister Westerlund was asked to hand out the prize at the ceremony on 1 February, at the premises of the insurance company Folksam, in Stockholm.

The prize is one of the largest medicine prices in the Nordic region, with its prize money of SEK 1 million (EUR 100,000), and this year, it is great to see dementia research being recognised.

Gunhild Waldemar, Professor at the University of Copenhagen, was recognised for her clinical studies on functional imaging of the brain in normal aging and dementia diseases, as well as for her pioneer work to create best care for patients with dementia diseases.

Kaj Blennow, Professor at the University of Gothenburg, was recognised for his basic studies of biomarkers for Alzheimer's disease and other neurodegenerative diseases, as well as for his epoch studies on molecular mechanisms in Alzheimer's disease.

3 February: Muistiliitto participates in preparation of draft of Finland’s Self-Determination Act

The Self-Determination Act has a key role to play when securing the good care and treatment of people with memory-related diseases, emphasised Merja Mäkisalo-Ropponen, Chairwoman of the Alzheimer Society of Finland (Muistiliitto), speaking on 3 February in Helsinki, at an annual meeting of leaders of local associations.
The Alzheimer Society of Finland is participating in the preparation of the draft of The Self-Determination Act. The last meeting of the working group is during February 2018 and the draft will proceed to the Finnish Parliament this year.

Ms Mäkisalo-Ropponen stated that The Alzheimer Society of Finland is monitoring the renewal of The Disability Services Act as well. The good news is that the restrictions related to age and diagnosis are going to be removed from the Act. However, Ms Mäkisalo-Ropponen expressed her concern about the caregiver burden. “They carry the heavy load – having the responsibility for taking care of their loved ones.”

There are 44 local associations in Finland. The Alzheimer Society of Finland gathers the agents of associations several times per year.

15 February: Association Luxembourg Alzheimer (ALA) starts care group for people in early stages of dementia

Since October 2017, the Association Luxembourg Alzheimer (ALA) has started a self-help group for people in the early stages of a neurodegenerative disease (specifically dementia). This group is for people who:

- have been diagnosed with dementia
- feel overwhelmed, alone and abandoned
- wish to exchange with other concerned persons in a protected environment
- seeking specialised support and coaching.

For now, the group consists of four participants. The themes are determined by the participants, according to their personal needs. Interviews are also planned so that participants can get to know each other.

Anyone interested in this group can contact ALA’s psychological service on (+352) 26 007-450.

The group meets every first Thursday of the month from 2pm to 3.30pm, at the headquarters of the ALA: 45, rue Nicolas Hein, L-1721 Luxembourg.

19 February: Finland’s Memory Activists involved in the development of palliative care, terminal care and euthanasia in their country

A form of participation at national level, citizens’ initiative, has been applied in Finland since 2012. It offers citizens the possibility to have their initiative considered by the Parliament. This spring, the Parliament will consider an initiative that promotes the legalisation of euthanasia in Finland.

The Finnish working group of people with memory diseases and their family members - Memory Activists - participated in the discourse about palliative care, terminal care and euthanasia by releasing a brief statement regarding the issue in December 2017.

Some of the perspectives that the Memory Activists wanted to emphasise were:

- The advanced directive should be respected in all care settings and kept up-to-date.
- Palliative care skills and procedures should be developed so that a patient can get excellent palliative care in all care settings.
- The diagnosis does not occur alone – memory-related diseases should be considered in the care plans of other diseases.
- The choices and principles regarding palliative care, terminal care and possibly even euthanasia should be equal in all parts of Finland and in different care settings.
- The end-of-life care plan should be discussed openly and honestly with both the patient and family members.

Death is not an easy subject; we often fear it. Faith in peaceful end-of-life care and death can alleviate these fears. The Memory Activists hope that their views are taken into account in the development of palliative care, terminal care and euthanasia in Finland.

21 February: Powerful new video from The Alzheimer Society of Ireland aims to educate healthcare professionals about supports needed after a dementia diagnosis

“I was told I had Mild Cognitive Impairment - that didn’t sound so bad. As I was crossing the car park, I met the original nurse who had assessed me, who apologised for not being with me for the diagnosis. I told her I was fine and thanked her. Again she apologised. In that moment I realised that either I hadn’t heard something or something hadn’t been said and I asked her straight out, “are you telling me I have Alzheimer’s?” And the answer was “yes”. “

These are the words of Kathy Ryan who was diagnosed with dementia in 2014. Kathy is Vice-Chair of the Irish Dementia Working Group which along with the Dementia Carers Campaign Network has launched a campaign to educate healthcare professionals about the supports people want and need when receiving a dementia diagnosis.

As part of this campaign a new video has been developed, which highlights different experiences people have had of receiving a diagnosis, including people of different ages, genders and with different types of dementia. This video also features Dr Tony Foley from the PREPARED project (Primary Care Education, Pathways & Research of Dementia), a three-year national primary care dementia project.

In the coming months, the two advocacy groups, which are both coordinated and supported by The Alzheimer Society of Ireland, will seek opportunities to present to healthcare professionals – including GPs, Geriatricians, Neurologists and
In 2017, the Alzheimer’s Society (UK) led a review on the Dementia Statements on behalf of Dementia Action Alliance. The Statements were first launched in 2010 and summarise the aspirations of people affected by dementia. Grounded in human rights law, they’re the basis of a rallying call to improve the lives of people with dementia and to recognise that they shouldn’t be treated differently because of their diagnosis.

A key change to the revised Statements was moving from “I” to “we”. This represents our collective voice and makes clear how people with dementia were consulted, and how they collaborated on making a change. Over 80 people with dementia and carers contributed to the review; and 9 people with dementia (three of whom were accompanied by their carers) and 3 former carers helped to produce the draft statements. The draft statements were based on themes from the evidence gathering - identity, care, community, carers and research.

The final Dementia Statements were agreed at a Consensus Event which was attended by people with dementia and carers as well as representatives of DAA organisations.

Hilary Doxford, an Alzheimer’s Society Ambassador living with dementia and a member of the Three Nations Dementia Working Group and former Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) argues that:

“Personally, I see the statements as a framework that all people working in the dementia arena can use to ensure they meet the need of those they try to help. The Statements are usable by everyone today. No excuses”.

As Ms Doxford has explained, the Dementia Statements are for everyone, from the state, to health care providers, businesses and society at large. To help disseminate the information, we have created a leaflet, which presents the Dementia Statements in a clear and engaging way. It also references some of our fantastic ambassadors who helped to develop the statements.

“I have Alzheimer’s – it does not identify me, and I and everyone else with dementia, will not be made ashamed of what is beyond our control. Writing the Dementia Statements has given us a voice and our voice needs to be heard.” - Shelagh Robinson, person with dementia and Alzheimer’s Society Ambassador

Read the revised dementia statements: https://goo.gl/y9NV5W

23 February: “Dementia Statements” have been revised and agreed, reports the Alzheimer’s Society (UK)

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8 February: All-Party Group on Dementia Hosts Awareness Session in Irish Parliament

Ireland’s All-Party Oireachtas Group on Dementia hosted their third dementia awareness session in the Irish parliament on 8 February. These sessions are an opportunity for Members of Parliament to discover ways of supporting families affected by dementia in their constituencies, learn basic facts about the condition and hear directly from people who are living with dementia.

Speakers at this session included former Minister for Justice Nora Owen, who spoke about supporting her husband who has dementia, and Maureen O’Hara, a dementia advocate who shared her experience of living well in her community.

The All-Party Oireachtas Group on Dementia was launched in October 2016. This group - co-convened by Deputy Mary Butler and Senator Colette Kelleher - is run in partnership with The Alzheimer Society of Ireland (ASI) and has over 20 members, representing all the main political parties in Ireland.

Pictured: Members of the Irish Parliament with Mrs Nora Owen, Ms Maureen O’Hara and others following the dementia awareness session on 8 February

14 February: Wales launches Dementia Action Plan 2018-2022 with dedicated budget of GBP 10 million a year

The Welsh Government has announced a new action plan to help people living with dementia in Wales. The new Plan to transform dementia care in Wales was launched on 14 February by Health Secretary, Vaughan Gething. This new innovative action plan will ensure people with dementia can live as independently as possible in their communities. Health Secretary Vaughan Gething said he wanted Wales to be a dementia friendly nation.

It is estimated that up to 50,000 people in Wales are living with the condition and with an ageing population this number will increase. The minister announced that GBP 10 million a year will be spent with the aim to help people with dementia live as independently as possible in their communities.

The new plan supports a number of initiatives including:

- Dementia risk reduction
- “Our revised Dementia: reduce your risk guidance’ sets out the lifestyle choices individuals can take which could lessen the risk of developing dementia.”
- Dementia diagnosis rates
- “We are taking action to improve dementia diagnosis rates in Wales, including extra training and support for primary care and care home staff.”
- Post-diagnostic support
- “We will be funding new support workers across Wales to help those who have received a dementia diagnosis.”
- Care in general hospital settings
- “We are supporting NHS Wales staff to ensure they have the knowledge and skills they need to provide the best care for patients with dementia.”
- Public awareness and support
- “We will be providing further funding to the Alzheimer’s Society in Wales for their Dementia Friends/Dementia Supportive Communities campaigns.”

The Ministerial Foreword of the action plan states:

“We have a clear vision for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities. We want to create a society without stigma – where people living with dementia continue to go about their day to day life with the wider public who are understanding and know how to provide support. This is not something that health and social services can do alone. Achieving a dementia friendly nation requires a cross-Government, multi-agency and society wide response. Our national strategy, Prosperity for All, challenges us to work differently, not just across portfolios within Government, but also with our partners and stakeholders”.

Alzheimer’s Society Cymru said:

“We are delighted that the Welsh Government has also included the Dementia Statements in the action plan, as this will underpin the implementation, which is absolutely amazing – to have the rights of people affected by dementia recognised in the document was one of the key ambitions”.

A full written statement from Health Secretary, Vaughan Gething on the new dementia plan can be read here:

https://goo.gl/C2RAxh

Pictured: L-R) Nigel Hullah, Sue Phelps, Morgan Griffith-David, Jayne Goodrick and Chris Roberts.

You can also find more information on the Alzheimer’s Society blog:

https://blog.alzheimers.org.uk/campaigns/dementia-action-plan-wales/
SCIENCE WATCH

22 January: Dementias Platform UK launches “Discovery Awards” - funding of up to GBP 50,000 for research

As of 22 January, Dementias Platform UK (DPUK) launched a call for applications for funding to the tune of GBP 50,000, to support new research proposals for analysis of DPUK’s cohort data to help further scientific understanding of the dementias.

The DPUK Discovery Awards committee will assess applications based on the following criteria:

- Importance - How is this research proposal in the public interest? How will this research contribute to furthering knowledge in the field?
- Originality - How will this project lead to new insights in the field?
- Support for DPUK’s mission - DPUK aims to make better use of its observational data for research into dementia. Please consider how this research proposal supports our mission and how findings will be disseminated.

The DPUK Discovery Awards are open to researchers or academics based at universities or in industry. The lead applicant should have a salary in place for the duration of the award and at least one Early Career Researcher should be part of the research team. Applications close at 5pm GMT on 6 April and award winners will be announced at the DPUK conference on 23 April. Winners can expect the funding award to be made available from June 2018 and the project should be completed by June 2019.

https://www.dementiasplatform.uk/for-researchers/dpuk-discovery-awards

29 January: FDA publishes draft guidance on developing AD drugs, comments must be submitted within 90 days

The US Food and Drug Administration (FDA) has released a new guidance note for developing drugs to treat early Alzheimer’s disease (AD). The draft is is being distributed for comment purposes only, and any comments and suggestions regarding this draft document should be submitted within 90 days of publication (i.e. 29 April 2018).

You can find the full draft guidance paper here:

https://go.o.gi/gMF68t

30 January: Swedish researchers assess the relationship between traumatic brain injury and the occurrence of dementia diagnosis

On 30 January, researchers from the Umeå University in Sweden published evaluations on the occurrence of a dementia diagnosis after a traumatic brain injury, in the journal PLOS Medicine.

Their findings are based on a nationwide cohort study taking into account all individuals (until 2005) in Sweden aged 50 and above, providing a basis of 3,329,360 people. The team tracked diagnoses of dementia and traumatic brain injuries (TBI) through nationwide databases from 1964 until 2012. Using this basis, the scientists then created three cohorts. The first cohort consisted of individuals diagnosed with TBI (n = 164,334) which was matched with two controls. The second cohort was composed of subjects diagnosed with dementia during follow-up (n = 136,233) and the third consisted of 46,970 full sibling pairs with discordant TBI status. Looking at their results the scientists concluded, that there is an association between the occurrences of dementia diagnosis after TBI. This probability was at the highest during the first year after TBI and associated with severe and multiple TBIs.

They further stated, that the risk decreases over time, but remains evident 30 years and above after trauma.

Regarding the limitations of the study, the scientists from Sweden marked the observational design of their analysis. Other hidden factors that shed further light into the association may influence the statistics. They highlighted that no causal inference should be made based on observational data. Examples of possible influences include the higher risk of falling and being involved in accidents for people with dementia, which coincides with a higher risk of TBI. Further, there may be misdiagnosis due to post-concussive symptoms amongst others.

https://go.o.gi/bNaATb

30 January: Clinical trials on Alzheimer’s disease: Is the socioeconomic status sufficiently taken into account?

On 30 January, a team of scientists from Italy and France published a systematic literature review on the reporting of characteristics relating to socioeconomic status (SES) in clinical studies targeting Alzheimer’s disease (AD), in the European Journal of Neurology. There is consistent evidence that associates social and economic circumstances with health. Although these might be important contributing factors to the efficacy of treatments, it is unclear if the SES is duly taken into account in treatment trials and if potential differences between populations are considered respectively discussed.

Their aim was to assess if characteristics relating to SES are adequately reported and what impact SES proxy measures might have on the efficacy of the medications.

The review encompassed randomised clinical trials on the currently marketed drugs for AD (cholinesterase inhibitors and memantine). The team considered four indicators of SES in the studies; educational level, lifetime job category, income and wealth. Of altogether 48 selected studies, 8 trials reported information on the educational level of the participants. Except for one study which performed ad hoc secondary
analyses accounting for SES, none of the other three SES indicators was reported.

The team concluded that the vast majority of studies they evaluated overlooked the relevance of SES. They stressed that this might significantly affect clinical manifestations as well as trajectories of people that are being treated and that a greater effort should be made to collect and report data on those SES indicators.

https://www.ncbi.nlm.nih.gov/pubmed/29383812#

30 January: Study completed on deep brain stimulation in Alzheimer’s disease

On 30 January, researchers from the Ohio State University published an article on a safety and efficacy study of deep brain stimulation (DBS) in Alzheimer’s disease (AD) in the journal IOS Press. The scientists specifically targeted the ventral capsule/ventral striatum region to modulate specific networks that are associated with the frontal area of the brain. So far the use of DBS has proven useful in some people with Parkinson’s disease to improve manifestations that respond to medication such as motor symptoms.

DBS involves an invasive procedure, a medical device called neurostimulator is implanted and sends electrical impulses to targeted areas of the brain. In this case, the scientists tried to modulate behavioural and cognitive networks as a novel treatment approach in three people with AD over a minimum of 18 months.

The participants underwent several assessments, the scientists conducted a semi-structured interview of which the score constituted the primary outcome. Additionally the researchers used positron emission tomography (PET) images which they compared over time.

Next, the team matched the three participants to subjects from a cohort study to compare results of potential effectiveness.

First of all, no significant adverse effects were reported. Further, the team reported that the three participants showed less performance decline and that two of three participants had less decline in performance than the comparison groups which did not receive DBS.

Dr Doug Brown, Chief Policy and Research Officer at Alzheimer’s Society, said: “This study showed that DBS is likely to be safe for people with AD but as the study only involved three people who showed varying degrees of improvement, it may not work for everyone in practice. It is also important to highlight that though DBS could help a person to manage symptoms of AD, there is no evidence to suggest that it slows down or prevents brain cell death. “Given that we haven’t had any new treatments for dementia in over a decade it’s encouraging to see techniques from other diseases being tested for dementia, but it will need further, more in depth research before we can draw any firm conclusions.”

https://www.ncbi.nlm.nih.gov/pubmed/29383812#

31 January: Researchers suggest a blood test to detect proteins linked to AD

In the study, published online on 31 January in the journal Nature, a team of Japanese and Australian researchers reported a screening test that could improve the diagnosis of Alzheimer’s disease (AD).

Researchers suggested that a blood test can predict levels of amyloid-β deposition, one of the first signs of AD, in the brain. The published study included 373 participants ranging from healthy to mild cognitive impairments or AD from Japan and Australia. Using high-tech mass spectrometry techniques, scientists identified participants with a biomarker in their blood plasma indicating a build-up of the β-amyloid in the brain. They reported that blood amyloid levels were accurately correlated with the degree of cognitive problems as well as findings identified by PET scans and cerebrospinal fluid measures. Although the new results are promising, researchers said that there are still several issues that need to be addressed before to consider a general clinical application such as further validation studies coupled with longitudinal data and standardised operating procedures for the analytical process.

https://www.nature.com/articles/nature25456

31 January: Study suggests bilingualism may delay symptoms of Alzheimer’s disease

A new study published in the journal Neuropsychologia revealed that people with mild cognitive impairment (MCI) and Alzheimer’s disease (AD), who are bilingual, are more likely to have delayed cognitive symptoms compared to those who are monolingual.

In the published study led by Concordia University (Montréal, Canada), scientists investigated specific regions of the brain, which are important for memory. The study involved 34 monolingual participants with MCI, 34 multilingual participants with MCI, 13 monolingual participants with AD and 13 multilingual participants with AD.

The study showed increased functional connections in some brain regions in bilinguals. In the brain areas related to language and cognition, both bilingual participants with MCI and AD showed thicker cortex than monolinguals. In fact, researchers described that memory was positively correlated with cortical thickness suggesting that being bilingual may delay cognitive symptoms.

https://www.ncbi.nlm.nih.gov/pubmed/29125888#

1 February: Ionis Pharmaceuticals is recruiting for Phase I/II trial of IONIS-MAPTRx

Currently, there is a lack of treatments that delay the onset or slow the progression of Alzheimer’s disease (AD). Most treatments focus on controlling the symptoms of AD and
do not treat the underlying cause of the disease itself. As a result, there is still a need to research AD treatment options that target the disease mechanism and not just the symptoms. The pharmaceutical company Ionis Pharmaceuticals is currently conducting a Phase I/II clinical trial called “MAPTRX-CS1 study” investigating IONIS-MAPTRRx for AD. The randomised and double-blind study aims to access the safety and tolerability of the investigational drug and compare it to placebo, which looks like the investigational drug, but contains no active medication. The company is currently recruiting participants with mild AD and aged 50-74 in several European countries including Finland, Germany, The Netherlands, Sweden and UK. The study duration for each participant will be approximately 10 months.

To learn more about this clinical trial, including eligibility criteria to join the trial, please check the Clinicaltrials.gov link below:

https://go.gi/Rk9ii5

2 February: Luxembourgish project of LCSB and Ministry of Health aims to reduce dementia

The Luxembourg Center for Systems Biomedicine (LCSB) of the University of Luxembourg and the Luxembourg Ministry of Health collaborate to help people efficiently reduce their risk of dementia, through the Dementia Prevention Program (pdp).

In the light of arising evidence that supports the possibility to reduce the individual risk of dementia, certain risk factors such as obesity, high blood pressure, depression, hearing loss, poorly controlled diabetes, and even smoking, social isolation and lack of exercise have been identified.

The pdp, coordinated by Reijko Krüger (neurologist and professor of neuroscience at LCSB) and his team, specifically addresses these issues.

The programme is designed as a collaborative effort for a personalised method and offers different approaches to influence risk factors of dementia. This collaboration includes intensive cooperation with the treating doctors, as Prof. Krüger emphasises: “We inform the doctors about the type and degree of the dementia risk factors we have identified in their patients. The doctors can then adjust their treatments, for diabetes or high blood pressure for example, following our findings.” This cooperative approach is essential for developing an effective and personalised prevention programme for each patient, Prof. Krüger states.

In addition to the contact with treating doctors, the experts are also in contact with the partners that provide courses and social activities, taking their vital feedback on how the pdp recommendations are being followed into account.

Further, the pdp team keeps in touch with participants, encouraging them to take suggested measures to potentially reduce their risk of dementia. “Physical activity and improved stamina help to become mentally fit again,” Prof. Krüger says.

More information (in French) is available on the website of the Luxembourgish Ministry of Health:


5 February: Research from the University of Southern California identifies “gatekeeper cells” as new potential target in Alzheimer’s and other neurodegenerative diseases

On 5 February, scientists from the University of Southern California published research on mechanisms that predate the accumulation of Alzheimer’s disease (AD) associated amyloid beta plaques and neurofibrillary tangles in the journal nature medicine.

In their unprecedented study, the team used a pericyte-deficient mouse model to test how cells regulate blood flow within the brain. Their evaluation encompassed a variety of tests including magnetic resonance imaging, viral-based tract-tracing, as well as behaviour and tissue analysis. Pericytes also referred to as “gatekeeper cells” are unique cells that wrap around blood vessels in the brain.

Their research showed that a dysfunction of these cells results in suffocation of the brain, metabolic stress, accelerated neuronal damage and evidently neuron loss. The cells naturally contract and dilate to control the flow of blood towards active parts of the brain. So far, previous research only showed that AD as well as other neurodegenerative diseases are accompanied by changes in blood flow and oxygen supply to brain cells as well as that at the same time pericytes die.

This research study added evidence that the loss of the gatekeeper cells impairs blood flow and results in insufficient oxygen delivery to the brain.

At the same time, the team concluded that it remains unclear what leads to the loss of pericytes in AD, highlighting that colleagues are working to further this line of research, scanning the brains of people who are genetically at risk for AD. In addition, they are also collecting cerebral spinal fluid and blood for analysis of vascular damage, including injury to pericytes.

https://www.nature.com/articles/nm.44829 Fe6 F

6 February: Unprecedented UK-based study assesses impact of person-centred care programme and staff training on people with dementia

On 6 February, researchers from the UK published a paper on the efficacy of a psychosocial person-centred care (PCC) intervention for people with dementia in the journal PLOS medicine.
The intervention called “WHELD” consists of a combination of elements taken from interventions evaluated in a previous proof-of-concept study. It focuses on training in PCC for care staff and on the promotion of tailored person-centred activities as well as social interactions. Further, it also involved the development of a system to trigger the appropriate review of antipsychotic medications by the prescribing physician attached to each care home.

The study was conducted in 69 UK nursing homes from 2013 until 2015. Interventions took place during a period of 9 months. Throughout the randomised trial, the team involved 847 participants living in care homes which either received treatment as usual (TAU; 443) or the person-centred intervention (WHELD; 404).

The outcome measures assessed at baseline and at 9 months included quality of life as primary outcome (DEMQOL-Proxy) and various secondary outcomes such as agitation, neuropsychiatric symptoms, antipsychotic use, global deterioration, unmet needs, pain and cost.

As a potentially cost-effective approach, the staff designated two so called “care-staff champions” at each home. These underwent a training delivered by a WHELD therapist to understand PCC, write strengths-based care plans (providing structured social activities that reflect people’s abilities and interest – for about 60 minutes per week per person), understand the evidence about the use of antipsychotic medication and develop ways to understand the individual needs of people who are distressed, amongst others.

Of the 847 participants, follow-up assessments were available for 553 (the majority of people that could not participate in the follow-up had died). The comparison of the TAU and WHELD groups showed, that there was a significant effect on the primary outcome quality of life (although measured as a proxy). In addition, also secondary outcome measures such as agitation and neuropsychiatric symptoms showed significant improvement in comparison to the control group.

The team also reported that their analysis showed cost advantages over usual care. While it is not surprising, that a person centred approach and investment of dedicated time towards care home residents results in a raise of quality of life and associated symptoms, a key issue for future studies is the sustainability of the intervention, which would need to be firmly embedded within the care home culture, the authors concluded. In addition, they highlighted that it will be important to further evolve interventions more tailored to the needs of people with more severe dementia.

On 9 February, US researchers from National Institutes of Health, Hamilton, published in the journal Acta Neuropathologica Communications an article on a test to improve early diagnosis of Parkinson’s disease (PD) and dementia with Lewy Bodies (DLB). They have modified a practical test for the early diagnosis of prion diseases to adapt it for PD and DLB.

Abnormal accumulation of α-synuclein (αSyn) have been observed in the brain of people with PD and DLB. In the published study, scientists quantified αSyn in cerebrospinal fluid of 12 people with PD, 17 people with DLB and 31 controls including 16 people with Alzheimer’s disease. The adapted test diagnosed both PD and DLB with high sensitivity and specificity. Interestingly, results were available within two days compared to the related assays requiring 5-13 days to perform.

On 9 November 2017, a team of scientists published their research on the potential protective effect of classical disease-modifying antirheumatic drugs (cDMARDs) on dementia in rheumatoid arthritis patients in the journal Alzheimer’s and Dementia. Rheumatoid arthritis (RA) is a chronic autoimmune disease causing pain and inflammation in the joints. The team looked at electronic medical records of patients over 18 years with RA attending general practitioners in the UK from 1995 until the end of 2011. The data obtained from the UK CPRD provided them with information on 3876 people that use or used cDMARDs. These were matched to 1938 nonusers, the scientists then assessed the impact of cDMARDs on dementia using survival models. Strikingly, the research team found a strong effect of cDMARD use. In their study sample of people with RA, the risk to develop dementia was halved. The scientists concluded that these results require replication in a randomised controlled study.

9 February: Scientists adapt brain disease test for PD and DLB

https://www.boehringer-ingelheim.com/PDE9-Inhibition-in-AD

9 February: Boehringer Ingelheim ends development of BI109306 in AD

On 9 February, the pharmaceutical company Boehringer Ingelheim announced the end of the development of BI409306 in Alzheimer’s disease (AD) after Phase II studies failures.

The experimental AD drug failed to meet its efficacy endpoints in two Phase II trials. Both Phase II studies were a randomised, double-blind, placebo-controlled trial evaluating the efficacy, safety and tolerability of BI 409306 compared to placebo given for 12 weeks in 457 participants wild mild cognitive impairment due to AD. The company plans to present the full results at the Alzheimer’s Association International conference (AAIC) in July 2018. Boehringer Ingelheim will continue to investigate BI409306 on ongoing Schizophrenia trials.

https://www.boehringer-ingelheim.com/PDE9-Inhibition-in-AD

13 February: Study assessing the protective effect of antirheumatic drugs on dementia in arthritis patients draws GBP 400,000 award to continue research

On 9 November 2017, a team of scientists published their research on the potential protective effect of classical disease-modifying antirheumatic drugs (cDMARDs) on dementia in rheumatoid arthritis patients in the journal Alzheimer’s and Dementia. Rheumatoid arthritis (RA) is a chronic autoimmune disease causing pain and inflammation in the joints.

The team looked at electronic medical records of patients over 18 years with RA attending general practitioners in the UK from 1995 until the end of 2011. The data obtained from the UK CPRD provided them with information on 3876 people that use or used cDMARDs. These were matched to 1938 nonusers, the scientists then assessed the impact of cDMARDs on dementia using survival models. Strikingly, the research team found a strong effect of cDMARD use. In their study sample of people with RA, the risk to develop dementia was halved. The scientists concluded that these results require replication in a randomised controlled study.
trial to validate cDMARDs as a potential therapeutic treatment for dementia. Professor Edwards (Oxford NIHR Biomedical Research Centre) and Clive Holmes (professor of biological psychiatry at the University of Southampton), along with a team at Queen’s University Belfast led by Dr Bernadette McGuinness, have been awarded GBP 400,000 by the Alzheimer’s Society to continue their research.

http://www.trci.alzdem.com/article/52352-8737(17)30062-8/fulltext

13 February: NIH releases study data on 4,500 individuals from ABCD study

On 13 February, the National Institutes of Health informed the scientific community in a press release that they provide access to an unprecedented baseline dataset (approximately 4,500 participants – 30 terabytes) from the Adolescent Brain Cognitive Development (ABCD) study. The ABCD study is largest long-term study on brain development and child health in the United States and gives scientists the opportunity to conduct research on the many factors that influence brain, cognitive, social, and emotional development.

https://goo.gl/QE46pM

13 February: Merck discontinues Phase III APECS study

On 13 February, the biopharmaceutical company Merck announced that it has decided to discontinue the Phase III APECS study. This decision followed the recommendation by the external Data Monitoring Committee reporting that verubecestat was unlikely to demonstrate a positive clinical effect if the trial continued.

The APECS trial was a randomised, placebo-controlled, parallel-group, double-blind Phase 3 clinical trial evaluating the efficacy and safety of verubecestat in people with prodromal Alzheimer’s disease (AD).

Data from the APECS study will be presented at an upcoming conference.

https://goo.gl/dnXtKA

20 February: AbbVie and Voyager Therapeutics launch gene-therapy collaboration for AD

On 20 February, the Cambridge biotechnology company Voyager Therapeutics and the Chicago-based AbbVie company announced a new collaboration to develop gene therapy treatments for neurodegenerative diseases including Alzheimer’s disease (AD). The collaboration will aim to produce therapeutic antibodies that target tau, a protein associated with AD.

Voyager Therapeutics will receive USD 69 million upfront payment and will add up to USD 155 million to perform research, preclinical development and Phase 1 studies of vectorised antibodies directed against tau. Then, AbbVie will have the option to licence one or more vectorised antibodies into clinical development for AD and other tauopathies.

https://goo.gl/RTm7q8

20 February: Unprecedented nationwide cohort study in France assesses contribution of heavy drinking to dementia

On 20 February, an international team of scientists published research looking back at data of over 30 million adults discharged from French hospitals between 2008 and 2013.

The analysis published in the journal The Lancet, included more than a million patients diagnosed with dementia. Strikingly, 5.2% (57.353) of the cases which had early-onset dementia were either related to alcohol by definition (22.338) or had been diagnosed with alcohol use disorders (10.115).

The scientists noted that the most prevalent cases of dementia under the age of 65, were related to heavy drinking and that it contributed markedly to dementia occurrence. They further concluded that heavy drinking should be considered as one of the major risk factors for this cluster of diseases and that it is associated with all types of dementia over the lifespan.

Their results led them to the suggestion of screening and interventions for heavy drinking to reduce the alcohol attributable impact of dementia.

https://goo.gl/CK7nmg

DEMENTIA IN SOCIETY

5 January: British Deaf Association Scotland gets go ahead for “Transforming the Deaf Dementia Experience” project

The British Deaf Association (BDA) Scotland has announced that, thanks to funding received from the Life Changes Trust, it will be able to embark on its “Transforming the Deaf Dementia Experience” project - a new community interest initiative to support transformational and sustainable improvements in the quality of life and well-being of Deaf people living with dementia, and their carers.

The project, funded over three years, will identify and work with Deaf people who have dementia, and their carers, enabling them to share and receive information, knowledge and experiences about living with and managing dementia through British Sign Language (BSL).

Central to the project is the development of a BSL Stakeholder Group. The Transforming the Deaf Dementia Experience project will ensure infrastructure is in place to support Deaf people living with dementia and their carers to participate as
stakeholders, so that they have a significant influence in the planning, delivery and evaluation of this new initiative. This will help strengthen the BDA’s support in Scotland for Deaf people living with dementia.

This project also aims to explore the Deaf community’s knowledge and understanding of dementia, attitudes towards those with dementia, and thoughts on where they would go for support or information. It hopes to reduce stigma and prejudice towards those living with dementia within the Deaf community.

https://bda.org.uk/transforming-deaf-dementia-experience-new-project/

15 January: NHS pilots project using replica bus stops to provide comfort to hospital patients with dementia

Following the successful response to a replica bus stop being placed in the garden of a Lincoln (UK) care home for residents living with dementia, the National Health Service (NHS) in the UK is keen to introduce the idea into hospitals.

Stagecoach East Midlands responded to a request from Bernadette House Care Home in Lincoln to provide them with a replica bus stop and timetable for their residents. The unique addition is now assisting with reminiscence therapy for residents living with dementia.

Having seen the story, the bus company was contacted by The Health Tree Foundation, the official charity for Scunthorpe, Grimsby and Goole hospitals, which is now keen to test out replica bus stops in some of its wards.

30 January: Bill Gates’ support for dementia research is prompted by his father’s illness

Late last year, Microsoft co-founder and billionaire philanthropist Bill Gates announced he was investing USD 100 million (EUR 81 million) to dementia research, half of which is going to the UK-based Dementia Discovery Fund - a private fund working to diversify the clinical pipeline and identify new targets for treatment – and the other half to be distributed among various start-ups working in this area of research.

This year, on 30 January, Mr Gates revealed the personal reason he has for taking such an interest in this field of research, speaking to special anchor Maria Shriver on American talk show TODAY (NBC network), revealing for the first time that his father, 92-year-old Bill Gates Sr., has been diagnosed with Alzheimer’s dementia. “More and more people are getting Alzheimer’s, and it’s a tragic disease,” said the tech mogul. “I really believe that if we orchestrate the right resources, it’s solvable”.

Mr Gates, who at 62, revealed he worries about developing Alzheimer’s like his dad, says his USD 100 million donation is only the beginning of his mission.

3 February: Photographer Chris Keulen wins prestigious Dutch prize for his reportage “Vulnerable Love”

Photographer Chris Keulen has won the Silver Camera (Zilveren Camera) - the most prestigious Dutch prize for photographers. He received the accolade for his reportage “Vulnerable Love”, about a man taking care of his wife, who is living with dementia.

Mr Keulen met Alda and her husband Kim in 2015, when she had been living with dementia for eight years. He took photographs of the couple over the next two years, during which time Alda moved into a nursing home in Limburg.

https://goo.gl/1fgRx7

13 February: Prince Henrik of Denmark has died with dementia

The Danish Royal Family said in a statement that His Royal Highness Prince Henrik died on 13 February, peacefully, at Fredensborg Palace, and was “surrounded by Her Majesty the Queen and their two sons.”

The 83-year-old French-born prince had previously been diagnosed with dementia, following a medical examination at Copenhagen’s university hospital, Rigshospitalet, the Danish royal household announced on 6 September 2017.
LIVING WITH DEMENTIA

9 February: Idalina Aguiar writes about her participation in the recent meeting of the EWGPWD

Last December, I was in Brussels together with the whole European Working Group of People with Dementia (EWGPWD), of which I am a member. This time we had the chance to be twice at the European Parliament. The first time we attended the AE Lunch Debate on the topic of timely diagnosis of dementia. The second time, we were in the European Parliament for the 4th European Parliament of Persons with Disabilities and to celebrate the 20th anniversary of the European Disability Forum (EDF). It was a historic moment in the European Parliament! It was great to be there together with some other 600 people with disabilities from all over Europe. The opportunity given to the working group (EWGPWD) to participate in the European Parliament for people with disabilities was a great achievement.

During the meeting we had the chance to contribute to two European projects PACE (palliative care) and ROADMAP (ethical and social implications of the project) and to discuss about the Joint Action on dementia. In this discussion the topic of timely diagnosis was addressed again. This is a topic which I feel strongly about. For me, the correct and timely diagnosis was very important, because I could understand what was happening to me, without having to be medicated for a supposed "depression".

For me (and my family), I think it is extremely important to have a correct and timely diagnosis, and above all about the type of dementia. For us, the diagnosis brought us together, changed the way we saw things, and above all the way we look at the future. My family and I think that it is important that the whole family is involved in the diagnosis of dementia. Accepting, facing and learning to live with dementia are important steps to take.

From the time that the person experiences symptoms, it is imperative that family physicians are encouraged to refer the patient to a relevant specialist and that this consultation be as soon as possible so as to have a diagnosis as correct as possible.

During the meeting it was great to meet a new member of the group from Slovenia, Tomaž, who was accompanied by Alenka. However, it was also a sad moment for me as it was the last meeting of Alv, one of the Vice-Chairs of the working group, together with his fantastic wife Berit. They are a great couple. I will miss them! We wish everyone a fantastic 2018, hoping it will be a year full of achievements in this unceasing struggle. Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words into English.

20 February: Helga Rohra writes about her participation in the recent INDUCT Winter School

Since the EWGPWD exists under the umbrella of Alzheimer Europe (AE), a strong involvement of people with dementia in projects is habitual.

After the INDUCT project’s schools in Maastricht and Salamanca, this time Witten in Germany was the location.

Participating PhD students were eager to learn more about a very challenging topic: “How to access to the experience of people with dementia”.

Over 5 days in January 2018, professors from Sweden and Germany among others gave valuable insights for the young researchers.

The highlight for many participants, I am delighted to say, was the lived and live experience that I, Helga Rohra, member of the EWGPWD, was able to share.

Together with Prof. Louise Nygård from Karolinska Institutet, Sweden a lively discussion emerged between the PhD students and me.

People with dementia were able to show, in an eloquent manner, that dementia is more than a mere diagnosis.

The way people with dementia need to be approached as participants by researchers of in-depth qualitative studies can be summarised thus:

• See the person - the ME not only my DeMEntia
• Include us from the very beginning in your projects
• See us as co- partners!

I myself as a representative of our EWGPWD felt valued to contribute to a topic that is of major importance.

The vivid discussions that were continued in the social communities online definitely showed that AE is a valuable partner and unique globally in including the expertise of people with dementia from its European Working Group.
**NEW PUBLICATIONS & RESOURCES**

**23 January: Why is the EMA important to European citizens? Three new videos help explain**

The European Medicines Agency (EMA) has published three video animations to explain how it works to help patients. The first one explains more about what the EMA does:

https://www.youtube.com/watch?v=ShezrN2gs_8

The second explains how it collects information on side effects, to keep medicines safe:

https://www.youtube.com/watch?v=txz52SyK1U

The third shows the process a new medicine goes through from the lab to the patient:

https://www.youtube.com/watch?v=56851W-eKE&t=1s

**31 January: Mental Health Europe publishes report on mapping and understanding exclusion**

In January 2018, Mental Health Europe and the University of Kent-Tizard Centre launched their new report, “Mapping and Understanding Exclusion in Europe”. This study looks at the state of mental health services across Europe (35+ countries) and provides exclusive data and testimonies about European mental health systems, ongoing human rights violations and the changes on the horizon.

The report shows that institutional care, the use of coercion, forced medication, loss of rights and reliance on involuntary hospitalisation of people living with mental ill health are not only a Central and Eastern European problem. It also points to more modern and progressive approaches and successful examples of community based services.

Read more about the report and download it here:

https://mhe-sme.org/mapping-exclusion/

**2 February: Training kit and research insights launched to help reduce health inequalities faced by LGBTI people**

A training package for Health Professionals on how to reduce health inequalities for lesbian, gay, bisexual, trans and intersex (LGBTI) people has been launched by the Health4LGBTI initiative. It is based on new research into the types and causes of health inequalities experienced by LGBTI people, as well as the barriers faced by health professionals and LGBTI people when providing and accessing services. The results of the research, which included a state-of-the-art review study and 12 focus groups in 6 EU Member States, are detailed in two reports available on the Health4LGBTI webpage.

The training package was formally launched on 2 February, at the Health4LGBTI project’s final conference where policy makers and members of the LGBTI community discussed the potential future implementation of this course across the EU.

“Reducing health inequalities experienced by LGBTI people: what is your role as a health professional?” comprises a trainers’ manual, a take-home reference manual for participations, course evaluation tools, and slide sets. Some of the course materials have been translated into Bulgarian, Dutch, English, Italian, Lithuanian, and Polish and are available on request. It will soon be available for download.

Find out more:

https://goo.gl/6iLSNx

**6 February: European Commission platform for Health promotion and disease prevention is aimed at public health policy makers**

The European Commission recently launched the Health Promotion and Disease Prevention Knowledge Gateway - a reference point for public health policy makers. On it can be found reliable, independent and up-to-date information on topics related to the promotion of health and well-being, in particular the prevention of non-communicable diseases.

This Knowledge Gateway provides short, impactful and concise briefs for each topic, focusing on the aspects most relevant to policy makers. The topics covered in this Knowledge Gateway were prioritised by EU decision makers working in the areas of public health and prevention of non-communicable diseases.

The content is to be updated periodically and new Briefs will be added regularly to reflect developments in the field and respond to the needs of EU policy makers.

The Knowledge Gateway has been jointly developed by two European Commission Directorate Generals (DGs), Joint Research Centre (JRC) and DG Health and Food Safety (SANTE).


**9 February: Documents and resolutions related to EPPD are on the EDF website**

All documents and resolutions related to the 4th European Parliament of Persons with Disabilities (EPPD), held at the European Parliament in Brussels and at which Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) was represented,
can now be found on European Disability Forum (EDF) website. These include the three resolutions adopted by the delegates:

- the EDF Manifesto in view of the European elections 2019
- the resolution on the European Disability Strategy 2020-2030

https://goo.gl/xQ7jL3

**JOB OPPORTUNITIES**

**6 February: The UK Dementia Research Institute is recruiting an Associate Director: Care research & technology**

The UK Dementia Research Institute is looking 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 GBP 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 deadlines for expressions of interest is 17 April.

[www.ukdri.ac.uk/joinus](http://www.ukdri.ac.uk/joinus)

**7 February: The European Patients Forum is recruiting a Project Officer on Patient Engagement**

The European Patients Forum (EPF) is recruiting a full time Project Officer on Patient Engagement to join its team in April 2018.

The Project Officer will support EPF’s participation in different European projects related to patient engagement, education and involvement. S/he will notably work on EPF’s project on medicines development EUPATI.

Application closing date is 28 February 2018. You can read the full job spec here:

http://www.eu-patient.eu/About-EPF/Job-vacancies/project-officer/

**9 February: EFPIA is recruiting an Assistant Communications Manager**

The European Federation of Pharmaceutical Industries and Associations (EFPIA) is offering a permanent contract covering a full time position as Assistant Communications Manager as part of the EFPIA Communications team. The Assistant Communications Manager reports to the Executive Director of Communications & Partnerships and is part of the Communications & Partnerships team, which is the voice of EFPIA to members, to stakeholders, in Brussels and across Europe. Application closing date is 9 March 2018. You can read the full job spec here:

https://goo.gl/4sQw4d

**22 February: University of Leeds seeks medical statistician for Postdoctoral Research Fellow position**

Are you interested in applying your statistical and/or mathematical training to medicine? Would you like to be involved in a prestigious methodology grant on a clinical trial design to evaluate complex interventions in institutional settings? Would you like to work within a highly successful, “impressive and inspirational” clinical trials unit, joining a team of over 30 statisticians?

The successful application will work on the MRC Methodology Research Programme funded project: “Open-cohort designs for cluster-randomised trials in institutional settings”. This programme of statistical research is bolted on to a cluster-randomised trial (DCM-EPIC) evaluating the effectiveness/cost-effectiveness of a quality improvement intervention, directed at staff in care homes, to enable person-centred care for people with dementia and their carers. It aims to develop novel statistical methods to design and analyse clinical trials and consists of 5 work packages: i) literature review, ii) user engagement, iii) statistical development, iv) statistical evaluation and v) practical guidance.

You will be responsible for performing a literature review, proposing statistical models, comparing methods for handling missing data, exploring methods for incorporating length of stay, developing sample size formulae, a simulation study and contributing to practical guidance and research outputs. Specialist methodological expertise will be provided by the Principal Investigator, Dr Rebecca Walwyn (Leeds), Co-Investigators, Dr Andrew Copas (UCL), Professor Amanda Farrin (Leeds) and Professor Claire Surr (Leeds). There will be an opportunity to undertake further specific training in the post. In addition, you may make a small contribution to the teaching programme, providing specialist advice to medical statisticians in the Clinical Trials Research Unit.

To apply, you must have a PhD, or equivalent qualification/experience, in statistics or a related discipline, as well as experience of medical statistics and conducting literature reviews and simulation studies.

The closing date for applications is 12 March 2018 and interviews are expected to take place shortly afterwards.

[https://jobs.leeds.ac.uk/Vacancy.aspx?id=10573&forced=1](https://jobs.leeds.ac.uk/Vacancy.aspx?id=10573&forced=1)
EDUCATION

13 February: Real-world epidemiology 3rd Oxford Summer School open for applications


The course will explore the existing sources of real-world data, discuss common types of study and designs for its use, and look in-depth into the issues and solutions linked to big health data usage.

The course is significant to participants from various backgrounds such as pharmacists, clinicians, academics (including statisticians, epidemiologists, and related MSc/PhD students); industry (pharmacy or device) or regulatory staff with an interest in the use of routinely collected data for research.

You can find more information on the university website: https://goo.gl/B8i3c5

Contact Alzheimer Europe:
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AE CALENDAR

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<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>8 March</td>
<td>PACE User Forum (Brussels, Belgium)</td>
<td>Ana, Vanessa</td>
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<tr>
<td>13 March</td>
<td>COFACE work/life balance coalition (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>13-14 March</td>
<td>European Alzheimer’s Disease Consortium (Turin, Italy)</td>
<td>Jean</td>
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<td>15 March</td>
<td>Workshop on dementia and black and minority ethnic communities - Bristol Professionals organised by the Race Equality Foundation (Bristol, United Kingdom)</td>
<td>Dianne</td>
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<tr>
<td>15-16 March</td>
<td>AD/PD Conference (Turin, Italy)</td>
<td>Jean</td>
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<tr>
<td>19-20 March</td>
<td>EWGPSD meeting (Luxembourg)</td>
<td>Ana, Dianne</td>
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<tr>
<td>20 March</td>
<td>PredictND Review Meeting (Amsterdam, Netherlands)</td>
<td>Jean</td>
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<td>22 March</td>
<td>EFPIA Think Tank (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>22 March</td>
<td>ROADMAP survey and interview data integration meeting (Edinburgh, Scotland)</td>
<td>Chris</td>
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<tr>
<td>26 March</td>
<td>AMYPAD Meeting (Barcelona, Spain)</td>
<td>Jean</td>
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CONFERENCES 2018

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>15-18 March</td>
<td>AAT-AD/PDTM Focus Meeting on Advances in Alzheimer’s and Parkinson’s Therapies, <a href="http://www.aat-adpd.kenes.com">www.aat-adpd.kenes.com</a></td>
<td>Torino, Italy</td>
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<tr>
<td>22-25 March</td>
<td>12th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmed.com/cony/2018/default.aspx">http://www.comtecmed.com/cony/2018/default.aspx</a></td>
<td>Warsaw, Poland</td>
</tr>
<tr>
<td>2-4 May</td>
<td>24th Nordic Congress of Gerontology (24NKG), <a href="http://www.24nkg.no">www.24nkg.no</a></td>
<td>Oslo, Norway</td>
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24-26 May
Research in Palliative Care for Older People: Overcoming methodological research challenges, http://eapm2018.forskningsweb.org/
Bern, Switzerland

7-8 June
Sydney, Australia

7-8 June
BestCare4Dem - Sharing effective community-based support in dementia, https://www.meetingdem.eu/
Amsterdam, Netherlands

4-6 July
British Society of Gerontology Annual Conference, www.britishgerontology.org
Manchester, UK

7-11 July
Berlin, Germany

26-29 July
International Conference of Alzheimer’s Disease International (ADI), https://www.adi2018.org/
Chicago, USA

29-31 October
28th Alzheimer Europe Conference “Making dementia a European priority”, www.alzheimer-europe.org/Conferences/Barcelona-2018
Barcelona, Spain

11-14 November
Sydney, Australia

22-25 October 2019
29th Alzheimer Europe Conference “Making valuable connections”
The Hague, Netherlands

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**33rd International Conference of Alzheimer’s Disease International**

**26 – 29 July 2018**

www.adi2018.org

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**BestCare4Dem**

Sharing effective community-based support in dementia

International conference

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**SAVE THE DATE! 7-8 June 2018**

We are looking forward to meeting you in AMSTERDAM

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**International conference**

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

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

The conference is intended for care providers, scientists and policy makers in the field of dementia care as well as for people with dementia and their informal carers.
28th Alzheimer Europe Conference
Making dementia a European priority
Barcelona, Spain
29–31 October 2018
www.alzheimer-europe.org/conferences  #28AEC
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
The closing date for letters of intent is 17 April 2018.