

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



Firstly, I hope that 2018 was a successful year for all our readers and that 2019 has got off to a good start.

From our side, I think the Alzheimer Europe team has every reason to be proud of its achievements over the past 12 months and I would like to thank everyone that supported us in our continuing efforts to make dementia a European priority: our European Working Group of People with Dementia (EWGPWD), national member associations, Expert Advisory Panel, strategic partners, sponsors, the 126 MEPs in the European Alzheimer's Alliance and the Alzheimer Europe Foundation and Board. We also owe a debt of gratitude to the EU and its health and research programmes, without which our work would not be possible.

December began in Brussels, with our final series of 2018 meetings, including a landmark meeting: our new Governmental Expert Group on Dementia came together for the first time. This is an exciting new initiative, made possible with the support of the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government. The group was brought together after initial discussions between these members resulted in agreement that losing the European Commission Expert Group, disbanded mid-year, would be detrimental. You can read more in the EU Developments section. Also in Brussels, we held our final lunch debate of the year at the European Parliament, on Dementia as a priority of the EU health programme. Other meetings in Brussels

included the 4th edition of our Alzheimer's Association Academy, with discussions around the importance of involving carers and people with dementia in everything we do. Our new Board held its first meeting and our corporate sponsors joined us for a Company Round Table meeting. Finally, the new EWGPWD held its first full meeting, which was an opportunity for members to say goodbye and thank you to Helga Rohra. Helga was one of the founding members of the group, as well as being its first Chairperson. I would like to extend my personal thanks to her for the important contributions she has made to the group over the past 6 years and to wish her all the best.

There has been plenty of good news on the EU research front this past month, with the European Parliament voting in favour of a huge budget increase for the Horizon Europe research programme for 2021-2027. The European Council also agreed an outline deal towards the approach and content of the programme.

In other news, the IMI-funded project AETIONOMY, has come to a close. You can read more about its outcomes and other project news in the EU Projects section.

Finally, we were also delighted to hear that the EU and the WHO have agreed to closer cooperation, going forward, following a series of high-level meetings.

On that positive note for international dementia policy going forward, I wish you all an excellent start to 2019!

Jean Georges
Executive Director

ALZHEIMER EUROPE

3 December: Alzheimer Europe and EWGPWD involved in Ageing Equal campaign



From 1 October (International Day of Older Persons) to 10 December (UN Human Rights Day), the Ageing Equal campaign was run by AGE Platform Europe. The 70-day campaign, emphasising ageism as a human rights violation, marked the 70th anniversary of the Universal Declaration of Human Rights.

Each week, the campaign focused on a different topic linked to ageism. The European Day of Persons with Disabilities is observed on 3 December each year, so the campaign focus was on ageism and disability during the week of 3 to 7 December 2018.

The members of the European Working Group of People with Dementia (EWGPWD) know what it is to live with stigma and to have to fight to enjoy the same (universal) rights as everyone else, and some of them agreed to be involved in this campaign, at the invitation of the European Disability Forum (EDF), which worked together with AGE Platform for this part of the campaign.

Tomaž Gržinič (Slovenia), Carol Hargreaves (UK - Scotland) and Chairperson Helen Rochford-Brennan (Ireland) provided testimonials on this topic, which were shared on social media (see #AgeingEqual) and on the campaign website (see <http://ageing-equal.org/>).

Tomaž: <https://ageing-equal.org/we-are-still-able-to-do-things-properly-and-with-quality/>

Carol: <http://ageing-equal.org/dementia-does-not-mean-the-end-of-my-world/>

Helen: <http://ageing-equal.org/older-people-are-traditionally-encouraged-to-accept-their-fate/>

Alzheimer Europe supported this campaign and Director for Projects Dianne Gove also wrote a blog post for the campaign website, on “Dementia as a disability”: <https://ageing-equal.org/dementia-as-a-disability/>

“Human rights do not diminish with age” was the campaign slogan. Nor do they diminish with dementia.

3-4 December: Alzheimer Europe Board approves 2019 Work Plan and Budget

The members of the newly elected 2018-2020 Alzheimer Europe Board held their first meeting on 3 and 4 December 2018 in Brussels. The Board formally approved the work plan and budget for 2019 and discussed various other financial and operational matters.

The next AE Board meeting will take place in Brussels on 25 and 26 February 2019.

4 December: Alzheimer Europe’s European Parliament lunch debate focuses on Dementia as a priority of the EU health programme

Alzheimer Europe held its final lunch debate of 2018 in the European parliament on 4 December. The debate focused on the topic of “Dementia as a priority of the EU health programme”.

Hosted by European Alzheimer’s Alliance member Marian Harkin MEP, the debate was well attended with 92 delegates from across Europe, comprising representatives from the European Working Group of People with Dementia (EWGPWD), national Alzheimer’s Associations, national government representatives, research partners and pharmaceutical representatives.

Geoff Huggins, Director of Health and Social Care Integration at the Scottish Government presented on the work of the second European joint action on dementia, *Act on Dementia*. Mr Huggins explained that the project was an example of an EU project funded from the health programme, building on the previous joint action project (ALCOVE). He outlined the project focused on identifying best practice for people with dementia within four work packages: diagnosis and post-diagnostic support; crisis and care coordination; residential care; and, dementia friendly communities. The project is due to conclude and report on its work in October 2019.

Impressions from the lunch debate



Our host, MEP Marian Harkin (Ireland) addresses delegates at the European Parliament



A strong Irish presence (L-R Carmel Geoghegan, MEP Marian Harkin, MEP Nessa Childers, Helen Rochford-Brennan, MEP Deirdre Clune)



Alzheimer Europe Chairperson Iva Holmerová welcomes delegates



Helga Rohra, departing member and former Chair of the EWGPWD, accepts a plaque honouring her commitment to the group



Alzheimer Europe Executive Director Jean Georges gives an overview of some of the work taking place at European level



Geoff Huggins, Director of Health and Social Care Integration at the Scottish Government presents the work of Act on Dementia



Nélida Aguiar, Carer for her mother Idalina (Madeira, Portugal) asks a question



MEP Deirdre Clune (Ireland) asks a question



Helen Rochford-Brennan, Chair of the EWGPWD, questions the panel about social health

Jean Georges, Executive Director of Alzheimer Europe, gave an overview of some of the work taking place at a European level, including providing an overview of some of the policy and legislative drivers from the European Union, including the European Social Pillar and associated Work Life Balance provisions. Additionally, he highlighted the contribution of Alzheimer Europe through the yearbooks and ethics reports, the contribution to research projects and the facilitation of the government expert group on dementia.

Following the presentations, there was an open floor discussion involving delegates, with questions posed for the presenters on future areas of focus, as well as contributions from people living with dementia and carers of people with dementia who shared their experiences of living with the condition. As part of the meeting, Helga Rohra was presented with a plaque by Iva Holmerová, Chair of Alzheimer Europe, thanking her for six years of service with the EWGPWD, including four years served as Chair of the group.

Alzheimer Europe's next European Parliament lunch debate will take place on 26 February 2019 and will focus on Dementia as a European research priority.

4 December: Alzheimer Europe updates sponsors on its activities

On 4 December, Alzheimer Europe (AE) hosted a Company Round Table meeting in Brussels. It was attended by representatives from AbbVie, Biogen, Essity, GSK, Janssen, Lundbeck, Nutricia, Otsuka and Roche.

Jean Georges, the AE Executive Director, updated the organisation's sponsors on its 2018 activities with a particular

focus on the activities that were sponsored by the companies and sponsors. Jean Georges highlighted the Carers' survey for which the organisation had received an educational grant from Roche.

Delegates were provided with an update on the literature review focused on dementia in ethnic minority groups, the yearbook dedicated to the existing national dementia strategies, the AE Public Affairs meetings and the Alzheimer's Association Academy, which brought together the member organisations with capacity building workshops. Attendees also discussed the involvement of AE in EU projects and other corporate affairs activities including the Clinical Trial Watch, the lunch debates and the Dementia in Europe Magazine.

It was also an opportunity to highlight Alzheimer Europe's planned activities and sponsorship opportunities for 2019. Jean Georges also addressed the European elections for 2019.

4-5 December: Alzheimer Europe organises its fourth Alzheimer's Association Academy

On 4 and 5 December 2018, Alzheimer Europe (AE) hosted the fourth edition of its annual Alzheimer's Association Academy. Participants included 31 representatives from AE member organisations; 4 company representatives, 4 members of the European Working Group of People with Dementia (EWGPWD) and 7 AE staff members. There were 9 expert speakers European and national institutions/organisations and topics were defined based on a survey of participants at the 2017 Academy and AE members.

The first day began with a session on "Involving carers of people with dementia in Alzheimer's associations" and was

moderated by James Pearson, from Alzheimer Scotland. This session included presentations by Štefanija Lukič Zlobec (Spominčica, Slovenia), who spoke about the experience of Spominčica in involving and supporting carers of people with dementia; Bernard O’Hagan (National Dementia Carers Action Network – NDCAN, Scotland, UK), who told delegates about the experiences of carers of people with dementia advocating for policy change at national level, in Scotland; and Mario Possenti (Federazione Alzheimer Italia, Italy), who shared the experience of Federazione Alzheimer Italia in surveying the views of carers of people with dementia. During their presentations the speakers addressed the key questions: How can Alzheimer’s associations effectively involve carers of people with dementia in their governance and activities? How should Alzheimer Europe effectively involve carers of people with dementia in its governance and activities? How are the interests of people with dementia and of carers represented by Alzheimer’s associations?

The second session of the day was on “Giving a voice to and involving people with dementia in Alzheimer’s associations” and was moderated by Iva Holmerová, Chairperson, Alzheimer Europe. This session included presentations by Dianne Gove (Alzheimer Europe), who discussed the findings of Alzheimer Europe’s mapping exercise on the development and growth of working groups of people with dementia in the European region; and Jesús Rodrigo (CEAFA, Spain), who spoke about PEPA, the Spanish Group of People with dementia, as an example of a recently-created working group. The speakers looked at how national organisations can better involve people with dementia in their governance and activities, and at some of the barriers identified.

Day two of the Academy began with a session on “Challenges for the introduction of Alzheimer’s innovation”, which was moderated by Jean Georges, Executive Director, Alzheimer Europe. This session included presentations by Tim Shakespeare (Alzheimer’s Society, United Kingdom), who shared the experience of the Alzheimer’s Society on preparing for the introduction of new Alzheimer’s medicines; Andy Bolan (Biogen), who discussed “Health System Preparedness of Six EU Countries for future Alzheimer’s Innovation”; and Krista Tromp (Erasmus Medical Centre, Netherlands), who spoke about how the introduction of preventative treatments impacts the ethical issues raised by genetic and biomarker risk disclosure. All three presentations helped give delegates at the Academy a clearer picture of how the introduction of disease-modifying treatments impacts on the role of Alzheimer’s associations, how health care professionals need to respond to the introduction of new treatments, whether healthcare systems have the necessary infrastructure and procedures in place for the introduction of new medicines, and how society might respond to the introduction of these medicines as well as ethical issues needing addressed.

The second morning session, was on “Promoting the participation of people in dementia research”, with moderator Charles Scerri of the Malta Dementia Society. This session

included presentations by Ana Belén Callado Gil (Fundació Pasqual Maragall, Spain), who gave the example of the foundation on the effective use of communication to increase research participation – specifically in its ALFA cohort; Marissa Zwan (VUMC, Netherlands), who presented “Hersenonderzoek” – the Dutch registry for brain research and nationwide online platform for recruitment and pre-screening of participants for neuroscience studies; and Piers Kotting (Join Dementia Research, UK), on increasing the participation of people in dementia research, using Join dementia research as an example. This session introduced some of the initiatives at national level to promote the involvement of people with dementia, carers and people at risk of developing dementia in dementia research, the role Alzheimer’s associations have in promoting opportunities for research participation, and whether or not it could be feasible to encourage common systems or databases for people interested in participating in dementia research.

The final session of the Academy was a consultation with the Prevention of dementia using mobile phone applications project (PRODEMOS). Krista Tromp was the moderator. The PRODEMOS project aims to make an evidence-based dementia prevention strategy using mobile Health accessible to those at increased risk of dementia who are usually not reached by preventive medicine. It is targeting socio-economically deprived populations in the EU and a population at risk of dementia in China. The final aim is to implement a flexible, fully-adaptable mHealth platform in a culturally appropriate form in a range of healthcare settings across the globe. Project researchers Marieke HOEVENAAR-BLOM, Edme EGGINK, both at Amsterdam Medical Centre, and Shanu SADHWANI (University of Sussex) asked delegates to reflect on a number of questions related to the app and some of the possible difficulties that they might encounter in creating and implementing it, as well as coming up with solutions and other ideas.

The two-day Academy was a very interactive event, with plenty of interesting and thought-provoking discussions. Given the success of its Alzheimer’s Association Academies to date, AE will host a fifth edition in December 2019.



4-5 December: New EWGPWD holds its first meeting

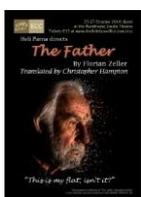


On 4-5 December 2018, the EWGPWD held its first meeting with the newly elected members of the group. During the first part of the meeting, members discussed their experiences during the last AE Conference in Barcelona which they all found very interesting and productive. The group was especially proud of the Special Symposium which had been very successful and attracted a lot of attention. The rest of the meeting was dedicated to a consultation with INDUCT. INDUCT is a European project funded through the H2020 Marie Skłodowska Curie Actions - Innovative Training Networks, and is aimed at developing a multi-disciplinary, inter-sectorial educational research framework for Europe to improve technology and care for people with dementia, and to provide the evidence to show how technology can improve the lives of people with dementia. Six Early Stage Researchers (ESR) and the training manager and the training coordinator from INDUCT were present in the meeting of the group. Each ESR had the opportunity to present his/her research project to members of the EWGPWD and supporters and receive input from them on relevant aspects of their research. They also had the opportunity to discuss the recommendations which will be developed as part of the project. Members of the EWGPWD were very enthusiastic about the different projects presented, all focusing on technology and dementia. The sessions were very dynamic and lively, giving ESRs and people with dementia the possibility to exchange their views.

Members and supporters also bade a fond farewell to Helga Rohra, a founding member of the group, first Chair of the EWGPWD (2012-2014, 2014-2016) and member since 2016. The EWGPWD wishes to thank Helga for her leadership, enthusiasm and dedication during these years of work and for her important contributions to the field of dementia. Helga, you will be missed!



13 December: Production of The Father – a play about Alzheimer's disease - donates proceeds to Alzheimer Europe



A production of the play *The Father*, which explores the theme of Alzheimer’s disease, was staged in Brussels from 23 to 27 October 2018. The English Comedy Club of Brussels (ECC), which staged the play, has generously donated some of the proceeds, totalling EUR 600, to the

Alzheimer Europe Foundation. We are very grateful for this support. Thank you, ECC!

14 December: Luxembourg hosts event to celebrate the Innovative Medicines Initiative’s 10th birthday



On 14 December, around 50 delegates from across Europe came to the National Laboratory of Health in Luxembourg to an Innovative Medicines Initiative (IMI) networking event entitled “Pharma meets

Academia”.

The meeting was convened by a range of high-level organisations from Luxembourg, such as the Luxembourg Centre for Systems Biomedicine (LCSB), Integrated Biobank of Luxembourg (IBBL) and the Luxembourg Institute of Health (LIH).

Presentations during the morning focused on IMI as well as its projects. Here, Magali Poinot (IMI) gave an introduction on how IMI is and has been building new models of collaborative research across Europe. Magda Chlebus (European Federation of Pharmaceutical Industries and Associations – EFPIA) succeeded this with visions towards pharma as well as patient-centred and integrated healthcare systems throughout Europe. The presentation also took a look towards a more comprehensive collaboration including new industry sectors as partners within IMI.

After that, IMI projects, PRECISEADS, HARMONY, ROADMAP as well as LITMUS, INNODIA and CANCER-ID were presented, including a five-minute introduction on Alzheimer Europe’s role as communication and dissemination co-lead of ROADMAPs activities by Christophe Bintener.

The following presentations focused on Luxembourgish projects showcasing their potential as a partner in research. Furthermore, there was a session on IMI management and grant writing to prepare attendees for future calls. Project Officers Christophe Bintener and Cindy Birck attended the meeting.

<https://imi10yearsluxembourg.b2match.io/home>

18 December: Photos, videos and presentations from #28AEC are online



Photos, videos and presentations (where approval has been received from the speakers) from the 28th Alzheimer Europe Conference (#28AEC) on “Making dementia a European priority” are now available on our website:

<https://www.alzheimer-europe.org/Conferences/Previous-conferences/2018-Barcelona>

Alzheimer Europe networking

On 3 and 4 December (Brussels, Belgium), the Alzheimer Europe Board met.

On 3 and 4 December (Brussels, Belgium), Alzheimer Europe convened a meeting of European government experts on dementia.

On 4 December (Brussels, Belgium), Alzheimer Europe organised a European Parliament lunch debate “Dementia as a priority of the EU health programme”.

On 4 December (Brussels, Belgium), Alzheimer Europe organised a company round table meeting with its corporate sponsors.

On 4 and 5 December (Brussels, Belgium), Alzheimer Europe organised its Alzheimer’s Association Academy with representatives of its national member organisations.

On 10 December (London, UK), Jean attended the GSK Health Advisory Board.

On 11 December (Vienna, Austria), Dianne and Jean attended the Legal and Ethical Advisory Board of the AETIONOMY project.

On 13 December, Cindy attended the virtual meeting with all EMA eligible patient and consumer and healthcare professional organisations.

On 14 December (Dudelange, Luxembourg), Cindy and Chris attended the IMI Networking event – Pharma meets Academia.

Sponsor of the month

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2019 activities.

Read more about sponsorship opportunities here:

<https://goo.gl/ckVNeC>



DONATE NOW!

Help us make dementia a priority

EU PROJECTS

22 November: ROADMAP project publishes article on regulatory and HTA considerations for disease-modifying drugs in AD



On 22 November, researchers from the ROADMAP project published an article on discussions and activities of their regulatory and health technology assessment expert group regarding project activities and outputs in the journal CNS Drugs.

The paper highlights that there is a lack of general agreement on validated outcomes for the very early stages of Alzheimer’s disease (AD). It discusses the need to fill in gaps between those outcomes that are used across clinical trials and the ones from real-world settings. Furthermore, it also revolves around the discussions on the role that real-

world evidence might have in signalling the impact of a possible disease-modifying therapy on caregivers as well as resource use but also long-term outcomes.

<https://link.springer.com/article/10.1007/s40263-018-0581-x>

5 December: INDUCT reports on recent consultation with EWGPWD



On 5 December 2018, the Interdisciplinary Network for Dementia Using Current technology (INDUCT) consultation with the European Working Group of People with Dementia (EWGPWD) took place in Brussels.

Within the INDUCT project, 15 Early Stage Researchers (ESRs) are conducting research on the evidence for and application of technologies to improve the lives of people with dementia. The EWGPWD is a group of people with dementia, who make sure that the agenda and activities of Alzheimer Europe are representative of their priorities and views.

The INDUCT ESRs were eager to ask the members of the working group for feedback on their projects and demonstrate the technologies they had been working on. In the morning, the ESRs presented their research projects and asked the working group members specific questions about their preferences concerning the language, content, and portrayal of the investigated technologies. The ESRs and working group members had interesting discussions on ethics, equal representation, communicating about research. In the afternoon, the ESRs presented some examples of the products of their research in a demomarket. Working group members shared their impressions of the technologies presented and ways to improve the products were discussed. The day was wrapped up with a summary of INDUCT’s experiences with the EWGPWD so far, both during the day’s consultation and during the entire INDUCT project.

“We had a really interesting discussion about Advance Care Planning (the topic of my project). Even though it is a delicate topic to discuss, the members of the EWGPWD were very open

and honest in sharing their opinions. This gave me not only a lot of valuable information, but also a great boost to continue this project.” – Annelien, ESR 12

In summary, the consultation was a very fun, information-packed day of sharing experiences and learning about dementia. The INDUCT ESRs valued this opportunity to tailor their research to the needs and expectations of people with dementia enormously. For further information, contact:

Email: Hannah.christie@maastrichtuniversity.nl

Twitter: @HChristie_

11 December: Study on computer-assisted prediction of progression in early AD published by members of former PredictND project



On 11 December, members of the PredictND project announced they have published an article on Computer-assisted prediction of clinical progression in the earliest stages of AD. It is available in open access in the journal *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*.

The PredictND project ran for 4 years, from January 2014 to January 2018, but participants are actively continuing to produce output.

Alzheimer Europe was a partner in the PredictND project.

<https://bit.ly/2QtwDs5>

13 December: AETIONOMY project findings will support new research directions for years to come



This month, AETIONOMY is coming to a close. The project leaders report on progress made during the life of the project and its outcomes:

AETIONOMY was started five years ago to explore the idea that conventional disease definition (that is, the expert clinical assessment of groups of symptoms leading to an eventual diagnosis) is an increasingly outdated concept in the current medical environment. Opportunities for so-called ‘precision medicine’, in which molecular features both identify and direct treatment for disease, have been observed in a range of disorders, most prominently in the oncology field. The AETIONOMY consortium chose to seek molecular characteristics in Alzheimer’s disease (AD) and Parkinson’s disease (PD) that might contribute to a ‘taxonomy’ of these diseases and help our community move towards a precision medicine approach.

AETIONOMY was conceived by a broad group of scientists - the consortium comprises clinicians with expertise in treating patients with neurodegenerative disorders, research scientists from several companies, and a group of data scientists. The project has developed innovative computational tools to

manage and interpret the complex healthcare and research data environment.

It was a Herculean task for the teams to clean, associate and relate data that had been collated to answer research questions over the years, and to make it available for our cause. Among the legacies of AETIONOMY are the resultant ‘cleaned’ data, managed in an environment that will support future researchers.

At the heart of the project was the collection of donated samples from patients and healthy controls who generously participated in the clinical study, alongside the generation of new data. This has helped us verify the computational models produced from historical data. In addition, the team has explored a range of molecular theories underlying disease progression.

The outcomes are still being explored as the project wraps up, and our findings will support new research directions for many years to come. Excitingly, the computational models appear to have identified groups of patients that differ significantly from each other. The differences can either be traced to molecular characteristics or describe different risk profiles for the development of neurodegenerative disorders. Both findings offer insights into future opportunities for precision medicine approaches and increased hope in the search for treatments. To learn more, please visit www.aetionomy.eu

The research leading to these results has received support from the Innovative Medicines Initiative Joint Undertaking under AETIONOMY grant agreement n°115568, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies’ in-kind contribution.

15 December: ROADMAP publishes project overview publication in Journal of Alzheimer’s Disease



On 15 December, the international ROADMAP Consortium who evaluated the usability of multiple data sources for new treatments in Alzheimer’s disease (AD), published an article on challenges in the optimisation of real-world evidence in the *Journal of Alzheimer’s Disease* providing a scientific overview of the project’s endeavours.

You can read the full publication here:

[https://www.alzheimersanddementia.com/article/S1552-5260\(18\)33556-8/pdf](https://www.alzheimersanddementia.com/article/S1552-5260(18)33556-8/pdf)

17 December: MOPEAD project launches second newsletter



Welcome to the 2nd MOPEAD Newsletter

On 17 December, the Innovative Medicines Initiative funded MOPEAD project launched its second newsletter. The newsletter includes news on the

most recent project developments in engaging with the general population as well as patients through various models such as online platforms and through the help of important stakeholders encompassing both general practitioners and diabetologists. You can read and subscribe to the newsletter here: <https://goo.gl/6V4fpZ>

18 December: MinD design evaluations begin



In December, MinD project colleagues from Fundació INTRAS and from Universitat Politècnica de Catalunya (UPC) in Spain, met at Nottinghamshire Healthcare NHS Foundation Trust, in the UK. The team continued preparing for the evaluation of the Good Life Kit (GLK) and for a further Public and Patient Involvement (PPI) Group event where the first GLK prototype was introduced.

The GLK aims to support people with dementia in approaching everyday life positively and confidently. The first prototype of the GLK arrived from partner Twente University in the Netherlands, where the prototypes are produced, in time for the PPI event. Colleagues worked together to plan the event, prepare the materials for the session in a user-friendly format, and send out relevant information to participants in advance.

A convivial PPI event allowed all participants to sample the GLK and suggest how it could be used within the evaluation. After the welcome, a warm-up task enabled everyone to try

out skills as interviewers to gather ‘essential’ group information such as who was wearing clean socks, who took their phone to bed and who had done their Christmas shopping!

Next, a ‘goldfish bowl’ activity enabled sets of volunteers to play the ‘This Is Me’ game, which is one of the three parts of the GLK, while others observed and made notes. Emergent experiences unlocked within the game were powerful, and players supported one another to share the vivid recollections. Lively discussion followed, producing some excellent feedback.

MinD colleagues then shared their experiences with own research in social robotics and previous experiences with and hopes for the PPI group at INTRAS, Valladolid, Spain. A lunch with seasonal treats encouraged friendly networking before two mixed teams each tackled the second and third part of the GLK – ‘You and Me’ and ‘Living the Life’.

It was noticeable with both ‘This Is Me’ and ‘You and Me’ that guidance needs to be simple and clear, while players also chose to make up their own rules, and this flexibility was seen as positive. After a lively day, brief moments in mindful spaces encouraged by the activities of ‘Living the Life’ enabled a tranquil wind-down before people departed, taking the remaining mince pies and chocolates home with them.



EU project acknowledgement

A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or 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 EU funding are:

- AETIONOMY - grant agreement 115568
- MOPEAD - grant agreement 115985
- PREDICTND - grant agreement 611005
- ROADMAP - grant agreement 116020



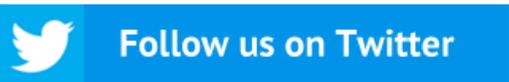
Members of the European Alzheimer’s Alliance



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

Austria: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübiger (EPP). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (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 Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Ádám Kósa (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei

(S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Gerben-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP); Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Jana Žitňanská (ECR). **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ana Miranda (Greens/EFA); Pablo Zalba Bidegain (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).



EUROPEAN ALZHEIMER'S ALLIANCE

4 December: Members of the European Alzheimer's Alliance participate in AE Lunch Debate



Alzheimer Europe (AE) would like to thank MEP Marian Harkin (Ireland) for hosting its lunch debate on "Dementia as a priority of the EU health programme" at the European Parliament in Brussels on 4 December. We would also like to thank MEPs Heinz K. Becker (Austria), Sirpa Pietikainen (Finland), Nessa Childers (Ireland) and Deirdre Clune (Ireland) for their active and positive participation, as well as MEP Martina Anderson (UK, Northern Ireland) who was represented at the meeting.

All MEPs present or represented are current members of the European Alzheimer's Alliance (EAA) - a non-exclusive, multinational and cross-party group of MEPs supporting AE and its members in making dementia a public health priority.

The EAA currently has 126 Members from 27 Member States of the European Union and all seven political groups in the European Parliament.

<http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance>

EU DEVELOPMENTS

1 December: European Council reaches outline agreement on Horizon Europe



The European Council (competition) has agreed an outline deal towards the approach and content of the Horizon Europe research programme for 2021-2027.

Research ministers debated a number of issues related to the programme, including the future of industry partnerships such as the Innovative Medicines Initiative and, more specifically, the allocation of funding to different pillars of the programme. A consensus was reached to allocate the majority of funding outside of partnerships.

The Ministers reiterated their support for a mission-focused approach to the Horizon programme, however, the content of these missions was not included within the conclusions reached by the Council. There was a broader commitment to ensuring that citizens and civil society are included in the research agenda setting process, including a call for the Commission to conduct a pilot into this.

This discussion is one of a number of ongoing areas of work in relation to the next Horizon Europe programme, with the Multiannual Financial Framework (MFF) ongoing which will ultimately determine the budget allocated to the programme.

Other issues relating to other aspects of the programme such as looking at issues of researcher "brain drain" and matters regarding the proposed European Innovation Council (EIC) were not agreed on and will be revisited under the Romanian Presidency of the European Council.

The full agreed conclusions of the meeting regarding the Horizon Europe programme can be found at: <https://www.consilium.europa.eu/media/31888/st15320en17.pdf>

1 December: World Health Organisation and European Union commit to working together on health



The European Union and World Health Organisation have agreed to closer cooperation in health matters

following a series of high-level meetings and events.

WHO Director-General Dr Tedros Adhanom Ghebreyesus met with European Commission President Jean-Claude Juncker and other senior European Commission officials, including health and food safety commissioner, Vytenis Andriukaitis. Mutual areas of interest and cooperation were identified during these meetings including the WHO's Global Action Plan for Healthy Lives and Well-Being for All and the Sustainable Development Goals.

Additionally, Dr Tedros addressed the European Parliament, as part of the 70th anniversary of the Universal Declaration of Human Rights (UNDHR) with a celebration of Human Rights Week. In his address, Dr Tedros emphasised health as a human right, noting it was identified as such both within the WHO's charter and in the UNDHR. Dr Tedros also signed a joint statement with the European Parliament as part of his visit and thanked MEPs for their commitment to health as a universal human right.

3 December: MEPs vote to open access to publicly funded research data



Members of the European Parliament’s research committee (ITRE) have accepted a draft legal text which would mean researchers who receive public funding would have to make their research data publicly available. The vote came as part of the European Commission’s proposals on the public sector information directive; the Commission’s initial proposal required member states to "support the availability of research data", however, the ITRE accepted an amendment which proposed that "all publicly-funded research data should be made open by default."

The provisions would apply to all research projects funded by governments in member states or by the EU itself, for example, those under the Horizon Europe programme. However, exceptions are included for reasons of "confidentiality" and "legitimate commercial interests."

In addition, the ITRE has proposed six categories of data which would be included within the legislation: geospatial data, earth observation and environment data, meteorological data, statistics (such as economic and demographic indicators), company and business registers, and transport data.

Although passed by the committee, the amendments still need to be approved by a plenary session of the European Parliament, before being subject to negotiations between the Commission, Council and Parliament.

3 December: Health alliance issues Brexit statement



An alliance of organisations within the health community from across Europe have come together to reiterate the importance of prioritising patient safety and public health in the ongoing debate around Brexit.

In particular, the statement emphasises that regardless of the outcome of the UK parliament vote on the Withdrawal Agreement, it is essential for an immediate focus on healthcare issues, including the regulation and supply of medicines and medical technologies in the post-Brexit relationship.

The statement calls for a series of immediate actions to be taken to protect patients and public health in the event of a no-deal scenario, including:

- A mutual recognition agreement for all CE marked medical technologies granted by a UK based notified body (for the EU27) or granted by an EU27 based notified body (for the UK).
- Temporarily exemption from any new customs and borders checks for medicines and medical technologies, including clinical trial materials.
- The introduction of measures to enable the continued UK participation in key data sharing platforms that protect

public health and medicines and medical technologies' safety in Europe.

The full statement can be read at: <https://bit.ly/2QqQXXj>

3-4 December: Government expert group on dementia meets in Brussels



A new Governmental Expert Group on Dementia has met for the first time since the European Commission disbanded a similar group in summer 2018. The meetings took place from 3-4 December in Brussels, bringing together government-nominated representatives from across Europe to discuss progress and developments in relation to dementia policy, practice and research.

Facilitated by Alzheimer Europe, the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government, the group was brought together after initial discussions between these members resulted in agreement that losing the European Commission Expert Group would be detrimental, as no other platform existed in which governments exchange knowledge and information.

In total, 17 governments attended the group, with apologies received from a further six who expressed an interest in participating in future meetings. Also in attendance as observers were representatives from Alzheimer Europe, European Commission, Organisation for Economic Cooperation and Development (OECD) and the World Health Organisation (WHO).

Each country provided an update in relation to their respective countries regarding dementia policy and practice, with a number of countries referring to their country’s national dementia strategy. Additionally, members heard from observer organisations who presented on relevant developments from their organisations, including in relation to the Global Dementia Action Plan and relation to respective work programmes.

Participating countries from the second Joint Action on Dementia, presented on the progress of work in their respective work packages: diagnosis and post-diagnostic support; crisis and care coordinate; residential care; and, dementia friendly communities.

The group agreed in principle that it should meet twice per year, with the times and dates to be confirmed. The group

agreed that using sessions to explore themes and specific issues areas of work, such as care coordination or diagnosis, would be most helpful to for members of the group.

4 December: EU Agency on Fundamental Rights publishes report on independent living for persons with disabilities



On 4 December 2018, The European Union Agency on Fundamental Rights (FRA) published a new report, “From institutions to community living for persons with disabilities: perspectives from the ground”.

The Convention on the Rights of Persons with Disabilities (CRPD) commits the EU and all of its Member States to realising the right of persons with disabilities to live independently in the community, which includes achieving deinstitutionalisation for those residing in institutional settings.

Much remains to be done to make this a reality in practice and this FRA report presents the main insights gained during fieldwork on the drivers of and barriers to deinstitutionalisation. Focusing on the local level, it gives voice to a diverse set of actors, most importantly, to people with disabilities themselves.

It also outlines input from the families of individuals going through the transition to community-based living, members of local communities, and the various people responsible for designing the process and implementing it on a daily basis. In so doing, it can serve as an important resource for policymakers looking to take this important work forward – with the ultimate goal of ensuring that people with disabilities can live independently in the community on an equal basis with others. Download the report: <https://bit.ly/2QRNp4q>

More information about the report: <http://fra.europa.eu/en/publication/2018/independent-living-reality>

Infographic “5 success factors on the road to independent living for people with disabilities”: <https://bit.ly/2QOkjmF>

12 December: MEPs vote to support an increased Horizon Europe budget



The European Parliament has voted in favour of Horizon Europe, the successor to the Horizon 2020 research programme, and called for an increase in the budget to EUR 120 billion – a significant increase in the EUR 94.1 billion proposed by the European Commission

The vote on 12 December is another step towards the implementation of the Horizon Europe programme, due to start in 2021. However, the final budget of the programme will be subject to negotiations between the Commission, Council and Parliament. The final amount for Horizon Europe will also be subject to the negotiations over the long-term budget for the EU as a whole, the Multiannual Financial Framework,

which is not expected to be finalised until around October 2019.

Other amendments were put forward in relation to Horizon Europe, including widening the criteria for winning grants under the research programme. Whilst wording put forward from the Commission stipulated that “scientific excellence” would be the defining criteria, MEPs amended the legislation to dedicate more money for “spreading excellence and widening”.

Additionally, an amendment which would have guaranteed that UK scientists would still be able to participate in EU-funded research was rejected. As it stands, neither the Commission text nor the one adopted by the European Parliament refers to the UK or Brexit.

13 December: EMA-PCWP-HCPWP organise virtual meeting with all EMA eligible organisations



On 13 December, the European Medicines Agency (EMA) Working Parties with Patients’ and Consumers’ Organisations (PCWP) and Healthcare Professionals’ Organisations (HCPWP) held a virtual meeting with all EMA eligible organisations. 41 attendees joined the meeting.

An update on the EMA relocation was provided to meeting delegates. In addition, outcomes on the Heads of Medicines Agencies (HMA)/EMA workshop on availability of authorized medicines held on 8-9 November in London were presented. A draft of the key principles for implementing electronic product information (ePI) within European Union (EU) was also reported. HMA and the European Commission organised a workshop on 28 November 2018 in London to agree with various stakeholders on common EU key principles to pave the way for implementing ePI in the EU.

Other topics discussed during the virtual meeting included the ‘Regulatory Science to 2025’ strategy, a strategic plan for advancing regulatory science over the next five to ten years, covering both human and veterinary medicines and an update on the EMA patient registries initiative. Cindy Birck represented Alzheimer Europe, a full member of the PCWP, at the meeting.



MEMBERS’ NEWS

22 November: Alzheimer’s Society (UK) celebrates Dementia Friendly Awards in England, Wales and Northern Ireland



The Alzheimer’s Society’s Dementia Friendly Awards took place in England and Wales on 22 November and on 19 November

for Northern Ireland. The awards celebrated and promoted the outstanding achievements of those uniting to making a real difference to people living with dementia in their communities.

Around 155 guests attended the England and Wales ceremony, including finalists, judges, special guests and sponsors. The awards were hosted by Ambassador Angela Rippon. Presenters included broadcasters and there was also a special guest speech from the Minister for Care, Caroline Dinanage MP. The Northern Ireland awards were hosted by television presenter, Sarah Travers, who welcomed around 130 guests to the awards ceremony.

Amongst the inspirational winners in England and Wales was Outstanding Contribution award winner, 11-year-old Charlie Phillips, who raises awareness of dementia at school, raises money for Alzheimer's Society in his community and helps to care for his grandmother who has Alzheimer's disease. You can watch Charlie's amazing story here: <https://bit.ly/2Ck4ETO> In Northern Ireland the Outstanding Contribution 2018 went to Alderman Gerardine Mulvenna for all her amazing work making Larne Dementia Friendly.

Jeremy Hughes, Chief Executive Officer, said:

"Five years ago when we started the Dementia Friendly Awards we looked for entrants. This year the 300 nominations and the calibre of the finalists and award winners shows that 'dementia friendliness' has come of age."

All our winners can be seen here on Alzheimer's Society's website here: <http://www.alzheimers.org.uk/Dementiafriendlyawards>

28 November: The Alzheimer Society of Ireland reports on its Emergency Dementia Summit



The Alzheimer Society of Ireland (ASI) held an Emergency Dementia Summit (EDS) in Dublin on Wednesday, November 28th to call on the Minister for Health Simon Harris and

Minister for Older People Jim Daly to make good on their public statements that 'dementia is a key priority' by directing urgently needed funds to dementia specific services in the health service national plan for 2019.

In Budget 2019, the Irish Government yet again ignored the shameful fact that people living with dementia are being deprived of a basic minimum standard of care, as evidenced by the recent mapping of dementia services undertaken by The ASI in conjunction with the Health Service Executive (HSE).

People living with dementia and family carers, including members of the Irish Dementia Working Group (IDWG) and Dementia Carers Campaign Network (DCCN), travelled from all over Ireland to the Summit in central Dublin to have their stories heard and to demand that the Government makes

good on their promises to allocate specific funds to the provision of dementia care services.

The Summit included focus groups with current carers and people with dementia, including the Summit Chair of the European Working Group of People with Dementia Helen Rochford Brennan who said: "Nobody is listening, we are at breaking point". The focus groups were followed by presentations by participants to politicians in the House of the Irish Parliament in Leinster House, Dublin.

"We are fed up listening to our Ministers saying that dementia is a key priority for them, but watch them continue to ignore our calls for ring-fenced dementia-specific funding," said The Alzheimer Society of Ireland CEO and Alzheimer Europe board member Pat McLoughlin.

"There are thousands of families up and down the country who have been struggling to access basic minimum level of supports and services for loved ones with dementia, and as a society we are failing to provide these people with the supports they need." The ASI will not stop advocating on behalf of all the people and families facing a dementia diagnosis.

Pictured: ASI staff, advocates & supporters outside Leinster House in Dublin.

28 November: The German Alzheimer's Association launches call for proposals for research on early Alzheimer's disease



On 28 November, the German Alzheimer's Association (Deutsche Alzheimer Gesellschaft – DalzG)

announced that the organisation is providing EUR 560,000 in research funds for 2019. The amount originates from an earmarked inheritance and will be distributed to one or more projects, which will focus on Alzheimer's disease (AD) in its initial stages. The subsidy amount will only be distributed to people or organisations that are active in Germany. Patient-oriented or healthcare-focussed research proposals will be prioritised. The official launch for proposal outlines starts in December 2018 and closes on 8 February 2019.

<https://www.deutsche-alzheimer.de/die-krankheit/forschung/forschungsfoerderung-der-dalzg.html>

6 December: Alzheimer Sverige welcomes news of Queen Silvia of Sweden becoming an ADI Ambassador



Her Majesty Queen Silvia of Sweden has become an Honorary Ambassador of Alzheimer's Disease International (ADI), in recognition of her personal commitment to work surrounding dementia, as well as elderly and end-of-life care.

Queen Silvia has a long-standing association with the dementia field, having initiated a dementia care training programme for hospital personnel in Sweden by the foundation Stiftelsen Silviahemmet, in 1996.

Queen Silvia said: "I am honoured to act as an Ambassador for Alzheimer's Disease International, an organisation which addresses many issues which are important to me. Dementia will continue to affect populations globally, especially rapidly ageing populations such as Sweden. In the continued absence of a disease-modifying treatment, more research must be pioneered into risk reduction and care improvements, including world leading risk-reduction research."

Krister Westerlund, Chairman of Alzheimer Sverige, said: "Alzheimer Sverige, proud members of ADI since 1986, are [today] happy to acknowledge that HRH Queen Silvia is committing her full attention to help persons with Alzheimer's disease and other dementias. As Chairman of Alzheimer Sverige, I have had the opportunity to involve Queen Silvia in our World Alzheimer's Month activities. Her work, as well as that of the Swedish Court, has been greatly appreciated by our members, and I am therefore extremely happy to see that Queen Silvia's efforts will receive global recognition."

<https://bit.ly/2L0LXaJ>

11 December: Stefanija L. Zlobec awarded Order of Merit by Slovenian President



On 11 December 2018, the President of Slovenia, Borut Pahor decorated Štefanija L. Zlobec, President of Spominčica (Alzheimer Slovenia), with the Order of Merit, in recognition

of her "honourable and precious work in the field of dementia".

Štefanija L. Zlobec said:

"This award is more important to persons with dementia and their carers than for myself. With this gesture from the President of Republic of Slovenia, dementia has made one step further and has gained more visibility and recognition, which is what I endeavoured from the very beginning, when I joined Spominčica.

"This gesture is important also to help raise public awareness and reduce stigma. It means we will have more support to implement all the goals of the National Strategy."

16 December: Croatian EdukAI conference to become international event



EdukAI 2018, Alzheimer Croatia's 4th Educational Conference on Alzheimer's disease was a huge success. It was

the biggest (300 participants) and best evaluated, until now. The most valued topics were those on the practice of caring for people with dementia and - less well-known in Croatia - non-pharmacological therapies.

For the first time, EdukAI attracted colleagues from Slovenia, Bosnia and Herzegovina, and Montenegro. Therefore, next year's EdukAI will be one with international participation, giving the opportunity to professional caregivers from neighbouring countries to present their activities and to exchange experiences. If Alzheimer Croatia's proposals to develop new EU Interreg projects with neighbouring countries is accepted, they are sure they will have a wealth of new conference topics.

Concluding the conference, participants emphasised the need for multidisciplinary teams to develop operational plans and networking to improve the lives of people with dementia, whether in their own homes or in care homes. They also stressed the need to adopt the standard for education of professional caregivers.

The conference supported the plans of the first two Croatian cities, the City of Zagreb and the City of Umag, to become dementia-friendly communities, to begin with the first actions of early detection of dementia in Croatia and education of their first responders, public transport and city offices.

16 December: Survey results show dementia is misunderstood and stigmatised in Croatia



Alzheimer Croatia has completed the first ever nation-wide survey in Croatia, on dementia awareness. Results are based on a statistically representative sample.

Survey results show that:

- 36% of Croatians think dementia is a form of mental illness
- 20% do not have any knowledge about what causes dementia
- Only 44% percent know dementia is not a disease itself
- 45% think that dementia is part of the normal ageing process
- 23% believe dementia is inherited
- And finally, interestingly, 6.4% of respondents said dementia is the result of stress.

Some of the survey results have given Alzheimer Croatia cause for concern and have confirmed its suspicions that one of the basic reasons for the country's low diagnosis rate is the prejudice and stigma surrounding it. The survey shows that dementia is both misunderstood and highly stigmatized in Croatia. Alzheimer Croatia says the results show people in their country are ashamed of dementia, and there is no easy "cure" for this widespread opinion.

The most positive results of the survey were achieved in the northern Adriatic region, where Alzheimer Croatia has recently completed extensive activities to improve public

understanding and change opinions, through educating citizens and carers, in the context of a cross-border European project.

This survey was executed free of charge by Promocija Plus, one of the leading Croatian research agencies, for the benefit of the 90,000 persons with dementia and their family carers in Croatia.

16 December: EMDA publishes complete guide for people with dementia and their families

For the past fifteen years, EMDA has published “the complete guide for people with dementia and their families” once a year. This year, EMDA published the latest edition of this guide for 2018-2019.



The complete guide includes much-needed information in order to cope with dementia. The guide includes extensive information on what dementia is, available clinics and medications, patient care and coping with behavioural problems, information about the rights of people with dementia and services that may be helpful, information on the activities of EMDA and information about the activities of other organisations and bodies that may be helpful.

The guide is easy to read, and the information is accessible. A great deal of emphasis was placed on easy orientation between subjects. EMDA hopes that the guide will contribute to enriching the knowledge about dementia and coping methods, in order to improve the lives of people with dementia and caregivers.

17 December: Alzheimer Austria reports on its recent activities and looks ahead to 2019



Aside from its active involvement in the recent annual dementia strategy platform meeting and lobbying around the rights of people with dementia to have more involvement in decision-making processes about matters affecting them (see report in our “Policy watch” news section), Alzheimer Austria has been busy with a number of other activities supporting people with dementia and their carers:

Transport

A guideline for public transport officials has been published, outlining recommendations for handling challenging situations for people with dementia, such as using ticket machines, or forgetting to purchase a ticket.

Alzheimer Austria contributed to a university research project on mobility and dementia, launched in 2016, which was concluded this autumn. The association was also involved in the publication of a brochure, “Well on track with dementia”: www.unterwegs-mit-demenz.at

Hospitals

Alzheimer Austria has conducted two projects in the field of dementia-sensitive acute hospital care:

- A survey to prepare for an impending hospital stay, to help make the person with dementia feel less vulnerable and more welcome and in control.
- A guideline to provide dementia education and training for every level of staff in acute hospital care settings.

Plans for 2019

Alzheimer Austria is planning to set up a national dementia working group with the help of Angela Pototschnigg. Ms Pototschnigg is a member of the European Working Group of People with Dementia (EWGPWD) and actively advocates for the rights of people with dementia.

Recent Austrian media reports on dementia have clearly demonstrated that journalists need some guidance on dementia-sensitive language. A guide is to be developed next year with the involvement of Alzheimer Austria’s “self-help group”.

18 December: EMDA looks back at 30 years of activities



EMDA – The Alzheimer’s Association of Israel – was founded in January 1988 by a group of families of people with dementia. The association, which is 30 this year, lists some of the key moments from its 30 years:

In 1989, Chairperson Dr Shmuel Moran met the CEO of Joint-Eshel (an organisation with which EMDA continues to cooperate today) resulting in a grant enabling it to employ a coordinator. By July 1989 EMDA had 4 branches.

In 1991, Shosh Efrat was nominated as Secretary General of the association, a post she held until 1999. She enabled the association to grow further and in 1993, the Medical Council of the association was founded, headed by Prof. Amos Korczyn. Members of this council are senior Israeli professionals in the field of dementia. Also in 1993, Yehudit Segal was chosen to head the association. By now, the association was already running twenty support groups throughout the country. EMDA was becoming known and respected among state institutions and was accepted as a member of Alzheimer’s Disease International (ADI).

In 1995, Ruth Goldberg became Chairperson of the association and in November 1996, ADI held its annual conference in Jerusalem.

In 1999, Yael Goshen was nominated as CEO - a post she held until 2005 - and the following year, after years of hard work and campaigning by EMDA, the Health Ministry finally made Alzheimer’s medications reimbursable.

In 2002, the first consensus conference was held in cooperation with the Health Ministry and the Israeli Medical Histadrut, under the banner “Treating Alzheimer’s and related dementias.”

Two years later, in 2004, the association began its "Activity for Health" project, which continues today. Volunteers receive instruction from Daphna Golan-Shemesh and Debbie Lahav, before visiting people with dementia in their homes, to get them more active and encourage them to use their skills.

Current CEO Gery Rot and current Chairperson Yona Eliad took up their posts in 2006. Also that year, the association officially became known as EMDA – The Israeli Association for dementia, Alzheimer's and related dementias.

Work with the Knesset (Israeli Parliament) has been fruitful over the years. In 2007, EMDA management and representatives of families met members of the Knesset, including the Minister of Health and in June 2009, "Alzheimer's Day" was held in the Knesset and the Bill for Alzheimer's patients was signed.

In 2010, the association launched the project "In the armchair with Picasso." The premise is that a person with dementia can "visit" a museum from the comfort of their own home, with the aid of pictures of famous artists.

In October 2011, a consensus conference took place at Bar-Ilan University, to determine guidelines for prevention, diagnosis and care of dementia. A follow-up conference dealt with aspects of non-pharmacological therapies.

In the summer of 2013, the office of the association moved to its present location in the nursing complex of the seniors' village "Neve Af'el" of the "Mish'an" network. Later that year the "National program for the treatment of Alzheimer's disease and other dementias" was launched. EMDA is one of the initiators and is active in its application.

In April 2014, another consensus conference took place, dealing with non-pharmacological therapies, with the aim of developing a series of recommendations, instructions and agreed tools for use as a basis for diagnosis, evaluation and therapy for people with dementia and their families.

In addition to local conferences and professional workshops, the EMDA organises a national conference, for professionals and family caregivers. Each year the conference has a different theme: Creativity and therapy tools - 2013; The question of foreign aides - 2014; Young patients - 2015; Care of the caregivers - 2016, to name but a few.

Aside from its Annual Conferences, EMDA's activities include support, instruction and information. It also runs a Hotline (in 7 languages) and publishes a quarterly journal in Hebrew and English, a monthly digital information page, and has a website providing information and guidance: <https://emda.org.il>

Some of its current projects are:

- "Activity for Health" developed 2 activity kits. "Activity for Health" for people with dementia who are still able to communicate, and "Through the senses" for people in the advanced stages of dementia.
- "Lituf", providing individual support for families affected by dementia, based on the model of Prof. Mary

Mittelman. 30 local authorities as well as the Israeli Health Service, have joined the project.

- Music brings you to life, inspired by "Music and memory" in the US.
- Dementia Friends: hour-long information sessions are given by "dementia ambassadors", volunteers who devote themselves to this aim.

EMDA functions with the help of volunteers all over the country. Its financial sources are membership fees and grants from funds and authorities. The association is run by a Management Committee nominated by members at the General Meeting. It follows NGO law.

Israel has a population of 8.5 million people, around 150,000 of whom are living with dementia.

18 December: United against dementia - Alzheimer's Society joins with global organisations to support new leaders in dementia research and care



Dementia is a global problem and only global collaboration can defeat it. Alzheimer's Society is proud to join with the Global Brain Health Institute (GBHI), US-based Alzheimer's Association and the latest European Joint

Programme – Neurodegenerative Disease (JPND) funding awards to tackle this issue together.

The GBHI pilot award for Global Brain Health Leaders funds research projects to discover prevention strategies and improve care and support for people around the world living with dementia. Twenty-one projects have been awarded, spanning 10 countries across Europe, the Americas and the Middle East, to outstanding researchers and professionals whose activities are set to have real world impact. The UK based awards will focus on the pressing issue of improving end of life care of people living with dementia.

The JPND programme is a collaborative effort of 15 countries across Europe, Australia and Canada to invest EUR 17.5 million over the next three years in dementia research, to drive progress towards new treatments and a revolution of health and social care. These researchers have provided an ambitious, collaborative, multi-disciplinary approach to address important issues, from system and services to the individual patients, their carers and families.

Dr James Pickett, Head of Research at Alzheimer's Society said: "Our funding supports research in the UK, but we know the reach of our work is far wider. Sharing findings internationally and setting up collaborations around the world makes research funding go further, and allows researchers to be a part of cutting-edge dementia research.

"As the only UK charity funding research into dementia care, cure and prevention, we are delighted to include the GBHI pilot award for Global Brain Health Leaders and the Joint Programme – Neurodegenerative Disease as part of our research portfolio."

19 December: SDWG values opportunity to ask Scottish Government questions that really matter to people with dementia



Members of the Scottish Dementia Working Group (SDWG) meet with the Minister for Mental Health, Claire Haughey MSP twice a year. SDWG members regard these

meetings as an invaluable opportunity to ask the Scottish Government questions that really matter to people with a diagnosis of dementia in Scotland. In order to represent the collective voice of lived experience, questions are developed following feedback from people with dementia within each local area in Scotland as well as contributions from SDWG members actively involved in the national priorities thought SDWG.

In November three clear themes were identified: timely access to post diagnostic support; the assessment process when applying for social security benefits and access to technology to live safely, securely and confidently as full citizens in society. The Minister recognised that there are areas of good practice across Scotland and that each Integrated Joint Board is at a different stage in implementing the commitments outlined in Scotland's Third National Dementia Strategy. Claire Haughey (MSP) added that there is still progress to be made to ensure services and support are available to people with dementia when they need it most.

The topics discussed echo SDWG's current priorities and our members will continue to campaign to ensure that everyone with a diagnosis of dementia is able to live well. As a member led group, SDWG look forward to reviewing our priorities in early 2019. The landscape of dementia services and support has changed dramatically since SDWG was established and it is essential that we continue to recognise both the progress made as well as the ongoing challenges. SDWG strive to represent as many people with dementia as possible and look for new and innovative ways for individuals to engage on a local and national level.

20 December: Federazione Alzheimer Italia reports on successful collaboration with European division of QBE Foundation



QBE Insurance Group is a group specialised in business insurances since 1886 in 37 countries. The QBE Foundation, active since 2011, deals with social responsibility programmes.

The commitment of the group's employees is at the base of the Foundation's activity (over EUR 2 million of funds collected internally).

For 2018-2019, the European division of QBE Foundation has chosen partners in eleven countries, including Italy (as well as Belgium, Ireland, Denmark, United Arab Emirates, France, Germany, Spain, Sweden, Canada and The United Kingdom) with national associations involved in Alzheimer's research and care and assistance for people with dementia, in order to implement fund-raising initiatives that the Foundation will integrate through various tools.

Federazione Alzheimer Italia welcomed this collaboration, initially providing a training course for the employees of QBE Italy. During World Alzheimer's Month (September) the Foundation organised two volunteer days in which the company employees helped Federazione Alzheimer Italia in its activities. On the occasion of its Christmas festivities, the fundraising organised by the employees continued: They set up a DIY market and a bake sale. At the end of the year, the employees of QBE Foundation really gave their best to support the Federazione Alzheimer Italia.

Thanks to these initiatives and to the hours put in by volunteers, Federazione Alzheimer Italia can continue working on two projects:

- The first is the dental care service in Milan that offers home visits with dentists specialised in treating people with dementia, where the person is unable to leave their home or for outpatient visits, conservative care, extractions, realisations/repairs of mobile prostheses.
- The second project is the helpline, Pronto Alzheimer, which offers support, advice and guidance to people with dementia and their families, throughout the country.

Grant Clement, president of QBE Foundation, said:

"QBE Foundation focuses on collaborating with charities that QBE employees already support in the community. We aim to support projects that make a long-term difference in people's lives and give them the chance to realize their ambitions".

Federazione Alzheimer Italia President Gabriella Salvini Porro said:

"Reducing stigma and increasing awareness about life next to a person with dementia is the first step necessary to share the commitment to realize a concrete project. And our commitment has always been, day by day, to improve the quality of life of people with dementia and their families".

When associations and the third sector meet, the results are amazing!



POLICY WATCH

27 November: Global Brain Health Institute and The Irish Longitudinal Study on Ageing (TILDA) host shared discussion on inclusivity in dementia



Following the World Health Organisation's (WHO) recent public consultation in developing a 'dementia-friendly initiatives (DFI)' toolkit, the Global Brain Health Institute (GBHI)

and The Irish Longitudinal Study on Ageing (TILDA) at Trinity College Dublin (Ireland) hosted a shared discussion (Chaired by Prof. Dominic Trépel, TCD) between Dr Helen Rochford-Brennan (Chairperson of the European Working Group of People with Dementia) and Dr Maggie Haertsch (Consultant, World Health Organisation) on 27 November 2018.

In this lively discussion, the panel explored issues of inclusivity and the exciting potential for well-designed initiatives that can change societies where people with dementia have a full life with meaning and purpose. The audience raised discussion with the panel on many issues such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the implications of different terms such as 'dementia-friendly' versus 'dementia-inclusive' societies, and the need for more people with dementia to be involved in the implementation (and evaluation) of such initiatives.

The key actions emanating from these discussions were to ensure the voice of the person with dementia is actively included within this fast evolving research and policy agenda.

More about the GBHI: <https://www.gbhi.org/>

5 December: World Dementia Council meets in London



World Dementia Council
Leading the Global Action
Against Dementia

The World Dementia council has met in London, calling for world leaders to "keep up pressure" in the fight against dementia. Key world leaders including former UK Prime Minister David Cameron and UK Secretary of State for Health and Social Care Matt Hancock MP are today meeting at the World Dementia Council summit in London to find solutions to end the dementia crisis.

The World Dementia Council are also launching a report challenging the international community to accelerate progress toward the 2025 goals, outlining key areas which leaders need to now tackle to improve the lives of people affected by dementia. The WDC have also announced a review into worldwide dementia friendly initiatives, to ensure they are meaningful and have real impact on people with dementia.

The report into progress against the review of the 2025 goals can be found here:

<https://worlddementiacouncil.org/sites/default/files/2018-12/Defeating%20Dementia%20Report.pdf>

16 December: Israeli Long-Term Care Benefit law now part of National Insurance Institute of Israel



המוסד לביטוח לאומי

The application of the Long-Term Care Benefit law in Israel that, up until now, was part of the welfare services will now be a part of National Insurance Institute of Israel. This information is pertinent to people living with dementia in Israel as many of them access services provided by the Long-Term Care Benefit law.

17 December: Austrian strategy platform meeting agrees people with dementia to be more involved in decisions affecting them



Gut leben mit
DEMENTZ

Eine Strategie im Auftrag des Bundesministeriums
für Arbeit, Soziales, Gesundheit und Konsumentenschutz

This year, Austria's annual dementia strategy platform meeting was held in Graz. At the meeting, Angela Pototschnigg - an ambassador for inclusion and the rights of people with dementia and a member of the European Working Group of People with Dementia (EWGPWD) – was invited to share insights into her needs and wishes with the 130 delegates. Delegates then discussed progress made on the implementation of the national strategy, "Living well with dementia", and shared examples of good practices.

Thanks to ongoing lobbying by Alzheimer Austria, one of the outcomes of this meeting was that people with dementia are to be included in decision-making processes affecting them more often.

The 2019 dementia strategy platform meeting will be held in Vienna under the banner "Inclusion and awareness".

<https://www.demenzstrategie.at/>

SCIENCE WATCH

15 November: Researchers explore link between lung disease and dementia



On 15 November, US researchers from the University of Minnesota's School of Public Health in Minneapolis published an article suggesting that lung disease may increase the risk of developing dementia or mild cognitive impairment (MCI) in the American Journal of

Respiratory and Critical Care Medicine.

Researchers analysed data from 14,184 participants, with an average age of 54, from the Atherosclerosis Risk in Communities (ARIC) study. These participants were followed for over 23 years. 1,407 cases of dementia were identified during that time period. Participants who had restrictive or obstructive lung disease in midlife had respectively a 58% and

33% higher risk for dementia or MCI compared to those without lung disease.

Researchers suggested that there is maybe a link between the two conditions and reported that people living with lung disease in midlife may have a greater risk of developing dementia later in life. Additional analyses showed similar results in both smokers and non-smokers.

<https://www.atsjournals.org/doi/abs/10.1164/rccm.201807-1220OC>

19 November: Denali Therapeutics announces Phase I data of DNL747



On 19 November, Denali Therapeutics, which is a biopharmaceutical company developing a broad portfolio of therapeutic candidates for neurodegenerative diseases, announced results from its Phase I study of DNL747, a brain-penetrant small molecule inhibitor of RIPK1.

The Phase I trial was a randomised, double blind and placebo-controlled study investigating the safety, pharmacokinetic and pharmacodynamics of DNL747 in 56 healthy participants. The experimental drug was generally well tolerated with no serious adverse events. The study met all these endpoints including CSF exposure levels, RIPK1 inhibition and pathway engagement at doses that were safe and well tolerate.

Denali Therapeutics plans to initiate Phase Ib clinical studies evaluating DNL747 in people with Alzheimer’s disease, amyotrophic lateral sclerosis and multiple sclerosis in collaboration with Sanofi.

<https://denalitherapeutics.com/investors/press-release/denali-therapeutics-announces-positive-clinical-results-with-its-lead-riple-1-inhibitor-molecule-and-intention-to-initiate-patient-studies-in-multiple-indications-in-collaboration-with-sanofi>

25 November: Actinogen Medical completes recruitment of participants for its Phase II clinical trial of Xanamem for AD



On 25 November, the Australian biotechnology company Actinogen Medical focused on innovative treatments for Alzheimer’s disease and the cognitive decline associated with neurodegenerative diseases, announced that it has recruited its final participant into Phase II XanADu clinical trial. The study is investigating Xanamem, which is a drug candidate designed to block the excess production of cortisol in the brain.

The Phase II trial is a 12-week, double-blind, randomised, placebo-controlled study investigating the safety, tolerability and efficacy of Xanamem in people with mild dementia due to Alzheimer’s disease (AD). XanADu started recruitment in 2017 and has enrolled 186 participants. Results are expected in Q2 2019.

<https://www.businesswire.com/news/home/20181125005155/en>

26 November: Research group publishes systematic analysis for the global, regional and national burden of dementia

THE LANCET *Neurology* On 26 November, researchers published a detailed analysis of the global prevalence, mortality and overall burden of dementia in the journal *The Lancet Neurology*.

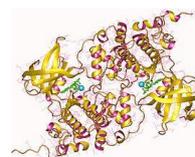
The Global Burden of Diseases, Injuries, and Risk Factors (GBD) study is unprecedented in its scope and constitutes an update of a previous review that covered the years from 1980 to 2015. The new study reports on GBD methods and incorporates information on dementia from vital registration systems, published research, health-service encounters on deaths, excess mortality, prevalence as well as incidence throughout 195 countries and territories from 1990 to 2016.

The research stresses that there has not only been an increase of the number of people who lived with dementia from 1990 to 2016, by 117% (20.2 to 43.8 million), but also that these resulted in overall 28.2 million disability-adjusted life-years (DALYs). Furthermore, the authors concluded that strikingly 6.4 million of these DALYs (a combination of years of life lost and years lived with disability) could be judged to have a causal link to modifiable GBD risk factors such as the Body Mass Index, smoking and consumption of too much sugar-sweetened beverages as well as high fasting plasma glucose.

The paper, including detailed information on the findings but also limitations, is available as open access publication here:

[https://doi.org/10.1016/S1474-4422\(18\)30403-4](https://doi.org/10.1016/S1474-4422(18)30403-4)

3 December: Researchers identify specific genes mutations that could be linked to dementia



On 3 December, US researchers from University of California, Los Angeles, published findings from a study investigating the gene networks mediating neurodegenerative dementia in the journal *Nature Medicine*.

In the published study, scientists studied three different strains of mouse models of frontotemporal dementia, a type of early-onset dementia. By analysing the interactions between genes, they reported that the three mouse models shared the key features of the disease including decreased survival and body weight and overproduction of the tau protein in the brain at different points of time. They identified two groups of genes involved in mutations that result in the overproduction of the tau protein in the brain and leading then to neuronal cell death.

<https://www.nature.com/articles/s41591-018-0223-3>

6 December: The Actifcare study group publishes article on profiles of caregivers as predictors of service use

Actifcare On 6 December, researchers from the international Actifcare study group published an article on the usefulness of caregiver profiles in predicting future service use for relatives with dementia in the journal *Aging & Mental Health*.

The team started with 451 couples of people with dementia and their informal caregivers. Participants of the study came from eight European countries and were only included when they did not use personal care yet, but were expected to do so within a year. Of the 451 couples, 442 participated in a follow up after six months and 339 came for the final data collection, one year after the start of the study. During these visits, the participants filled out a variety of questionnaires, providing their demographics information and details on service use.

In order to shed light on the question whether or not the caregiver profiles would predict the use of dementia care services and first of all to understand the circumstances that have an influence on the use of formal care, the researchers based their analyses on five previously developed profiles (as reported in Janssen et al., 2017), trying to include as many characteristics as possible.

The authors conclude that after doing the statistical analyses, the previously developed profiles proved to have a predictive value. Furthermore, the team reasoned that knowledge on the different profiles and their impact on the use of informal care could be useful to health care professionals so that they can ensure optimal access to services, which in turn would help people to be able to stay independently at home for longer.

A detailed overview of the service use distribution across caregiver profiles as well as interpretations can be found in the publication:

<https://www.tandfonline.com/doi/abs/10.1080/13607863.2018.1544215?journalCode=camh20>

10 December: Axsome Therapeutics announces outcomes of interim analysis of its AD agitation drug



On 10 December, the clinical-stage biopharmaceutical Axsome Therapeutics, which develops novel therapies for the management of central nervous system disorders including Alzheimer’s disease (AD), announced positive results from an interim analysis from its ADVANCE-1 trial of AXS-05. The investigational product AXS-05 is an oral AD agitation drug combining dextromethorphan and bupropion.

The Phase II/III study is a multicentre, randomised, double-blind and controlled trial to evaluate the efficacy and safety of AXS-05 in people with agitation associated with AD. Approximately 435 US participants were to be randomly assigned to receive AXS-05, placebo or bupropion for five

weeks. Based on the first results of the analysis (approximately 30% of the target number of participants), an independent data monitoring committee conducted an interim analysis for futility. The committee recommended the continuation of the trial and no further enrolment of participants to the treatment arm of the study. Axsome Therapeutics will follow these recommendations.

<https://bit.ly/2VuCvkl>

10 December: Axovant Sciences announces results of its Phase II study in people with LBD experiencing rapid eye movement sleep behaviour disorder



On 10 December, Axovant Sciences, a US-based biopharmaceutical company developing innovative therapies for neurological disorders, announced results of its Phase II clinical trial of nelotanserin in people with Lewy Body Dementia (LBD) who experience rapid eye movement sleep behaviour disorder (RBD).

The Phase II study is a multicentre, randomised, double-blind and placebo-controlled clinical trial evaluating the efficacy of nelotanserin in 34 participants with LBD who were experiencing RBD. Although the experimental drug was generally well-tolerated, it failed to meet its primary endpoint of reducing the frequency of sleep disorder events compared to placebo as measured by sleep laboratory video assessment. The company announced that it will discontinue the clinical development of nelotanserin.

<http://investors.axovant.com/news-releases/news-release-details/axovant-reports-results-exploratory-phase-2-clinical-study>

12 December: Eli Lilly and AC Immune sign a collaboration agreement to develop new treatments for AD



On 12 December, the clinical-stage biopharmaceutical company AC Immune and the global pharmaceutical company Eli Lilly announced that they have signed a license and collaboration agreement to

develop tau aggregation inhibitor small molecules for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD). They will focus on AC Immune’s ACI-3024, also called Morphomer Tau.

AC Immune will conduct the initial Phase I development of ACI-3024 and Eli Lilly will fund and conduct further clinical development. Financial terms of the agreement include an upfront payment to AC Immune from Eli Lilly of about \$80 million and \$50 million in exchange for a note, convertible to equity at a premium.

<https://www.businesswire.com/news/home/20181212005145/en>

13 December: The ISTAART society publishes white paper to advance research on dementia across ethno racial populations

On 13 December, The Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART) published a white paper in the Journal of Alzheimer's disease and Dementia.

The publication aims to provide a synthesized overview of the current knowledge regarding different ethno racial factors within the field of Alzheimer's disease and related dementias (ARD) research.

The different fields have been selected and reflected as and by groups with professional interest areas including biomarkers, interventions and symptoms among others.

Apart from the overview of current knowledge, the publication also offers identified gaps and addresses recommendations to address these, stressing the need to leverage on the expertise of professional interest areas, in order to design and implement research programs.

[https://www.alzheimersanddementia.com/article/S1552-5260\(18\)33556-8/fulltext](https://www.alzheimersanddementia.com/article/S1552-5260(18)33556-8/fulltext)

13 December: Scientists teamed up to publish major multicentre study on subjective cognitive decline and rates of incident AD and dementia

On 13 December, an international team of researchers published an article on subjective cognitive decline (SCD) in community-based and memory clinic settings including an assessment of the occurrence of Alzheimer's disease (AD) dementia and non-AD dementia cases in the journal Alzheimer's and Dementia. Furthermore, they also reported determinants of progression to dementia.

People with SCD do not have measurable cognitive impairments, but have the impression that memory or other thinking abilities are not properly working or getting worse.

This large multicentre study involved 11 cohorts, bringing together data on 5.521 participants of which 2.978 had SCD and 1.391 participants who contributed to the analysis as controls without SCD. The analysis was especially important since SCD can be a predecessor of dementia (both AD and non-AD dementia) but the number of people with SCD that will



eventually develop AD dementia and other forms of dementia has not been estimated before.

Statistical analyses showed that within a year almost 18 out of 1000 people with SCD would develop a form of dementia (11.5 AD related, 6.1 non-AD related), in comparison to a little over 14 in those without SCD (10.1 AD related, 4.1 non-AD related). The team further reported that the rate of people that would develop dementia was higher for those who were assessed in a memory clinic in comparison to those who came from a community-based setting, although the participants from the memory clinics were younger. In addition to that, analyses showed that higher age, a low score in a neuropsychological pen and paper test as well as a genetic factor (apolipoprotein E ε4) came along with a higher risk of dementia.

<https://doi.org/10.1016/j.jalz.2018.10.003>

27 December: Study supports genetic diversity in AD mouse models introducing a new population for preclinical research



On 27 December, researchers from the United States published an article on a study introducing a new Alzheimer's disease (AD) mouse model in the journal Prion.

Current clinical research on AD relies on traditional AD mouse models that usually have only one respectively a few genetic backgrounds. This composes a challenge for the interpretation of results, since investigations in this field have shown that the genetic background has a strong effect on the levels of the protein Amyloid-β associated with neurodegeneration.

Since there is a lack of research on the effect of the genetic background on cognitive performance, the scientists hypothesized that the genetic background also plays a role in modifying cognitive decline in these animal models.

For that purpose, the team combined an already established mouse model of AD with a genetically diverse reference panel to generate mice which were comparable in high-risk human mutations but whose other genomes were different.

After showing that the variation of the other genes modified the impact of human AD mutations, the team validated the model, demonstrating its overlap with human AD and introducing the model as a new resource for AD research.

<https://doi.org/10.1016/j.neuron.2018.11.040>

LIVING WITH DEMENTIA

29 November: Idalina Aguiar tells us about her former EWGPWD colleague Nina Baláčková's visit to Madeira Island



I recently had the privilege of a visit from my (former) European Working Group of People with Dementia (EWGPWD) colleague, Nina Baláčková of the Czech Republic, to our wonderful island, Madeira. After a few tours around the island, we visited the Madeira branch of Alzheimer Portugal and the day centre "Garouta do calhau" (place of memories), for people with dementia like me.

I was delighted to show Nina the activities I carry out on my island, about living with dementia and to show the work we do for a better, more inclusive society for people with dementia and their carers.

We also went to the Madeira FNAC shopping centre, to be part of an information-sharing activity. There, in front of a varied audience, we had a conversation on the theme "Life with dementia". Together with our caregivers/supporters, Nina and I aimed to demystify dementia for members of the public present. We talked about how it is possible to cope with dementia, despite the limitations it imposes on us. Nina and I had the opportunity to share our first-hand experience of living with dementia. We talk about what we do, the way we approach things and especially the experience we have had since joining the EWGPWD.

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



JOB OPPORTUNITIES

11 December: Cardiff University School of Psychology seeks Research Associate



Cardiff University School of Psychology is looking for an early-career scientist for a Research Associate position. This post is funded by a grant from the European Research Council at the Cardiff University Brain Research Imaging Centre (CUBRIC).

The successful candidate will work with Dr Jiaxiang Zhang and other collaborators on the neural mechanisms of human decision-making, integrating multimodal brain imaging and computational modelling.

Cardiff University Brain Research Imaging Centre (CUBRIC) houses a unique combination of state-of-the-art facilities and world-leading expertise, with 4 human MRI systems (2 x Siemens Prisma, 1 x Siemens Connectom, 1 x Siemens 7T), MEG, EEG, TMS, TDCS, clinical research units and testing labs. Further details of CUBRIC can be found on <http://sites.cardiff.ac.uk/cubric>.

This is a full-time, fixed-term position for 3 years. The proposed start date is 1 March 2019 (negotiable).

Job Reference: 8077BR

For informal enquiries about the project, please contact Dr Jiaxiang Zhang zhangj73@cardiff.ac.uk.

Apply here: <https://bit.ly/2EvsZZq>

Closing date: 11 January 2019.

Please be aware that Cardiff University reserves the right to close this vacancy early should sufficient applications be received.

17 December: Age Scotland seeks a Dementia Team Manager and Dementia Policy Officer



Age Scotland has been awarded an investment from the Life Changes Trust, allowing it to deliver a National Forum

for Dementia Policy and Practice. In the context of this new venture, the charity is looking to recruit a Dementia Team Manager to lead on the delivery of the National Dementia

Forum, and a Dementia Policy Officer to provide the Forum and its sub-groups with technical support and expertise in dementia and related issues.

The Forum will bring together people with experience and expertise in dementia, locally and nationally, with the aim of evidencing what will create better lives for people with dementia and unpaid carers. It will allow for constructive scrutiny of policy and practice in many areas, including housing and dementia, sport and dementia, the arts and dementia, and human rights and dementia.

You can find further information about these two posts and how to apply by clicking the links below. Both calls for applications will close on 11 January 2019.

Dementia Team Manager: <https://bit.ly/2Gmo1jm>

Dementia Policy Officer: <https://bit.ly/2Lq5em8>

NEW PUBLICATIONS AND RESOURCES

30 November: New app aims to create positive shared experiences for people with dementia and their support networks



Dementia Australia has created a new app to help people connect and communicate better with a family member or friend living with dementia. "A Better Visit" aims to provide enjoyable shared experiences

for people living with dementia and those in their support network, via a collection of small games designed to be played together. The games emphasise content creation and positive feedback through familiar activities, sounds and visuals to stimulate memories and spark social interaction. The app can be downloaded for free, here:

<https://itunes.apple.com/au/app/a-better-visit/id1433291135>

30 November: NICE publishes guidelines on discussing and planning support after a dementia diagnosis



In November 2018, the National Institute for Health and Care Excellence (NICE) in the UK published guidelines to help people with dementia and their family and carers get the right support for them, following diagnosis.

A diagnosis of dementia can be very difficult for

the person and their family and planning for the future may not seem like an immediate priority. However, timely planning, based on information that should be available at the time of diagnosis, can make a real difference to the person's quality-of-life.

This quick guide explains the information and support that people can expect from social care and health services (in the UK) to enable them to plan for their life after a dementia diagnosis. It covers:

- What information to expect
- Planning for now
- Planning for your future
- Support for carers.

<https://bit.ly/2QHAK44>



Contact Alzheimer Europe:

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

Alzheimer Europe Board:

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

Alzheimer Europe Staff:

Executive Director: Jean Georges; **Communications Officer:** Kate Boor Ellis; **Conference and Event Coordinator:** Gwladys Guillory; **Director for Projects:** Dianne Gove; **Project Officers:** Christophe Bintener, Cindy Birck, Ana Diaz; **Policy Officer:** Owen Miller; **Finance Officer:** Stefanie Peulen; **Administrative Assistant:** Grazia Tomasini.

AE CALENDAR

Date	Meeting	AE representative
25 January	Launch meeting of VirtualBrainCloud project (Berlin, Germany)	Jean
30-31 January	Launch meeting of RadarAD project (London, UK)	Ana, Dianne and Jean

CONFERENCES 2019

Date	Meeting	Place
16-18 January	13 th Human Amyloid Imaging, http://www.worldeventsforum.com/hai/	Miami, Florida
6-7 February	3 rd HBP Student Conference on Interdisciplinary Brain Research, https://education.humanbrainproject.eu	Ghent, Belgium
14-17 February	11 th Panhellenic Conference on Alzheimer's Disease and Related Disorders, http://www.alzheimer-conference.gr	Thessaloniki, Greece
19-20 March	2019 Alzheimer's Research UK, https://www.alzheimersresearchuk.org	Harrogate, UK
20-23 March	13 th Göttingen Meeting of the German Neuroscience Society, https://www.nwg-goettingen.de/	Göttingen, Germany
26-31 March	The 14 th international conference on Alzheimer's & Parkinson's diseases, https://bit.ly/2Jyvw3t	Lisbon, Portugal
4-7 April	13 th World Congress on Controversies in Neurology, http://www.comtecmed.com	Madrid, Spain
14-17 April	BNA2019 - Festival of Neuroscience, http://meetings.bna.org.uk/bna2019/	Dublin Ireland
5-8 May	Understanding and Targeting Alzheimer's disease, https://www.fens.org/Meetings/The-Brain-Conferences/Understanding-and-targeting-Alzheimer-disease/	Copenhagen, Denmark
15-18 May	World Psychiatric Association and Psychiatric Association of Macedonia Thematic Congress, wpadementia2019.com	Ohrid, Former Yugoslav Republic of Macedonia
20-21 May	8 th European Conference on Clinical Neuroimaging, https://www.euroccn.com/	Brussels, Belgium
21-22 May	Alzheimer's Society Annual Conference, https://www.alzheimers.org.uk	London, UK
29 June-2 July	5 th Congress of the European Academy of Neurology (EAN), Congress, https://www.eanpages.org/event/5th-ean-congress-in-oslo-norway-norges-varemesse	Oslo, Norway
1-4 July	Royal College of Psychiatrists' International Conference, https://www.rcpsych.ac.uk	London, UK
19-20 September	International MinD Conference 2019, http://designingfordementia.eu	Dresden, Germany
22-25 October	29 th Alzheimer Europe Conference "Making valuable connections"	The Hague, Netherlands
4-7 December	Clinical Trials in Alzheimer's Disease, http://www.ctad-alzheimer.com/ctad-2019	San Diego, USA

29th Alzheimer Europe Conference

Making valuable connections

The Hague, Netherlands

23–25 October 2019

www.alzheimer-europe.org/conferences

 #29AEC

