

# ALZHEIMER EUROPE NEWSLETTER

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## WELCOME



Since our last newsletter, there have been a number of changes within Alzheimer Europe. At our AGM in Barcelona, members voted in a new Board for the 2018-2020 term and welcomed two new provisional member organisations, from Macedonia and Estonia. A warm welcome to them and to our three new Board members, Marco Blom, Pat McLoughlin and Karin Westerlund and thank you to outgoing members Marie-Odile Desana, Sabine Henry and Štefanija Lukič Zlobec for their service.

The European Working Group of People with Dementia began a new term at its meeting in Barcelona. The group welcomed four new members and reconfirmed Helen Rochford-Brennan and Chris Roberts as Chair and Vice-Chair. Members also bid a fond farewell to Nina Baláčková, a founding member of the group in October 2012 and Vice-Chair in 2013-2014. I would like to express my heartfelt thanks to Nina for her important contributions these past six years.

You can find more details about all this in the Alzheimer Europe section of this newsletter, which covers the different internal meetings we organised during our successful 28<sup>th</sup> Annual Conference in Barcelona. We are delighted with the feedback received during and since. Many thanks to our 800+ delegates for being so positive and also for being so active on social media - the overall statistics are impressive, with almost 25 million tweet impressions of the #28AEC hashtag! Let me also take this opportunity to congratulate the four winners of the poster awards: Luisa

Bartorelli, Lucas Paletta, Bie Hinnekint and Nélide Aguiar.

Aside from #28AEC, we are delighted to tell you that an article on continence care, co-authored by our Director for Projects Dianne Gove, has been published in open access in the International Urogynecology Journal. Congratulations, Dianne and colleagues!

We continue to develop our Clinical Trials Watch, an online resource providing up-to-date accessible information on clinical trials currently recruiting participants in a least one European country. This month, a new study from Avanir Pharmaceuticals has been added, bringing the total to 11 clinical trials currently reported in the database.

I would also like to share that our article, outlining the key areas of European public policy and public health work currently taking place in relation to dementia, was published in Health Europa Quarterly.

Finally, also on the policy front, we were pleased to learn that the European Parliament and European Council have reached a provisional agreement on the European Accessibility Act. This Act will set out new EU-wide minimum requirements on accessibility on a number of products and services. The agreement will be submitted to the Council's Permanent Representatives Committee for approval, after which the European Parliament will vote in plenary.

Our December newsletter will be published on 7 January 2019. Until then, I wish you all an excellent festive season and a positive end to another eventful year!

**Jean Georges**  
Executive Director

## ALZHEIMER EUROPE

**16 October: Article on continence care, co-authored by Dianne Gove, is published in open access**

**IUJ** On 16 October 2018, an article on “Development of quality outcome indicators to improve the quality of urinary and faecal continence care” was published in open access in the International Urogynecology Journal. It was co-authored by Dr Dianne Gove, Director for Projects, Alzheimer Europe., together with Adrian Wagg, Kai Leichsenring and Joan Ostaszkiwicz.

Despite the range of treatment options available, relatively few people with incontinence find a total cure. Daily management with toileting and containment is hugely important and to the authors’ knowledge, there are no outcome measures to benchmark good care. The aim of this study was to create a set of key performance indicators (KPIs) to measure outcomes for toileting and containment.

The International Urogynecology Journal (IUJ) is the official journal of the International Urogynecological Association (IUGA).

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

**28 October: 2018-2020 European Working Group of People with Dementia confirmed**



The European Working Group of People with Dementia (EWGPWD) began its fourth two-year term of office at a meeting held on 28 October 2018 in Barcelona, prior to the 28<sup>th</sup> Alzheimer Europe Conference (#28AEC). During this meeting, the group welcomed four new members.

The EWGPWD for 2018-2020 is composed of the following 14 members:

**Chairperson:** Helen Rochford-Brennan (Ireland)

**Vice-Chairperson:** Chris Roberts (UK – England, Wales and N. Ireland)

**Members:** Idalina Aguiar, Portugal; Stefan Eriksson, Sweden (new); Tomaž Grižinič, Slovenia; Amela Hajrič, Bosnia & Herzegovina; Carol Hargreaves, (UK - Scotland); Bernd Heise,

Germany (new); Miha Kastelic, Czech Republic (new); Petri Lampinen, Finland; Thomas Maurer, Switzerland; Angela Pototschnigg, Austria (new); Helga Rohra, Romania; Geert Van Laer, Belgium.

EWGPWD members also bid a fond farewell to Nina Baláčková (Czech Republic). Ms Baláčková was a founding member of the EWGPWD, having joined in October 2012. She was also Vice Chairperson in 2013-2014. Alzheimer Europe and the EWGPWD wish to thank her for her important and positive contributions and her friends and family members, who supported her at meetings.

The EWGPWD was launched by Alzheimer Europe and its member associations in early 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently and members electing their own Board. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe with full voting rights.

During the group’s first three terms of office (2012-2014, 2014-2016, 2016-2018), the members of the EWGPWD have actively participated in Alzheimer Europe’s annual conferences, given keynote presentations in the European Parliament, contributed to consultations for European projects in which Alzheimer Europe is involved, as well as to other areas of work for the organisation. Members of the group have also contributed to research conducted by external organisations on topics such as outcome measures that are meaningful to people with dementia and their carers, travel, social health and people with dementia as peer-researchers, and have attended a number of international dementia-related events, representing the group.

The full group, as well as outgoing member Nina Baláčková, participated in the meeting of 28 October in Barcelona, to prepare for their involvement in the #28AEC conference programme, including the Special Symposium “I have dementia and life goes on”, held on 30 October 2018.

Executive Director Jean Georges, Director for Projects Dianne Gove and Project Officer Ana Diaz attended the meeting.

*Pictured: The EWGPWD 2018-2020, together with care partners and supporters.*

**29 October: Alzheimer Europe continues to comply with EMA’s strict eligibility criteria**



On 29 October 2018, the European Medicines Agency (EMA) confirmed that Alzheimer Europe continues to comply with its strict eligibility criteria, as defined by its Management Board, and can continue to be involved in its activities.

The list of all the patients' and consumers' organisations that are involved in EMA activities can be viewed here:

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

**29 October: Alzheimer Europe holds Board meeting in Barcelona**

The members of the Alzheimer Europe Board held a meeting on 29 October 2018 in Barcelona, Spain. They discussed various financial and operational matters, including final preparations for the Annual General Meeting that took place later that day. This was the last meeting of the 2016-2018 Board. The members of the new Alzheimer Europe Board (2018-2020) will hold their first meeting in Brussels on 3 and 4 December 2018.

**29 October: Alzheimer Europe has a new Board and welcomes two new member organisations**



Alzheimer Europe is pleased to present the Office holders and members of its new 2018-2020 Board, following the elections that took place during the Annual General Meeting (AGM) on 29 October 2018 in Barcelona.

Chairperson: Iva Holmerová (Czech Republic)

Vice-Chairperson: Charles Scerri (Malta)

Honorary Secretary: James Pearson (UK - Scotland)

Honorary Treasurer: Maria do Rosário Zincke dos Reis (Portugal)

Members: Stefanie Becker (Switzerland), Marco Blom (Netherlands), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen (Finland), Helen Rochford Brennan, Chairperson of the European Working Group of People with Dementia and ex-officio Board member with full voting rights (Ireland), Jesús Rodrigo (Spain), Karin Westerlund (Sweden).

The Office holders and Members of the Board were elected by representatives from Alzheimer Europe's full member associations that took part in the AGM. The new AE Board will serve a two-year term and will hold its first meeting in December 2018.

Alzheimer Europe wishes to thank outgoing Board members Marie-Odile Desana (France), Sabine Henry (Belgium) and Štefanija Lukič Zlobec (Slovenia) for their service.

Also during the AGM, Alzheimer Europe was pleased to welcome two new provisional member organisations.

Alzheimer's Disease Association Macedonia and NGO Living with Dementia, Estonia were formally voted in, bringing the number of members to 42, hailing from 37 countries.



*Members of NGO Living with Dementia (Estonia) with Alzheimer Europe Executive Director Jean Georges at the conference in Barcelona.*



*Dr Dragan Ilievski, President of the Alzheimer Disease Association of Macedonia, at Spominčica (Alzheimer Slovenia) conference in September 2018, with (left to right) Paola Barbarino (Alzheimer's Disease International), Štefanija Lukič Zlobec (Spominčica) and Iva Holmerová (Alzheimer Europe Chairperson).*

**29-31 October: Alzheimer Europe holds successful 28<sup>th</sup> Annual Conference**

The 28<sup>th</sup> Alzheimer Europe Conference (#28AEC) "Making dementia a European priority" was held in Barcelona on 29-31 October 2018, under the Honorary Patronage of Her Majesty Queen Sofia of Spain. More than 800 participants from 46 countries attended the conference, which boasted 239 speakers and 175 poster presenters, sharing their research, projects and experiences in an atmosphere of collaboration. Iva Holmerová, Chairperson of Alzheimer Europe (AE) opened the conference, thanking HRH Queen Sofia for her Patronage and extending a special welcome to the 35 people with dementia attending the conference, as well as their

supporters. Following Ms Holmerová, Cheles Cantabrana, Chairperson of the Confederación Española de Alzheimer (CEAFA), thanked Alzheimer Europe for helping to put dementia in the spotlight in Spain and emphasised the importance of Spain taking the final step to approve its national dementia strategy, the creation of which has been one of the focal points for her organisation in recent years. Next, Noemí Martínez, Vice-Chairperson of Fundación Alzheimer España (FAE), highlighted some positive changes in recent years, for people with dementia and their carers but stressed that there are still too many differences across Europe with regards the length of time from diagnosis to end-of-life. Improving early diagnosis rates will be one of the focus points for her organisation, going forward.

Gemma Tarafa, Commissioner for Health (Spain) and Santiago Marimón Suñol, a person living with dementia from Spain also welcomed delegates during the opening ceremony.

The keynote lecture was delivered by Dr Jose Luis Molinuevo from BarcelonaBeta Brain Research Center. In his presentation “Will we be able to prevent Alzheimer’s disease?” he gave an overview of the challenges and opportunities regarding the prevention of Alzheimer’s disease (AD). He expressed the rationale behind preventing AD and the reason why prevention may be a key way forward to tackle it. However, he stressed, this is far from easy and there are many challenges along the way.

On 30 October, the first plenary session on “Dementia as a policy priority” was chaired by Jesus Rodrigo (Spain) and opened with the first of four “Meet the researchers of tomorrow” sessions. Anja Leist, Associate Professor at the University of Luxembourg, presented the World Young Leaders in Dementia (WYLD) network, which brings together young professionals in the field of dementia, supporting the work of the World Dementia Council. The second speaker was Carmen Orte, Director General of IMSERSO (Instituto de Mayores y Servicios Sociales), who presented “Dementia as a health and social priority in Spain”. Geoff Huggins, Director of Health and Social Care Integration at the Scottish Government took the

floor next, delivering a presentation on the EU Joint Action (JA) ‘Act on Dementia’, which began in March 2016. Dr Dan Chisholm, Programme Manager for Mental Health at the World Health Organisation (WHO) Regional Office for Europe (Copenhagen, Denmark) spoke next, about prioritising dementia internationally and specifically about the WHO’s Global Action Plan on the public response to dementia 2017-2025. The final speaker in Plenary 1 was Prof. John Gallacher, Project Co-ordinator of the IMI ROADMAP project (Real world Outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data Access Platform), who shared the work done by the project so far.

The second plenary session, which took place on the same day, focused on “Dementia as a human rights priority” and was chaired by Charles Scerri (Malta). The session opened with the second “Meet the researchers of tomorrow” session, delivered by Stina Saunders, a fellow at the IMI EPAD project (European Prevention of Alzheimer’s Dementia) and a doctoral candidate at the University of Edinburgh. Her talk focused on engaging research participants as collaborators working towards a common goal with the study team. Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD), took the floor next, to talk about promoting a human rights-based approach to dementia through the active involvement of people with dementia. Dr Fernando Vicente, advisor to the General Directorate of the Institute of Older People and Social Services (IMSERSO) of the Ministry of Health, Social Services and Equality, was up next. Addressing the room in Spanish (simultaneously translated into English), Dr Vicente spoke about Human Rights in Spanish health and social legislation. Dr Dianne Gove, Director for Projects at Alzheimer Europe was the fourth speaker, giving delegates an overview of AE’s work on dementia and disability. Dr Karen Watchman, Senior Lecturer in the Faculty of Health Sciences and Sport at the University of Stirling, closed the second plenary session with a talk on dementia and intellectual disability.



AE Chairperson Iva Holmerová welcoming delegates to the conference



José Luis Molinuevo delivering the keynote lecture



Entertainment for delegates at the opening reception



Dan Chisholm, WHO Europe, addressing delegates in Plenary 1



Plenary 2 speaker panel



Sébastien Libert presents one of the Meet the researchers of tomorrow sessions



Plenary 4 speaker panel



Some of the 175 posters presented at 28AEC



Alzheimer Nederland inviting delegates to #29AEC next year

The third plenary session “Dementia as a care priority” took place on 31 October. It was chaired by Myrra Vernooij-Dassen (Netherlands) and opened with the third “Meet the researchers of tomorrow” session, with Sébastien Libert, a PhD student based at University College London, and part of the Interdisciplinary Network on Dementia Using Current Technologies (INDUCT). The next speaker was Gail Mountain, Professor of Applied Dementia Research and Director of the Centre for Applied Dementia Research at the University of Bradford. She used her presentation to urge delegates to work together to reconsider the appropriateness of commonly-used outcome measures in dementia practice and research. Marjolein de Vugt, professor of psychosocial innovations in dementia at the Mental Health and Neurosciences research school, Maastricht University then presented the ‘Partner in Balance’ programme, followed by Manuel Martín-Carrasco, Medical Director of the Father Menni Psychiatric Clinic of Pamplona, who spoke to delegates about reducing the use of antipsychotics in residential and nursing homes. The final speaker in Plenary 3 was Martina Roes, Chair of Nursing Science and Health Care Research at the Department for Nursing Science, Faculty for Health, University of Witten/Herdecke. She closed with a presentation on “fostering and sustaining relationships with people with dementia”.

The last plenary session focused on “Dementia as a research priority” and was chaired by José Manuel Ribera Casado (Spain). It began with the fourth and final “Meet the researchers of tomorrow” session, presented by Isadora Lopes Alves, who is currently doing her postdoctoral research for the IMI AMYPAD project (Amyloid Imaging to Prevent Alzheimer’s Disease) at the VUmc, Amsterdam. Next, Maria Isabel Gonzalez Ingelmo, Managing Director of the National Reference Centre for Alzheimer’s and Dementia Care of the

Institute for Older Persons and Social Services (IMSERO), under the auspices of the Spanish Government, informed delegates that her organisation is committed to promoting research into non-pharmacological therapies, through networking and transferring knowledge. Mercè Boada, Founder and medical director of Fundació ACE, used the next presentation to stress the important role EU research collaborations, such as the MOPEAD project, can play in helping to improve the diagnosis of AD. Next up to the podium was Philippe Amouyel, Professor of Epidemiology and Public Health at the University Hospital of Lille, with a presentation on the genetics of AD. The final speaker at Plenary 4 was Professor Clive Ballard, who is part of a growing team of dementia researchers at the University of Exeter Medical School. His presentation looked at pharmacological options for the treatment of behavioural symptoms of dementia and specifically at the recent international Delphi consensus paper. The three-day conference also featured 32 parallel sessions on diverse topics for delegates to choose from. It was formally closed by AE Chairperson Iva Holmerová, who thanked conference co-hosts CEFA and FAE, as well as all speakers and poster presenters. She also said a special thank you to the various sponsors of the conference:

The health programme of the European Union, Roche, Lilly, Biogen, Abbvie, Otsuka, Amgen, the Alzheimer Europe Foundation, Robert Bosch Stiftung, the Lufthansa group, Oneworld and Skyteam.

Ms Holmerová, together with colleagues at Alzheimer Nederland, invited all delegates to mark the dates of the next Alzheimer Europe Conference (#29AEC) in their calendars. “Making valuable connections” will take place in The Hague (Den Haag) from 23 to 25 October 2019.

The 28<sup>th</sup> AE Conference in Barcelona received funding under an operating grant from the European Union's Health Programme (2014-2020).

**30-31 October: Five special symposia held during #28AEC in Barcelona**

On 30 and 31 October 2018, during the 28<sup>th</sup> Alzheimer Europe Conference (#28AEC), five special symposia were held:

**SS1: MOPEAD - Citizen's engagement in early patient engagement for Alzheimer's disease: Call to action**



During this special symposium, the MOPEAD project introduced its plans and methods in learning how to enhance earlier identification of mild AD dementia and prodromal

AD. Project leaders gave a call to action for citizens' engagement and spoke about the manifold learnings the project has already established. MOPEAD aims to ultimately establish an enhanced portal for bringing volunteers into clinical trials, to speed up research and development. As well as exploring ways to engage with potential trial participants, the symposium also looked at barriers, such as the reluctance of General Practitioners (GPs) to take part. Participants were: Adrián Rodrigo Salas (Spain), Octavio Rodríguez Gómez (Spain), Anders Wimo (Sweden), Andreea Ciudin (Spain) and Annette Dumas (Belgium).

**SS2: I have dementia and life goes on**



This special symposium, organised by Alzheimer Europe's European Working Group of People with Dementia (EWGPWD), was chaired by Helen Rochford-Brennan, the group's

Chairperson. The entire group participated and shared a few words about themselves and their lived experience.

Finnish member Petri Lampinen then gave a speech about his experience of receiving a diagnosis of frontotemporal dementia, the impact it had on him and his family and his approach to living life to the fullest. UK member Chris Roberts translated for the audience.

Carers and supporters of the EWGPWD's members joined them on the stage and together they made the statement: "Many voices together make our voice stronger". As every year, the EWGPWD Symposium was incredibly popular and there was lively audience participation, during the closing Q&A session.

**SS3: Dementia in ethnic minority groups**

To close the first full day of the conference, in the evening of 30 October 2018, Alzheimer Europe organised a special

symposium on its current work in the area of dementia care and support among ethnic minorities. In keeping with ongoing efforts to promote the rights and wellbeing of people with dementia, Alzheimer Europe has chosen to work on a project to help develop and improve intercultural care and support for people with dementia and carers from minority ethnic groups in Europe. Members of AE's expert group discussed a broad range of issues related to five key areas: Prevalence, diagnosis, assessment; Interpreter-mediated dementia assessments; Involving local minority ethnic groups; Initiatives organised by Alzheimer associations; and Live-in/migrant carers.

The five speakers, Thomas Rune Nielsen, Charlotta Plejert, Mohammed Akhlak Rauf, Michal Herz and Debi Lahav, presented some of the latest research in these areas



and highlighted key issues needing attention in Europe. The ongoing work, carried out with input from external contributors as well as members of the expert group, will result in the publication of a report and recommendations, as well as a database of existing intercultural practices and initiatives, for policy makers and health and social care service providers across Europe. This work has been made possible through funding from the European Commission and the Robert Bosch Stiftung

**SS4: Biogen - Getting health systems ready for medical innovation: a new era for Alzheimer's**

New innovations are a crucial part of addressing the huge and rising unmet need in managing Alzheimer's disease. This Biogen symposium looked at results from a new RAND study on EU health system preparedness (six countries: France, Germany, Italy, Spain, Sweden and the United Kingdom) and featured presentations on health infrastructure challenges from various perspectives. This panel session was moderated by Jodi Liu, Associate Policy Researcher and co-author of the new RAND report "Assessing the Preparedness of the Health Care System Infrastructure in Six European Countries for an Alzheimer's Treatment".

Presentations were given by: Monika Kripp (Austria), Helga Rohra (Germany), Craig Ritchie (United Kingdom). The session was well attended by a mixture of researchers, healthcare professionals, caregivers, persons with dementia and many more.

**SS5: Roche - The carer's voice in national dementia plans**

In May 2017, in response to what has become a public health priority around the world, the 194 countries, members of the WHO World Health Assembly, adopted unanimously the Global Action Plan on Dementia. All 194 countries committed to adopting national dementia plans by 2025. Approximately 30 countries have adopted a dementia plan and about 30 countries have plans currently in development.

This special symposium, organised by Roche, looked at whether these national plans are considering the perspectives and needs of people that care for people with Alzheimer's disease and dementia – at whether the carer's voice is being heard.

The presenters were Tania Dussey-Cavassini, daughter, carer and Former Vice-Director General of the Swiss Federal Office of Public Health and Chris Lynch, Deputy CEO of Alzheimer Disease International and the session was moderated by Christin Bexelius (Switzerland).

### 15 November: AE adds a new trial to its Clinical Trials Watch



Alzheimer Europe (AE) continues to develop its Clinical Trials Watch (CTW), an online resource providing up-to-date accessible information on clinical trials currently recruiting participants in a least

one European country. The service, launched in September 2016, provides information on phase III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer's disease (AD).

On 15 November, AE added a new clinical trial resulting in 11 clinical trials currently reported in the database. The new study is a Phase III randomised, double-blind and placebo-controlled trial evaluating the safety and efficacy of AVP-786 for the treatment of agitation in people with dementia of the Alzheimer's type. Avanir Pharmaceuticals is running this trial and is recruiting participants in France, Hungary, Italy, Spain and UK.

Further information about the CTW is available on: <http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch>

For more information about the CTW please contact Project Officer Cindy Birck: [cindy.birck@alzheimer-europe.org](mailto:cindy.birck@alzheimer-europe.org)

### 16 November: AE Foundation awards prizes for #28AEC posters



Following Alzheimer Europe's 28<sup>th</sup> Annual Conference (#28AEC), the Alzheimer Europe Foundation has

awarded a prize to the top four poster presentations, as voted by conference participants via poster evaluation forms. The winner for each day of the poster presentations (30 and 31 October) has been awarded EUR 750 and the runner-up for each day was awarded EUR 250.

The two winners and two runners up were:

- 30 October winner: Luisa Bartorelli (Italy), "The new Alzheimer village of the Fondazione Roma: A positive approach for people with dementia".
- 30 October runner-up: Lucas Paletta (Austria), "PLAYTIME: Motivation, emotion and assessment in serious games for dementia intervention".

- 31 October winner: Bie Hinnekint (Belgium), "CasAperta, music and arts café by people with dementia and their carers".
- 31 October runner-up: Nélida Aguiar (Portugal), "Perpetuating memories".

Congratulations to all four!

Some of the winners have made the generous decision to donate their prize money: Lucas Paletta and his colleagues gave their prize money to Sozialverein Deutschlandsberg, an organisation that works with people with dementia living at home, in remote rural areas near Graz, Austria; Nélida Aguiar donated her winnings to garouta do Calhau, a day centre for persons with dementia; and Bie Hinnekint and her colleagues decided use their prize fund to organise further CasAperta music-salon Sunday afternoons.

The Foundation has also awarded a free subscription for the 2019 conference in The Hague to one lucky participant, drawn at random from the submitted poster evaluation forms: Congratulations to Romaine Rizzo (Malta) - we look forward to welcoming you to The Hague for #29AEC!

The Alzheimer Europe Foundation would like to thank all 187 conference delegates who voted and all poster presenters for their excellent contributions at the conference.

### 28 November: Initiatives and materials needed to promote intercultural dementia care and support



In the context of its project on dementia and minority ethnic groups (funded by the European Commission and the Robert Bosch Stiftung), Alzheimer Europe is currently developing a basic

database/online repository of initiatives and materials for people with dementia and carers from minority ethnic groups in Europe. These might, for example, cover awareness raising, promoting timely diagnosis, training of professional carers or the provision of services and support which respect the cultural and linguistic diversity of minority ethnic groups in Europe.

We would like to share information about a wide range of initiatives, however big or small (e.g. dementia cafés for Turkish carers in Germany, information or video clips about dementia in languages spoken by specific minority ethnic groups, cultural awareness training for healthcare professionals etc.). We hope that this will eventually help service providers, policy makers and health and social care professionals to create or improve intercultural dementia care and support across Europe. In addition, some of the materials may be of interest to people with dementia and carers themselves. If you have information about such initiatives and materials (within Europe), please send details to: [dianne.gove@alzheimer-europe.org](mailto:dianne.gove@alzheimer-europe.org)

## Alzheimer Europe networking

On 29 October (Barcelona, Spain) Ana attended the annual INTERDEM meeting.

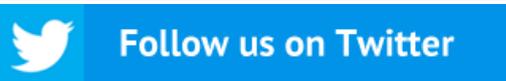
On 29 October (Barcelona, Spain), Owen attended the 6<sup>th</sup> meeting of the Programme Board of the European Act on Dementia programme (2<sup>nd</sup> Joint Action on Dementia).

On 6 November (Amsterdam, Netherlands), Jean met with representatives of the University of Eastern Finland to discuss an EU grant application.

On 21 November, Cindy attended the ADI webinar on research participation “Let’s Talk About Dementia Research: Demystifying Trials, Access and Understanding”.

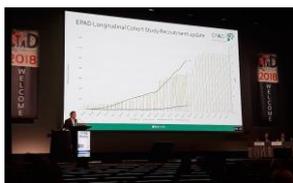
On 26 November (Ramat Gan, Israel), Jean met with representatives of EMDA, the Israeli Alzheimer’s Association and participated in a symposium on the development of national dementia strategies

On 27 November (Ramat Gan, Israel), Jean participated in the 30<sup>th</sup> Anniversary Conference of EMDA, the Israeli Alzheimer’s Association.



### EU PROJECTS

#### 27 October: EPAD releases its first data set v500.0 at CTAD



On 27 October, Professor Craig Ritchie gave a talk at the 11th Clinical Trials on Alzheimer’s Disease (CTAD) conference in Barcelona on behalf of the European Prevention of

Alzheimer’s Dementia (EPAD) consortium. He presented a summary of EPAD’s First Formal Data Lock (EPAD V500.0) and predictors of amyloid status. The huge efforts on behalf of the participants in the EPAD study as well as the hundreds of research staff working on the study have resulted in a milestone where EPAD has entered the important phase of data analysis and the delivery of new knowledge. The EPAD members took the opportunity at the CTAD conference to officially release its first wave of data including the baseline data from its first 500 research participants. Additionally, five EPAD posters were presented during the event.

Further information can be found on the EPAD website [here](#).

#### 29 October: INTERDEM members meet in Barcelona during the AE Conference



The annual INTERDEM meeting was held in Barcelona on 29 October 2018. In the morning, six new INTERDEM members provided a short presentation about their work. This was followed by the business meeting, which was moderated by the Chair of INTERDEM, Myrra Vernooij Dassen. In this session, the membership rules and the budget rules for INTERDEM involvement in projects were explained to members. There was also some discussions about the need for a new Manifesto to update the recommendations which were included in the article published in 2011. Updates on the

INTERDEM Academy and website were also provided. The morning ended with a very dynamic session, moderated by Martin Orrell, and with several laptop presentations. In the afternoon, Bob Woods chaired a session on the topic of “New insights in dementia research: Staff training” with presentations by Claire Surr on the provision of dementia education and training to health and social care staff, Margareta Halek on the implementation of case conferences in Germany and Yun-Hee Jeon about training of interventionists in a large-scale pragmatic trial in Australia. During the last part of the meeting, there was an opportunity for members to share ideas for new research proposals and discuss opportunities to collaborate in future calls. Ana attended the meeting on behalf of AE.

#### 30-31 October: The ROADMAP project journey featured at #28AEC

On 30 and 31 October, ROADMAP’s journey during the initial Phase 1 of the project was featured at Alzheimer Europe’s 28<sup>th</sup> Conference “Making dementia a European priority” in Barcelona, Spain. This included a plenary talk by Project Coordinator, John Gallacher, as well as four parallel sessions including participants from numerous Consortium partners, representatives from the European Working Group of People with Dementia, as well as members from ROADMAP’s Expert Advisory Group.



Prof. John Gallacher, Project Coordinator of the IMI ROADMAP project (Real world Outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data Access Platform), closed the engaging first plenary session. He shared the work done by the project so far: The ROADMAP project has demonstrated the ability of academic, industry, patients and regulatory partners to work together on a highly complex, widely distributed, and tightly time-constrained project; established a broad-based and evidence based consensus on the priority outcomes for dementia treatment pathways; developed a comprehensive database of available European

real world data; demonstrated that the current evidence base is inadequate for disease progression modelling and detailed health economic evaluation; and has made a strong case for the collection of new data that is intentionally designed to enable early detection and disease progression modelling.

The first session looked at relevant outcomes from the perspective of different stakeholders as Alzheimer’s disease (AD) and dementia progress. It also looked at how these indications were collected using a variety of methods such as literature reviews, Public Patient Involvement, pan-European surveys as well as stakeholder interviews.

ROADMAP mapped the critical ethical, legal and social issues that arise from creating a real-world evidence platform that re-uses existing health data pooled from different sources, but it also addressed ethical concerns and topics that arose during the course of the project itself. These have yielded interesting outputs and the second session was convened by the Ethical, Legal and Social Implications (ELSI) team who will provided insights on the ethical challenges in AD research and practice when using real-world data.

Another focal point involved the third session with perspectives on real-world data in AD from regulatory and Health Technology Assessment bodies, including the prospective future data collection and further research in this area. These perspectives have been collected via ROADMAPs Expert Advisory Group, which has sought to find the weak spots as well as opportunities for the future in ROADMAPs plans.

Visualising the available AD-related data in different types of European data sources and identifying gaps has proven to be a powerful tool for the design, planning and validation of the models and strategies used to guide future recommendations to enhance AD research. Therefore, the fourth session was dedicated to focus on the presentation of steps taken during the development of ROADMAPs 3D data and outcome assessment, the “Data Cube”.

More information on the presentations including the timetable, overview of speakers and titles of presentations as well as the abstracts can be found [here](#). The video of the plenary talk and parallel sessions will shortly be available [here](#).

**31 October: MOPEAD project reports on progress in recruitment of people for AD research at AEs Conference**



On 30 October, the MOPEAD (Models Of Patient Engagement for Alzheimer’s Disease) held a Special Symposium at Alzheimer Europe’s 28<sup>th</sup> conference, in Barcelona. Over 75 conference delegates came to hear about the IMI-funded project strategies, developed to identify people with mild cognitive impairment (MCI) and prodromal Alzheimer’s disease (AD).

Mercè Boada (Project Coordinator), presented MOPEAD’s rationale due to the need to change the time of diagnosis in the disease continuum. Alzheimer’s disease (AD) is still diagnosed late, when symptoms become hard to manage. By evaluating four different patient engagement strategies (Citizen Science, Open House, Primary and Tertiary Care settings) in five European countries (Germany, Slovenia, Spain, Sweden and the Netherlands), the project aims to help understand the obstacles to timely diagnosis, overcome barriers to access symptomatic treatment and services as well as to motivate citizens’ participation in research and clinical trials.

The project is a two-stage process: a pre-screening is organised for the general population followed by a full evaluation in case a participant meets the diagnostic criteria. Progress in pre-screening is in its mid-stage phase and already reveals challenges and opportunities.

Octavio Rodríguez Gómez showed that there are important differences in the recruitment efficiency across the strategies and countries. The project operates in a modular way: the implementation of the patient engagement strategies did not start or finish at the same time. This is attributed to long Ethics Review Board review in some countries and difficulties in reaching the required number of participants.

Although the Citizen Science strategy (on-line cognitive test and marketing campaign) started late in the project course, Adrián Rodrigo Salas presented promising results: already 15,000 people visited the platform, over 600 citizens have completed the test and more than 120 were referred to a memory clinic for further evaluation. Slovenia is the first country that already reached the required number of participants for pre-screening.

The Open House recruitment (in a Memory Clinic) is completed in three countries (Slovenia, Spain and Sweden).

Recruitment in Primary Care and Tertiary Care settings (involving diabetologists) is running relatively slow. Current results show that it is more difficult to engage primary care practitioners (PCPs). This is particularly the case in the Netherlands. Besides a possible negative PCP attitude towards early diagnosis of AD and limited time, the reasons are unclear. This is why a survey will be conducted among PCPs in Europe to identify the reasons for this low engagement. Equally, patient engagement in the PCP setting also revealed that the general population seems to be reluctant to undergo a diagnostic evaluation, even when the pre-screening shows possible cognitive impairments. A potential reason may be that the people were not aware of memory problems prior to the pre-screening, and fear to receive a diagnosis of AD when no effective treatment is available.

Despite Type 2 diabetes (T2D) patients having an almost two-fold higher risk of developing dementia than people without diabetes, the Tertiary Care engagement strategy shows disappointing results. Besides Spain who has reached the required number of pre- screened participants, the other

countries are lagging behind. Andreea Cuidin presented some of the challenges linked to this low engagement: the lack of engagement of the medical staff and patients who do not wish to proceed to neuropsychological evaluations, due to the presence of comorbidities. She identified some solutions that could help redress the situation: better motivate the medical staff, better explain to the patients the importance of an early detection of cognitive impairment in order to better adapt their treatment.

The two salient pre-screening findings show that the Citizen Science and Open House strategies, where individuals voluntarily engage in the pre-screening, lead to a higher rate of individuals willing to participate in a comprehensive evaluation. In the PCP and Tertiary Care settings, where PCPs and diabetologists identify individuals with possible MCI or prodromal AD, often did not want to have a full examination in a memory clinic and dropped-out of the project.

The Symposium ended with a Call to Action: it is paramount to engage citizens, healthcare professionals and patients' organisations to raise awareness about the value of early diagnosis of AD.

The video recording will shortly be available [here](#).

### **31 October: MOPEAD project launches German version of its online cognitive screening platform**



On 31 October, the Models of Patient Engagement for Alzheimer's Disease (MOPEAD) project fulfilled the launch of its fourth model to help identify cases of Alzheimer's disease in its fifth participating country, Germany.

It constitutes of a website offering an online cognitive screening test for people between the ages of 65 – 85, helping participants find out if they could have cognitive problems. Those, whose tests indicate a possible impairment, will be advised to visit a MOPEAD memory clinic in order to get a full evaluation.

The website is also promoted in Spain, Sweden, Slovenia as well as the Netherlands. It was designed to reach a large number of citizens through online campaigns adapted to each of the countries.

You can find the German version of the website [here](#).

### **2 November: The EPAD project publishes two new articles**

In October 2018, two articles about the EPAD project were published.



On 29 October, the journal *Dementia* published an article entitled "Research participants as collaborators: Background, experience and policies from the PREVENT Dementia and EPAD programmes". The article led by Sarah Gregory from the University of Edinburgh (UK) described how the PREVENT Dementia panel forms the basis for

participant involvement within EPAD project and highlighted the role of patients and the public as collaborators in dementia research.

On 30 October, the *Journal of Alzheimer's Research & Therapy* published online an article entitled "Secondary prevention of Alzheimer's dementia: neuroimaging contributions". The article discussed the use of neuroimaging markers in subject selection for inclusion or stratification in secondary prevention trials, their potential to serve as outcome markers in trials, and for monitoring trial safety. The article formulated practical considerations, neuroimaging recommendations for the EPAD Longitudinal Cohort Study. The article also mentioned the EPAD sister project Amyloid imaging to prevent Alzheimer's disease (AMYPAD) as a large subgroup of the EPAD participants will also undergo amyloid PET, financed through AMYPAD.

### **21 November: INDUCT congratulates Professor Van den Block for PhD Supervision Award**



Last September, INDUCT supervisor Prof. Dr. Lieve Van den Block received the very first Excellent

PhD Supervision Award of the Vrije Universiteit Brussel (VUB) in Belgium. Prof. Van den Block supervises INDUCT ESRs 11 and 12 in their research projects on complex health technologies in dementia, in particular on advance care planning and palliative care interventions.

The award was initiated to promote styles of good supervision and support towards doctoral candidates. VUB PhD candidates were called upon to nominate their supervisor for this prestigious prize by writing a 500-1000 word essay. The jury said to have been moved by the nomination essays and were very happy to award Prof. Van den Block with this prize.

Some elements from the nomination essays:

"In my opinion, Prof. Van den Block deserves praise for the way in which she stimulates collegiality."

"Lieve sets the bar high and expects the same from her students. Yet there is still room to make mistakes and to learn from them; Lieve hands out compliments, not only when things are going well, but also when she notices that you are putting in hard work and giving it your best shot."

"With a critical gaze, Prof. Lieve Van den Block follows my work progress; her perfectionism brings out the best in me."

All INDUCT members would like to congratulate Prof. Van den Block with this outstanding achievement!

### **23 November: 3<sup>rd</sup> MinD project symposium held in Spain, design evaluation preparations made**



In November, colleagues of the MinD team met in The Netherlands and in Valladolid, Spain to continue preparing for the evaluation of the Good Life Kit prototypes. The Good Life Kit aims to

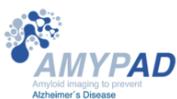
support people with Dementia in approaching everyday life positively and confidently. Colleagues from INTRAS worked in the Netherlands, hosted by Zorggroep Sint Marten and supported by University of Twente, on the Spanish translations and other detail for the evaluation at INTRAS in March 2019. They also met with the design students from University of Twente who are producing the Good Life Kit prototypes, which are being produced in four languages (Dutch, English, German, Spanish).

In the second half of November, colleagues from Nottinghamshire Healthcare NHS Foundation Trust, Alexianer St Hedwig Hospital and Architectural company Duit met at INTRAS to continue work on the evaluation preparations, on publications. Most importantly, INTRAS hosted the third MinD symposium on 20 November in Valladolid, Spain, which brought together related projects and presented a first glimpse of the prototypes to the public.

The Symposium ran from 10:00h to 14:00h at Universidad Europea Miguel de Cervantes (UEMC) in Valladolid. The first part was dedicated to the “Be Mindful” project, in which INTRAS also is a partner, about mindfulness techniques applied in a training program for social services and health professionals and subsequent therapeutic interactions with mental health patients.

The second part was dedicated to the MinD project with a project overview presented by Professor Kristina Niedderer from Manchester Metropolitan University, a summary of the Spanish data collection by Dr Michele Zanasi from Alexianer St Hedwig Hospital, Berlin, insights into practices of design, co-design and co-production by Alessia Macchi, Julie Gosling and Binta Jammeh. Rosa Almeida and Raquel Losada made the introductions and chaired the discussion.

**26 November: AMYPAD PNHS enrolls its first research participant in Amsterdam**



On 26 November, the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project released its seventh external newsletter and reported a major milestone

that was achieved for the Prognostic and Natural History Study (PNHS). After the great news of ethical and regulatory approval of this study, the team at VUmc has recruited the first PNHS participant on the 1 October in Amsterdam!

It was a day to celebrate, marking the beginning of a large European study to understand the value of quantitative amyloid PET imaging for modelling and assessing Alzheimer’s Disease (AD) dementia risk in individuals without dementia. The study set-up is in strong collaboration with EPAD, as most participants will be recruited from EPAD’s longitudinal cohort study (LCS), and data will be shared between the sister projects to reach their common objectives.

Since the first recruitment, the VUmc team has contacted other 21 participants, of which 14 have already agreed to participate. Most potential participants are very enthusiastic about the project and the prospect of supporting research into AD prevention, and the team is confident recruitment will keep a good pace throughout the study.

In addition, other two sites are undergoing ethical reviews, namely the teams in Barcelonaβeta and the University of Edinburgh – the AMYPAD team hopes to hear good news from them soon. In the meantime, teams in Toulouse, Geneva and Cologne are getting ready to submit the study to their local committees and the expectation is that the main participating sites will all be actively recruiting by the end of the first quarter in 2019. It is a really exciting time for AMYPAD and for the PNHS in specific. This ambitious Europe-wide project will recruit up to 2000 participants and follow half of them longitudinally within the next 3 years.



**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:

- AMYPAD – grant agreement 115952
- EPAD – grant agreement 115736
- MOPEAD - grant agreement 115985
- 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 Spyrali (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).

## EU DEVELOPMENTS

### 6 November: Alzheimer Europe published in Health Europa Quarterly



Alzheimer Europe has had an article published in Health Europa Quarterly, outlining the key areas of European public policy and public health work currently taking place in relation to dementia.

Written by Executive Director, Jean Georges, and Policy Officer, Owen Miller, the article sets out a number of areas of ongoing work, including:

- The World Health Organisation's Global Action Plan on dementia.
- Research projects underway as part of the Horizon 2020 research programme.
- The second European Joint Action on Dementia.

The article also outlines a number of areas of Alzheimer Europe's work, including:

- Our publications and research, including the Carers Suvery and Yearbook.
- The Clinical Trials Watch project.
- Our work to establish a dementia expert group to replace the group disbanded by the European Commission.

You can read the article here:

<https://www.healtheuropa.eu/dementia-in-europe/88813/>

### 6 November: European public health steering group holds first formal meeting



The European Commission's Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases has held its first formal meeting since being formalised in July 2018. The group replaces the previous Expert Groups on dementia, cancer etc. which the European Commission disbanded early in 2018.

Member State representatives, several Commission services and the European Investment Bank discussed policies and initiatives in the area of public health, including future cooperation with the Expert Group on Health Information in relation to providing relevant health data and intelligence to support decision-making of the Steering Group. The Steering Group also decided that mental health would be the priority area for best practices and screening of implementable research results in 2019.

The Steering Group was provided with an overview on the future planning for investing in health and people at the European level with an objective to seek synergies between different funding programmes. DG EMPL and DG Connect provided input on the relevant funding programmes, with the EIB providing an overview on health investments.

The next meeting of the Steering Group is scheduled for February 2019 and will be a joint meeting with the Research Programme Committee.

### 8 November: European Union reaches provisional agreement over Accessibility Act



A provisional agreement on the European Accessibility Act has been reached by the European Parliament and European Council. The European Accessibility Act will set out new EU-wide minimum requirements on accessibility on a number of products and services, including computers, smartphones, TVs, ATMs, payment terminals, e-books, e-readers, websites and mobile applications of private companies and ticket machines. Also included are emergency services number and telephony services.

However, a number of areas are not included within the agreement, including transport, microenterprise services provide services, household appliances and does not include any provisions in relation to accessible buildings or infrastructure. The agreement will be submitted to the Council's Permanent Representatives Committee for approval. Once approved there, the European Parliament will vote in the plenary session. More information can be found here:

<https://bit.ly/2f1qSyT>

### 13 November: Patient organisations issue joint statement on HTA involvement



Alzheimer Europe has signed a joint statement issued by a consortia of 14 patient organisations on the involvement of patients in the European Cooperation on Health Technology Assessments (HTA). In light of the ongoing development of

European Commission proposals for a unified approach to HTAs in the EU, the statement focuses on four areas:

- Quality of HTA through patient involvement.
- What is meant by adequate patient involvement.
- Legitimacy of patient involvement.
- The concept of 'nothing about us, without us'.

The statement looks at a number of areas of existing practice in patient involvement, including reference to existing regulations on patient involvement in relation to pharmaceutical research, as well as drawing on best practice from national HTA bodies.

The signatories of the statement call on European Institutions to incorporate measures to guarantee the meaningful involvement of patients in the European Cooperation on HTA. The statement additionally calls for the European Cooperation to enact its own rules on how to work with different parties, adopt necessary policies to regulate potential conflicts of interests (financial, intellectual, and participatory).

More information on the Health Technologies Assessment: <https://bit.ly/2DL7o1b>

The full statement and list of signatories can be found at: <https://bit.ly/2RjXPa9>

### 14 November: European Commission and United Kingdom reach tentative withdrawal agreement



The European Commission and the United Kingdom Government have reached a tentative agreement over the UK's withdrawal from the European Union. The document confirms that the UK will leave the EU on 29 March 2019 and will enter a transition period ending on 31 December 2020.

During this transition, the agreement would have little impact on change in terms of the country's scientific relationship with the EU, with the UK government having committed to underwrite Horizon 2020 funding for all existing and future successful UK bids (those submitted from now until the end of 2020), even if an agreement between the UK and the EU is not reached. The guarantee would cover the lifetime of researchers' projects, even if they last beyond 2020.

However, the UK's ability to participate in the Horizon Europe programme, beginning in 2021, is not covered within the agreement and will be addressed as part of a later trade agreement. This will be determined only after March 2019.

An accompanying document sets out a framework on which the future UK-EU relationship will be built and includes "science and innovation" part of the future "basis for cooperation" on which the future agreement would be built. However, a final version of this framework must be agreed on before the withdrawal text is signed.

The deal is now subject to approval by the UK Parliament (expected to be voted on in December 2018), with the European Parliament and Council also both being required to provide their support for the agreement.

The full withdrawal agreement is available at:

<https://bit.ly/2B7aho2>

### 18 November: Eurocarers publishes informal carers strategy document



Eurocarers, the European association working with and for carers, has launched a proposal for an EU Strategy to support and empower informal carers across Europe. The strategy, entitled 'Enabling carers to care', defines the 10-Steps identified by the Eurocarers network which are required to implement a carer-friendly policy environment seeking which recognises, supports and empowers informal carers across Europe.

It is designed to help policy makers (as well as stakeholders who can improve the lives of carers and who can influence the support provided to carers) acting at EU, national and regional level to consolidate and build on existing approaches, as well as yielding new evidence-informed initiatives in favour of carers' rights.

The full report can be accessed at: <https://bit.ly/2BE8p6n>

**18 November: European Disability Forum launches voting rights petition**



The European Disability Forum (EDF) has launched a “European elections for all” petition, calling on the leaders of Europe, including national governments and electoral commissions to ensure that people with disabilities have the ability and right to vote.

The EDF notes that there are around 80 million people with disabilities living in Europe and highlights that many experience barriers to voting including stairs in polling stations, complicated voting instructions, difficult to read voting ballots and deprivation of the legal right to vote for people who are deemed to lack capacity (including persons with intellectual disabilities).

The European Union Agency on Fundamental Rights has published information on the voting rights of people living within each of the 28 member states. This information can be found at: <https://bit.ly/2KGO1pD>

You can sign the petition here: <https://bit.ly/2AuC5B8>



**MEMBERS' NEWS**

**18 October: Alzheimer Larissa Greece organises “Tiritomba” museum visit**



On 18 October, Alzheimer Larissa Greece, in collaboration with the Municipal Larissa Elderly Care Nursing Home, arranged an interactive tour of the “Tiritomba” museum for people with cognitive or intellectual disabilities. The visit was open to individuals living in the community as well as to those living in care homes.

The museum curator gave a brief introduction about the founders of the troupe and their passion for puppet play, which led to the creation of more than 300 dolls. She presented the major play characters, including animals, humans, and fictional fairies and sprites, and demonstrated how the players used the puppets.

Cognitive impairment may create and re-inforce fear of unknown or forgotten situations. The aim of the visit was to enhance social interaction as much as possible and to facilitate verbal and non-verbal communication. The visit was successful in introducing knowledge and persons into the visitors’ life, allowing inquisitive behaviour and experimentation.

Society volunteers enabled visitors to interact with the dolls, as this was a first-time behind-the-scenes challenge. Most of the visitors were reserved about approaching and touching the exhibits. Given some time, they were successful in noticing characteristics and expressions, guessing the role of each

puppet in the play. They were able to recognise some of their favourite childhood characters and even identify with some of the figurines, because of their common features or clothes. They all responded to the call of the curator to sing the Italian folk song Tiritomba, the theme of which was adopted by the troupe in 1984. Visitors also had the chance to see where and how puppets are made. Some of them were brave enough to “wear” them.

**24 October: Alzheimer Bulgaria delighted to announce the launch of its Dementia Friends programme**



The global movement "Dementia Friends" was launched in Bulgaria, through the work of Alzheimer Bulgaria and with financial aid from a grant provided by TELUS International Bulgaria.

The programme envisages a more tolerant and participatory future for people with dementia in Bulgaria, via the introduction of a novel model for one-to-one interaction with people with dementia.

Students from Sofia and Pleven, will undergo a one-day training, during which they will be introduced to communication techniques. They will also be trained on how to interact with people with dementia more effectively and successfully, by displaying patience and empathy.

Following this one-day training workshop, the students will start visiting people in two care homes in Sofia and Pleven (as a standard, one visit per week of one hour will be planned, for each volunteer). During the visits the students from professions such as psychology, nursing and social work, will play cognitive/memory games with the residents. They will solve puzzles, talk about past events and feelings, look at photos, read newspapers or go for short walks within nursing home premises.

The idea is to pilot the model for quality care, as a novel approach that has not been implemented in Bulgaria before, as well as providing the students with practical experience with patients in their field.

The first information session with students took place on 24 October at Sofia University, when the programme was presented to thirty 2<sup>nd</sup> year Psychology students.

**25 October: The Alzheimer Society of Ireland hosts annual AlzTalks event**



The Alzheimer Society of Ireland (ASI) hosted its annual celebratory AlzTalks event at the Hawkswell Theatre in Co. Sligo, Ireland in October. AlzTalks looks to shatter the stigma and

misconceptions that often surround dementia, with a mix of personal testimonies, music and performance.

The event featured speakers Jacinta Dixon (Dublin) and Kevin Quaid (Limerick) from the Irish Dementia Working Group (IDWG) and members of the Dementia Carers Campaign Network (DCCN) Rachel McMahon (Limerick) and Helena Quaid (Cork), sharing their touching real life stories of their journey with dementia. The Chair of the European Working Group of People with Dementia (EWGPWD) Helen Rochford-Brennan was the Ambassador for the night.

All of the presentations from the event will be made available on the ASI dedicated AlzTalks YouTube channel, which was created to bring dementia out of the shadows and enable the many different voices of dementia to be heard all over the world. You can watch the videos here: <https://bit.ly/2eXqq2H>

This provides a platform to allow awareness-building and perception-changing of dementia, given that a lack of understanding and stigma is still rife. Having people speak about their own lives and experiences creates a better understanding of the unique experiences of people living with dementia.

*Pictured: Speakers from L-R - Helena, Kevin, Helen, Jacinta & Rachel.*

### 13-14 November: Finnish Memory Conference brings together professionals in Helsinki



Finland's annual Memory Conference took place in Helsinki on 13 and 14 November. The event gathered together researchers, professionals

working in local associations of the Alzheimer Society of Finland, and experts by experience. The theme of the conference was "Memory-friendly Acts".

The situation of the upcoming Self-Determination Act raised a lot of discussion in the conference. The law is not going to proceed to the Finnish Parliament during this parliamentary term.

The sessions of the conference dealt, among others, with the fundamentals of good care for persons with memory-related diseases (dementia). The themes of the lectures varied from the power of compassion, to creativity as a tool of good care. One session was dedicated to brain health: how music, dance and arts can support and improve brain health.

Functional workshops were introduced for the first time in the conference. Participants had the opportunity to try out how, for example, dance and drawing can be utilised as a tool of understanding and therapy.

### 21 November: ADI holds webinar on "Demystifying dementia research"



On 21 November, Alzheimer's Disease International (ADI) held the first in their 'Let's Talk About Dementia Research' series, titled "Demystifying Trials, Access and Understanding". The panel included representatives from the pharmaceutical industry, researchers and clinicians conducting research and clinical trials, care specialists, people living with dementia and their care partners, and staff and volunteers working for Alzheimer's and dementia associations.

This first instalment of the series received great engagement, with over 200 participants from 50 countries from a mix of professional and personal backgrounds. Various barriers to participation in dementia research were identified. Notably, lack of knowledge and access were recurring themes in this discussion. A poll at the end of the webinar revealed that 80% of participants said they would volunteer for dementia research. This finding echoes the recent Generations survey of 10,000 adults across 10 countries which revealed that 79% of people surveyed said they would be willing to participate in research, but lacked information on how to get involved.

Eileen Taylor, who joined the webinar as a panellist from Brisbane, Australia, presenting her own experience with dementia trials, said: "Listening to this has kind of given me hope that things might change."

Craig Ritchie, Chair of Psychiatry of Ageing at the University of Edinburgh and Director of the Centre for Dementia Prevention said: "I wake up every morning and do research because I hope things will get better, but I'm actually in a privileged position as an academic researcher, because I want to turn hope into expectation."

Paola Barbarino, ADI's Chief Executive said: "This is a global first as far as I know. These webinars will give everyone complete freedom to discuss their innermost thoughts, hopes and concerns in a totally open environment with people who have first-hand experience of clinical trials. I have been through this harrowing process personally and think it is really important that we bring more candid and understandable information to the public if we are to recruit to trials in the future."

The second in the series of webinars is scheduled for February 2019, with the panel currently being finalised. ADI will take a deeper look at barriers and enablers, access to trials in lower and middle income countries and also starting to consider pre-symptomatic and younger volunteers.

A recording and transcription of the first webinar will be available at: [www.alz.co.uk](http://www.alz.co.uk)

For information about the Generations survey, see: <https://www.alz.co.uk/news/largest-alzheimer-survey>

Alzheimer Europe Project Officer Cindy Birck attended this webinar.

**22-23 November: Alzheimer Portugal reports on its 30<sup>th</sup> anniversary celebratory conference “Dementia – An Holistic Perspective”**



The conference took place on 22-23 November at the Gulbenkian Foundation, Lisbon.

With 461 participants it was a great opportunity to discuss the following main topics: Politics, Research, Intervention, Stigma and Rights.

After a tribute to the founder of Alzheimer Portugal, Professor Carlos Garcia, Helen Rochford Brennan gave a brilliant talk on her experience as a person with dementia, her work as a Human Rights activist and finally as the Chairperson of the European Working Group of People with Dementia (EWGPWD).

Chaired by a journalist and with the participation of António Leuschner, who is leading the Coordination Group of the National Health Plan for Dementia, a representative of the Institute of Social Security, the President of Alzheimer Portugal and Jim Pearson, Director of Policy and Research at Alzheimer Scotland and Honorary Secretary of Alzheimer Europe, a very interesting plenary session on “Dementia: a Global Commitment, a Nacional Priority” took place.

It was a privileged moment to hear about the Scottish experience, now that the Regional Dementia Plans are being prepared, and to highlight the importance of the Labour and Social Security Ministry being also involved and committed to the recognition of dementia as a national priority.

Research was another of the main topics, singled out in the session “Clinical Research - Towards a Better Patient’s Involvement”, chaired by Celso Pontes - the Coordinator of the Alzheimer Portugal Scientific Committee. Experts from Novartis, Merck and Roche, Nélida Aguiar, as a carer of a person with dementia and an expert on Ethics, Fátima Vaz, explained to a lay audience what clinical trials are, what the decision to participate entails, the balance between risks and benefits, the rights and responsibilities of the participants, how the process is developed from defining the study until the drug reaches the market, the importance of communicating clinical trial results, informed consent, and finally ethical issues.

The importance of a better and more effective collaboration between all the stakeholders (researchers, pharmaceutical companies, regulators, patients and patients’ organisations) was a key message of the conference.

One of the highest points at the conference was a presentation by Joaquim Gil, a person with dementia who attends one of Alzheimer Portugal’s day care centres (Centro de Dia Memória de Mim). He was diagnosed a year ago with Alzheimer’s dementia. He is a very brave man; the only speaker who spoke without PowerPoint or anything written on paper. He spoke from the heart and stressed his gratefulness to his wife and daughter. Both of them were there and it was very meaningful and touching to see how proud of him they are. Joaquim Gil already has some anomic pauses, but these did not stop him from expressing his thoughts and feelings.

The conference was also an opportunity to discuss legal rights of people with dementia. With the participation of a carer, a Professor in Law and a Public Attorney, this session was chaired by Paula Guimarães, Member of the Scientific Committee of Alzheimer Portugal who some years ago participated in the Lawnet Project.

The discussion was about the new legislation on the promotion of autonomy of people with incapacity, approved in July 2018 by the Portuguese Parliament and published on 14 August.

This legislation is an initiative of the Government with the special involvement of the Minister of Justice, and will come into force in February 2019.

The Act, inspired by the “Betreuungs-gesetz” from German Law, will end the approach of “interdiction” and “incapacitation” as previously applied by the Civil Code of 1966. Instead, a legal framework promoting greater flexibility and autonomy will apply. It complies with the UNCRPD.

This is a new paradigm meaning a huge challenge for judges, public attorneys, lawyers, people with dementia, facilities attended by them, and their families. Alzheimer Portugal is committed to contributing to the best possible implementation of the new paradigm.

Towards the end of the conference, the Vice-Chair of Alzheimer Portugal, Manuela Morais, announced the best poster winner and the prize – a registration at the 29<sup>th</sup> Alzheimer Europe Annual Conference in Hague - “Making Valuable Connections”.

At the closing ceremony the State Secretary for Justice explained in lay language what the new law on the promotion of autonomy of people with incapacity states and promises, which was really appreciated by the participants.

The conference “Dementia – an Holistic Perspective” made Alzheimer Portugal feel proud of what it has achieved in its 30 years so far, while at the same time feeling certain that the coming years will be very demanding, as things are finally changing in Portugal (the National Health Plan for Dementia, the new legislation on the promotion of autonomy of people with incapacity, the development of the Dementia Friends campaign), and the number of people with dementia needing our support does not stop increasing.

**26 November: The Alzheimer’s Society (UK) is delighted that 2018 is a record year for its Memory Walk**



Memory Walk is Alzheimer’s Society’s flagship fundraising event taking place in

September and October. It is a series of family-friendly sponsored walks (ranging between 4 and 8km) across England, Wales and Northern Ireland, taking different routes through cities, parks or woodland.

The premise behind Memory Walk is simple and our walkers find the social aspect of Memory Walk important. The walks are a chance to be with other people who are going through or have been through similar experiences to them. They provide an opportunity to remember and celebrate loved ones who have passed away or are living with dementia.

This year, and for the first time in the history of Memory Walk, over 100,000 people signed up and raised over £7 million, coming together to walk towards a world without dementia.

For those that aren’t near one of the 40 organised walks, there is an option to organise their own as part of “Your walk. Your Way.” We have more than doubled the amount of people organising their own walk this year with over 3,800 organisers raising over £400,000, including an amazing 65 schools. 2,600 volunteers helped to make this year an overwhelming success.

This year saw the introduction of longer walks (15-22km) and night walks which provided supporters with a different event to take part in.

A television advert for Memory Walk features Gill and her daughter Claire. You can read more about Gill and Claire’s story here: <https://bit.ly/2QmMqca>

Find out more about Memory Walk here: [www.memorywalk.org.uk](http://www.memorywalk.org.uk)

**26 November: Panhellenic Federation reports on two important conferences held recently in Crete**



The 6<sup>th</sup> Pancretan Interdisciplinary Conference on Alzheimer’s Disease and Related Disorders and the 2<sup>nd</sup> National Conference on Active

and Healthy Ageing were held successfully on 27-30 September 2018, at the Galaxy Hotel in Heraklion, Crete by the Association of Alzheimer Disease and Related Disorders Pref. of Heraklion ALLILENGII.

Distinguished speakers presented their work in the field of diagnosis and treatment of the disease, support for patients and carers, prevention of physical and mental vulnerability in the “Third Age” and the promotion of good health.

A large number of health professionals involved in the care of people with dementia and their families attended the conference, including doctors, psychologists, social workers, nurses, dieticians, occupational therapists, music therapists, speech therapists and physiotherapists, as well as biologists, students, caregivers and family members of people with dementia and members of the general public (300 participants).

The Greek Minister of Health Andreas Xanthos greeted the conference delegates and stressed the importance of such scientific events to raise public awareness and disseminate scientific knowledge and co-operation. He also guaranteed the intention of the Government to support efforts related to the promotion of health in vulnerable groups.

In summary, the conference emphasised the need for regular meetings of specialised scientists, and information about the results of their research, as well as highlighting the priority that state policies must give to care, prevention, support and treatment for people with dementia and their families.

**26 November: The Alzheimer’s Society wants to “Lift the lid” on sex and intimacy taboos**

A new Alzheimer’s Society resource will help care home staff address taboos. Last year, Alzheimer’s Society began a new project to tackle sex and intimacy taboos in care homes. We involved 10 homes in the UK run by Bupa, Four Season and St John’s Trust to better understand the situation and explore potential solutions.



Some care home staff told us that they had never considered residents’ sex and intimacy needs at all. Others said they didn’t know how to broach the topic, were concerned about issues of consent or lacked clear guidance.

The evidence suggests that care home staff want to get this right but don’t know where to start. We worked with care homes to create Lift the Lid – a ‘workshop in a box’ for care home staff that challenges their perceptions and behaviours through three creative activities. This helps them to develop a sex and intimacy policy so that staff can feel confident about providing all-round person-centred care, in line with guidance from regulators such as the Care Quality Commission.

Dr James Pickett, Head of Research at Alzheimer’s Society, said, “Sex and intimacy in the context of a care home raises countless questions that many people don’t know how to answer or don’t even want to think about. When you consider that 70% of people in care homes are living with dementia, the conversation gets even more complicated.

“It can be a really taboo topic, but we believe care home staff are best placed to tackle this challenge and make a real difference. We’re all different, so there is no “one size fits all”

solution. Lift the Lid is a flexible tool to help care home staff talk through the issues in a creative and constructive way.

“Dementia research isn’t only about finding a cure. We’re also investing in vital care research like Lift the Lid, because we owe it to the 850,000 people in the UK currently living with dementia to understand the condition better so that they can live better.”



## POLICY WATCH

### 1 November: The German Ethics Council publishes comprehensive statement on coercion in care

On 1 November, the German Ethics Council published an official statement on coercion in the social and healthcare sector. In



this document, the Council states that, in the context of formal care, methods of restraint should be avoided wherever possible and only considered as “Ultima Ratio” - i.e. after all other possibilities have been exhausted. The Council notes that there can be emergencies in which the use of coercion may need to be considered as a last resort, revealing challenging and ambivalent trade-offs in this decision-making process.

The Ethics Council pursues three objectives with their publication:

- Raise public awareness on the challenging topic of coercion in the ambivalent trade-off between the duty to avoid self-harm in the care context and the individual right to self-determination.
- Raise politicians’, policy makers’ and practices’ awareness about implementation and regulation deficits of restraint measures as well as provide recommendations to address these gaps.
- Support health and social care professions in the reorientation of their self-conception and practice as professional carers.

A guiding thought is that conditions, structures and processes should be arranged in a way that, whenever possible, avoids resorting to coercion.

The German Alzheimer’s association, Deutsche Alzheimer Gesellschaft (DAzG) welcomed the Council’s position and added that the topic of coercion also plays a role in the context of informal care at home. Carers may sometimes be overwhelmed with challenging situations and fall back on restraint measures such as locking the people they care for in their room. The German Alzheimer’s association therefore

stressed that carers should have access to counselling and other support actions.

You can read the statement of the German Ethics Council here: <https://bit.ly/2PWsaPj>

You can read the comment of the German Alzheimer’s Association here: <https://bit.ly/2BCZZMB>

### 22 November: OECD publishes health at a glance report



The Organisation for Economic Cooperation and Development (OECD) has published “Health at a Glance: Europe 2018” which presents a comparative analyses of the health status of EU citizens and the performance of the health systems of the 28 EU Member States, 5 candidate countries and 3 EFTA countries.

This is part of the ongoing “State of Health in the EU” initiative.

The publication has two parts. Part I comprises two thematic chapters, the focusing on the need to promote better mental health and possible strategies for reducing wasteful spending in health. In Part II, the most recent trends in key indicators of health status, risk factors and health spending are presented, together with a discussion of progress in improving the effectiveness, accessibility and resilience of European health systems.

Pages 108 and 109 offer dementia prevalence estimates, suggesting that for 2018, an estimated 9.1 million people aged over 60 are living with dementia in EU member states, up from 5.9 million in 2000. The overall number of people living with dementia in EU countries is expected to rise by about 60% over the next two decades to reach 14.3 million in 2040.

You can read the full report at:

<https://doi.org/10.1787/23056088>

### 27 November: Overwhelming majority of French public disagrees with government’s decision not to reimburse anti-dementia drugs



The results of a recent survey on French people’s understanding of Alzheimer’s disease (AD) and dementia have shown that public opinion about the recent announcement by the French Government to stop reimbursing anti-dementia drugs is very negative, with 80% of respondents disagreeing with the decision.

While there are some who doubt the very existence of AD and believe dementia to be simply the natural ageing of the brain, the survey shows that 90% of French people know that AD is indeed real and that it can also affect younger people.

Published on the occasion of the 25<sup>th</sup> edition of World Alzheimer’s Day (21 September 2018), this survey was conducted among 1,001 people aged 18 and over as well as a sample of 791 people aged 60 and over.

The survey was conducted by the ODOXA polling institute on behalf of France Alzheimer, the Société Française de Neurologie (SFN) and the Fondation pour la recherche sur Alzheimer. You can read the full press release (in French) here: <https://bit.ly/2DKvQwi>

You can download the survey results (in French) here: <https://bit.ly/2DOBrBT>

## Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for our 2018 activities and two new sponsors for our 2019 activities.

Read more about sponsorship opportunities here: <https://goo.gl/cKVNeC>

### 2018 sponsors



### 2019 sponsors



## SCIENCE WATCH

### 24 October: Cortexyme presents Phase I data of COR388 for AD



On 24 October, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, presented Phase I data of COR388 at the annual Clinical Trials on Alzheimer’s disease (CTAD) conference in Barcelona, Spain.

The Phase I study was a randomised, double-blind, placebo-controlled trial to evaluate the safety and tolerability of repeated doses of COR388 in 24 older healthy participants and 9 people with AD.

The experimental drug was found to be safe and well tolerated in healthy older volunteers and people with AD at a range of doses for up to 28 days. Although the study showed cognitive improvement in the treatment group compared to placebo, the results were not statistically significant. The company expects to start a Phase II clinical trial of COR388 in people with mild to moderate AD in 2019.

<https://bit.ly/2O57E9a>

### 25 October: The IDEAS study reports that amyloid PET scans change treatment plans in two-thirds of cases

On 25 October, Dr Gil Rabinovici from the University of California in San Francisco gave a talk at the 11th Clinical Trials on Alzheimer’s Disease (CTAD) conference in Barcelona, Spain. His talk was entitled “Impact of Amyloid PET on the management of cognitively impaired patients: Results from the IDEAS study”. He presented some final results from the Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) study. The study will determine the clinical usefulness on patient-oriented outcomes of a brain positron emission tomography (PET) scan that detects amyloid plaques, a core feature of Alzheimer’s disease (AD).



The study finished enrolling in January 2018. For the first part of the study, 11,409 participants were analysed. 60% of the participants were clinically diagnosed with mild cognitive impairment (MCI) and 40% with dementia. The amyloid PET scans determined that 55% of the MCI group and 70% of the dementia group were amyloid-positive. The study reported that amyloid PET scans changed the treatment plans in two-thirds of the cases and that clinicians prescribed the approved Alzheimer’s drugs after seeing positive scans. Researchers are collecting further data and expect to deliver them in 2019.

<https://bit.ly/2BniB30>

### 26 October: Anavex reports new clinical data of Anavex 2-73 for AD



On 26 October, Anavex Life Sciences Corp - a clinical-stage biopharmaceutical company developing differentiated therapeutics for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD) - presented new clinical Phase II data for Anavex 2-73 at the annual Clinical Trials on Alzheimer’s disease (CTAD) conference in Barcelona, Spain.

Results showed a maintenance of activities of daily living and a significant reduction of cognitive decline in people with AD as measured by the Alzheimer’s Disease Cooperative Study-Activities of Daily Living (ADCS-ADL) evaluation and the Mini Mental State Examination (MMSE) for those who received the higher concentration of ANAVEX 2-73 through 148 weeks. In addition, the experimental drug demonstrated favourable safety and tolerability.

“We continue to build on the body of clinical evidence to support the development of ANAVEX 2-73 as we further our recently initiated Phase 2b/3 study, and we will continue our targeted precision medicine approach to advance ANAVEX 2-73 as a potential therapeutic option for patients with Alzheimer’s disease who will most benefit from treatment.”, said Christopher U Missling, Ph.D., President and Chief Executive Officer of Anavex.

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

**26 October: Research suggests potential tie between loneliness and risk of dementia**



On 26 October, researchers from the United States of America and France published an article on loneliness and its potential association with risk of dementia in *The Journals of Gerontology: Series B*.

Previous studies have found mixed results on the tie between loneliness and increased risk of dementia. The team therefore aimed to investigate their research question through a large and diverse study population of more than 12,000 participants whose data was drawn from the Health and Retirement Study.

The information on who had probable dementia was assessed every two years during a period of ten years using a telephone interview (TICSm) with which the cognitive status was assessed. In order to estimate how lonely people are, participants were asked how much of the time they feel the lack of companionship, left out and isolated from others.

The results of the statistical analyses showed that those study participants (with enough available follow-ups), who indicated that they feel lonely during the initial interview, were also more likely to develop dementia in future (by 40%), independent of their social integration.

Even though these results are interesting, caution on how they are interpreted is necessary. Although the researchers mentioned that the TICSm telephone interview is well validated, there could be differences to a clinical diagnosis conducted in a specialised clinic. In addition, it should be highlighted that the study was not composed to explain how loneliness contributes to the risk of developing dementia. Nevertheless, these findings underline the probable importance of addressing loneliness as a potentially modifiable risk factor of dementia, supporting the importance of further research in this area.

<https://bit.ly/2zgB9Q8>

**30 October: Researchers explore link between retina and AD**



On 27-30 October, researchers presented two studies on eye scans to help detect Alzheimer’s disease (AD) at AAO 2018 — the 122<sup>nd</sup> Annual Meeting of the American

Academy of Ophthalmology. Background of this explorative detection method is the hypothesis that during the course of AD, small blood vessels in the retina at the back of the eyes change.

The first study examined this possible link between retinas and AD, using an imaging test called optical coherence tomography. This technique allows the scientists to see the distinctive layers of the retina and permits to measure their thickness. Using this technique, the team compared the retinas of people with AD, mild cognitive impairment (MCI)

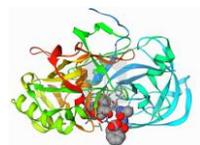
and no form of cognitive impairment. They reported that they found a loss of blood vessels as well as observed that a certain layer of the retina was thinner in people with AD when compared to people with MCI or no cognitive impairment.

Another study investigated retinas and cognition in 400 people that had a family history of AD. The team reported that they observed thinner retinas in people with a family history and that this correlated with a poor scores on neuropsychological tests. Although these findings may support the hypothesis, further studies with follow-ups of the same participants are needed, since these would shed further light into how retinas change on an individual level during the disease course and if these changes are accompanied by severity of cognitive impairment.

<https://www.medicalnewstoday.com/articles/323515.php>

**2 November: Scientists report preliminary results on BACE inhibitors that were in development for the treatment of AD**

In February 2018, the biopharmaceutical company Merck announced that it has decided to discontinue the Phase III APECS study. The APECS trial was a randomised, placebo-controlled, parallel-group, double-blind Phase III clinical trial evaluating the efficacy and safety of verubecestat in people with prodromal Alzheimer’s disease (AD). Verubecestat belongs to a group of AD drugs called BACE inhibitors, which block the production of the beta secretase enzyme involved in the formation of toxic amyloid proteins. Researchers presented data at the Clinical Trials on Alzheimer’s disease (CTAD) conference held on 24-27 October in Barcelona (Spain). The trial enrolled 1,454 participants. They reported that verubecestat caused a significant small cognitive deficit in people with prodromal AD compared to control.



Additional disappointing results were shared at CTAD from Phase II and Phase III studies with BACE inhibitors that were in development for the treatment of AD. Janssen’s atabecestat was stopped in May 2018 because of its liver toxicity. Preliminary findings from the Phase II/III EARLY trial suggested that atabecestat might has resulted in worsening on cognitive measures. In the meantime, Eli Lilly’s presented data of the Phase II NAVIGATE trial stopped for lack of efficacy. The study investigating LY3202626 showed a no-significant deficit on cognition in participants receiving the experimental drug. In addition, participants receiving verubecestat and LY3202626 had lost more brain volume.

The cognitive deficits observed with BACE inhibitors do not appear to come with increased neurodegeneration. Researchers at CTAD made some recommendations and agreed that further analysis are needed.

<https://bit.ly/2E3Hmrv>

**5 November: Scientists investigate the potentials of selective HDAC inhibition to target multiple AD hallmarks**

**PNAS** On 5 November, researchers from the University of Miami Miller School of Medicine published an article on the inhibition of HDAC3, proposing a possible usefulness for further investigation in Alzheimer’s disease (AD) drug development, in the journal Proceedings of the National Academy of Sciences.

So far, research on nonselective histone deacetylase (HDAC) proteins has led to unsatisfactory results in research. Although, scientists were able to show positive effects in other indications, there has been a variety of unwanted side effects. The team therefore was interested in testing whether or not a selective inhibitor could be better fit.

Their results showed that the applied inhibitor RGFP-966, both decreased the accumulation of proteins related to the pathology of AD in vitro and was also accompanied by a lessened memory impairment in an AD mouse model. While these results cannot be directly translated to the effects of selective inhibition in living humans, they provide a possible indication that this approach could be further investigated.

<http://www.pnas.org/content/early/2018/10/31/1805436115>

**12 November: Researchers from UCL present findings on intensity of carotid artery forward compression waves and cognitive function**

**Circulation** On 12 November, a team of researchers from the University College London presented findings on the possible link between increased carotid artery forward compression waves (FCW) during mid- to late-life and future cognitive decline at the Annual Conference of the American Heart Association.

In order to test their hypothesis, the scientists used information of 3.192 participants (aged 58-74) from the Whitehall II Study. Participants underwent ultrasound as well as cognitive examinations undertaken throughout a follow-up period of 11-14 years.

After adjusting their statistic models for confounding influences such as health-related risk factors and behaviours, the team found that although increased carotid artery forward compression waves were linked to a higher rate of overall cognitive decline, there was no relationship between pulse pressure and change in cognitive function. This led them to the conclusion that elevated carotid artery forward compression waves are independently linked to a faster rate of cognitive decline.

[https://www.ahajournals.org/doi/10.1161/circ.138.suppl\\_1.13364](https://www.ahajournals.org/doi/10.1161/circ.138.suppl_1.13364)

**15 November: Alector starts Phase I trial of AL002 for AD**

On 15 November, Alector, a biotechnology company developing immuno- neurology therapies to treat

neurodegenerative diseases, announced the launch of its Phase I trial of AL002 for the treatment of Alzheimer’s disease (AD). AL002 is an antibody that targets TREM2 (triggering receptor expressed on myeloid cells 2) which is a receptor expressed on microglia - the immune cells that reside in the brain.



The Phase I study, called the INVOKE study, is a multi-centre, randomised, double-blind and placebo-controlled trial evaluating the safety, tolerability, pharmacokinetics and pharmacodynamics of AL002 in healthy adults and people with mild to moderate AD. The company expects to recruit approximately 52 participants. The primary outcome is the evaluation of the safety and tolerability of AL002 measured by the incidence of adverse events and dose limiting adverse event (DLAEs).

<https://bit.ly/2zvAL0Z>

**19 November: Study assesses dementia and mortality in people with Down syndrome**



On 19 November, an international team of scientists from the United Kingdom, China and Singapore published an article on dementia and mortality among adults with Down syndrome (DS) in the journal JAMA Neurology.

The information for the statistical analyses was gathered through the London Down Syndrome Consortium cohort. The researchers identified 211 people (aged 36 and older) with DS. Using the information on 27 participants that died during the study period, the scientists found that crude mortality rates for individuals with DS and dementia were 5 times higher than for those without.

Furthermore, the team reported that those who carried the APOE ε4 gene respectively had comorbidities were exposed to a higher risk of dementia and death.

While this sample is relatively small with a maximum of 65 months follow-up time, the authors acknowledged that there is a need for further research, which includes more participants during a longer period of time. Nevertheless, the authors stated that the association of multiple diseases and risk of developing dementia as well as mortality risk underlines the need for effective recognition and treatment of common health comorbidities in people with DS.

<https://jamanetwork.com/journals/jamaneurology/fullarticle/2714719>

**20 November: Amoneta Diagnostics describes its biobank of biological samples from patients with dementia and cognitively intact subjects**



Amoneta Diagnostics is a life sciences biotechnology company that identifies, develops and qualifies innovative biomarkers for the development of diagnostics and diagnostic tools in the field of neurological diseases. The Amoneta Diagnostics team is coordinating both the ADKIT

(EuroTransBio; GA # 931/14/C1) and the ADDIA (H2020; GA # 674474, ClinicalTrials.gov Identifier: NCT03030586) projects. Thanks to these two European programs, Amoneta diagnostics has developed a biobank of biological samples from patients with Alzheimer’s disease (AD). The biobank is certified NFS96 900: ID 112741164528.

The AD biobank has been officially launched during the ADDIA annual meeting in Strasbourg (France) in July 2018. The sample collection has started in March 2016 for the ADKIT study and in January 2017 for the ADDIA study. The liquid biopsies have been collected from patients with AD and other neurodegenerative diseases, including dementia with Lewy body, frontotemporal dementia, corticobasal degeneration and progressive supranuclear palsy, and from healthy controls.

This biobank comprises high-quality and anonymised biological material and its associated information:

The biological material consists in following liquid biopsies: whole blood, plasma, serum, peripheral blood mononuclear cells (PBMCs), blood RNA and DNA, cerebrospinal fluid (CSF), urine and saliva samples.

The afferent information includes demographic, clinical, neurocognitive scores and neuroimaging data (volumetric 3D MRI), CSF Aβ1-42 and CSF tau data, and blood biochemistry and haematology results.

Together with Amoneta Diagnostics, several organisations have been involved in the development of the AD biobank including Besançon CHU, Brescia IRCCS, Brussels Cliniques Universitaires Saint-Luc, Brussels Erasme Hospital, Colmar Hospital, Firalis SA, Geneva University Hospital, Istanbul faculty of Medicine, Lausanne CHUV, Lille CHU, Montpellier CHU, Nice CHU, Paris AP-HP, Strasbourg University Hospital; with the support of Alzheimer Europe.

The company is pleased to share its AD biobank for research purposes. The biobank gives the opportunity to a large number of research investigators to collaborate on the use of the biological samples.

For further information please visit the ADDIA website or contact: [biobank@firalis.com](mailto:biobank@firalis.com)

## LIVING WITH DEMENTIA

### 30 November: EWGPWD Chairperson reflects on progress made during her 4 years so far

Throughout my four years as Vice Chair and Chair of, the European Working Group of People with Dementia (EWGPWD) I have met many people living with dementia throughout Europe.

I have listened and borne witness to their experience as they struggle to be active citizens and fight society’s perception that they lack capacity to make choices about their lives.

But there is progress, and as we approach the end of the year I want to reflect on the positive and in particular acknowledge the rising sound of the lived experience; how it is being heard and most importantly, valued. Because sometimes it is important to focus on the good news!

In my advocacy work I speak a lot about my dark days after diagnosis. In those dark days I never thought I would be where I am now. It took time to accept my diagnosis in particular to accept that there is no cure for Alzheimer’s disease. But I still have a life. A very different life from what I imagined, it’s a very full, joyful and fulfilling new life. I call it my Alzheimer life.

In my travels throughout Europe, meeting people who are passionate about quality dementia care is energising. I see changes in how those of us living with dementia are viewed and, slowly but surely, I am beginning to see a new understanding of our human rights. We must ensure our human rights are not violated but it is also very important to keep in mind we have a human responsibility. And critically, I see real value being placed on the lived experience, sharing my story is very rewarding as it is educating the public on how people with dementia can live happy lives with minor adjustments for an inclusive community.

Research has been such a rewarding experience, and one thing I really enjoyed and would like to highlight is the EWGPWD’s strong collaboration over the last two years with the ROADMAP project, which is about real world outcomes for better care in the context of Alzheimer’s disease. It has been very satisfying to see that our input has been highly valued and has influenced the development of the project, particularly with regard to the definition of outcomes and ethical issues. I was also personally involved in meetings with other experts from Health Technology Assessment (HTA) bodies and this was a really interesting experience. This project is now coming to an end and I hope that we can keep this nice collaboration going in the future. I look forward to working on other European projects such as PARADIGM, SPAN+, INDUCT, EPAD and hopefully many new ones!

In my home country of Ireland my work has been truly acknowledged over the past year. I received three awards for advocacy work in changing the perception of Alzheimer’s in Ireland.

- Sligo Person of the Year presented by my Local Council.
- Sligo Business, Economic and Social Inclusion: A Lifetime Achievement Award.
- National University of Ireland Galway awarded me an Honorary Doctor of Laws.



The Honorary Doctorate is particularly significant because it acknowledges my work in advocating for Human Rights of people living with dementia. In accepting the award I acknowledged all of us with dementia, my colleagues on the EWGPWD and the Irish Dementia Working Group who all work so hard to ensure the lived experience is heard.

We all work to ensure the human rights of people living with dementia are upheld. And as we go in to this holiday season I encourage all European citizens living with and without dementia to remember we are all human, we are all the same, all trying to find our own path.

I am now a carer for my husband without support, I am struggling with household tasks as I observe my dementia progressing. But I live with hope and I focus on the positive. And this holiday season it seems appropriate to think of children's author C. S. Lewis, who said "It is not the load that breaks you down, it's the way you carry it".

*Mile Buiochas* (many thanks) to Alzheimer Europe, The Alzheimer Society of Ireland and my volunteer travel support Carmel Geoghegan, for helping me to achieve another great year of advocacy.

*Nollaig Shona agus Athbhliain faoi Mhaise Duit* (Happy Christmas and New Year's Eve)!

Helen Rochford Brennan, Chairperson, EWGPWD.

## DEMENTIA IN SOCIETY

### 20 November: Dementia Friends movement highlights importance of youth involvement



20 November was Universal Children's Day and Dementia Friends (UK) used the occasion as a platform to highlight work being done in Costa Rica - the first country in Latin America to implement Dementia Friends.

13 year old Dementia Friends Champion Jose Pablo Roman is leading the youth and intergenerational approach in his country and has helped kick-start the Dementia Friends movement in schools around the country. He discovered Dementia Friends through his father (a volunteer with the National Alzheimer Association in Costa Rica).

"Dementia Friends helps create understanding about dementia.... It is important to work with communities [and to] raise awareness of dementia among the youth because they will continue the work started by older generations" Jose commented.

The President of the National Alzheimer Association in Costa Rica, Dr Norbel Roman said, of their plans for a Dementia Friends youth approach:

"We are using the platform of Dementia Friends to influence the national educational system. With a message of sensitisation we plan to reach all educational systems and plan for school children to visit care homes as part of the curriculum."

<https://bit.ly/2RirGQ3>

### 21 November: Irish short film about dementia gains international acclaim



A short animated film called Late Afternoon has been gathering international attention and critical acclaim. The movie, written and co-directed by Louise Bagnall and produced by Irish animation studio Cartoon Saloon, depicts a woman with dementia, who reaches deep into

her memories whenever she sees her reflection. The main character, Emily, is voiced by Irish actress Fionnula Flanagan, who also worked with Cartoon Saloon on their 2014 movie Song of the Sea.

Late Afternoon recently received the award for Best Animation Short at the Chicago International Children's Film Festival and at the Tribeca Film Festival in New York. The latter qualifies it to be considered for the Oscars.

Cartoon Saloon was nominated for an Oscar in 2017 for its movie The Breadwinner, about a girl under Taliban rule in Afghanistan. Watch the trailer for Late Afternoon here:

<https://www.youtube.com/watch?v=HmYiBLZg0LO>

### 21 November: What is the Three Nations Dementia Working Group? New video explains

On 21 November, the Three Nations Dementia Working Group (3NDWG) launched a video, to tell people more about the group and what it does.



The 3NDWG is a working group of people living with dementia across England, Northern Ireland and Wales.

A steering group of 12 people with dementia drawn from the membership leads the 3NDWG, including Chris Roberts, Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and former Vice-Chair Hilary Doxford.

Find out more about the group via its new video: <https://bit.ly/2AtRQrQ>

Or via its website: <https://www.3ndementiawg.org/>

Pictured: The 3NDWG steering group, March 2018.

### 30 November: "Head Full of Honey" takes a poignant look at love, loss and dementia

The movie "Head Full of Honey", directed by Til Schweiger, is due to be released on 30 November 2018. It is an American remake of the 2014 German film "Honig im Kopf", which Mr Schweiger also directed, acted in and co-wrote with Hilly Martinek. Oscar nominee and Golden Globe Winner Nick Nolte (The Prince of Tides, 1991) plays the



leading role of Amadeus, a man with Alzheimer's dementia, who has just been widowed after 50 years of marriage. Amadeus embarks on a final road-trip to Venice with his granddaughter Matilda (played by Mr Nolte's real-life daughter Sophie Lane Nolte) as she tries to help her grandfather navigate his increasing forgetfulness.

Actors Matt Dillon and Emily Mortimer star as his son and daughter-in-law respectively. Watch the trailer here:

<https://bit.ly/2DOUP2a>

## JOB OPPORTUNITIES

### 31 October: Become an Atlantic Fellow at the Global Brain Health Institute



During October 2018, applications opened for the 2019/2020 Atlantic Fellows for Equity in Brain Health programme at Global Brain Health Institute. All suitable candidates are encouraged to submit a full application. These are competitively reviewed by a selection committee from each partner organisation. Applications require two letters of support to demonstrate regional commitment to an applicant's success, as well as a personal statement from the applicant that describes their passion and interest in the program. Short-listed applicants will be interviewed virtually by a GBHI representative, after which a final selection will be made. Up to 40 positions will be filled annually. Closing date: 3 January 2019.

Questions about the application process? Contact [apply@gbhi.org](mailto:apply@gbhi.org)

For more information or to apply, visit: <https://bit.ly/2DwgRpw>

### 7 November: University of Bradford seeks Chair in Applied Dementia Studies



The University of Bradford Faculty of Health Studies Centre for Applied Dementia Studies is looking to hire a new professor in applied dementia studies.

The successful candidate will be committed to working to improve the lives of people with dementia and their supporters. They will have proven leadership and management abilities in addition to a robust track record in research, education and scholarship. They will have the ambition and drive to further develop the Centre for Applied Dementia Studies working with its professoriate and academics, the Faculty of Health Studies and the wider University. They will also be committed to building upon our established partnerships, locally, nationally and internationally.

This is a full-time, permanent position.

Job Reference: HR0067347.

Interview Date: To be confirmed

If you would like to find out more please contact Professor Gail Mountain: [g.mountain@Bradford.ac.uk](mailto:g.mountain@Bradford.ac.uk)

The University of Bradford strives to be an equal opportunities employer and welcomes applications from all sections of the community. Closing date: 6 December 2018.

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

### 20 November: DZNE seeks Psychologist with a focus on gerontopsychology



The German Center for Neurodegenerative Diseases (DZNE) is a unique non-university research centre, which is dedicated to dementia, as well as other neurodegenerative diseases.

The DZNE is currently looking to recruit a Psychologist (f/m) with a focus on gerontopsychology. Closing date: 30 November 2018.

To find out more: <https://bit.ly/2Fwd2mX>

To apply: <https://jobs.dzne.de/en/jobs/10251/form>

## NEW PUBLICATIONS AND RESOURCES

### 21 November: European Brain Council publishes report on the future of dementia policy



The European Brain Council (EBC) has published, "Driving policy to optimise care for people with Alzheimer's disease in Europe today and tomorrow" outlining its priorities for dementia focused primarily on patient-focused and sustainable care. The paper was developed collaborative by a number of stakeholders including EBC, European Federation for Neurological Associations and Merck. You can read the full report at: <https://bit.ly/2A8Rx5P>



## AE CALENDAR

Date	Meeting	AE representative
<b>3 December</b>	Meeting with Gates Ventures (Brussels, Belgium)	Jean
<b>3-4 December</b>	European Government Experts meeting (Brussels, Belgium)	Charles and Owen
<b>4 December</b>	Alzheimer Europe Board and European Parliament lunch debate "Dementia as a priority of the EU health programme" (Brussels, Belgium)	AE members, Board and staff
<b>4 December</b>	AE Corporate Round Table meeting (Brussels, Belgium)	AE Board, sponsors and staff
<b>4-5 December</b>	EWGPWD meeting (Brussels, Belgium)	Ana and Dianne
<b>4-5 December</b>	Alzheimer's Association Academy (Brussels, Belgium)	AE members, Board and staff
<b>10 December</b>	GSK Health Advisory Board (London, United Kingdom)	Jean
<b>11 December</b>	Legal and Ethics Advisory Board meeting for the AETIONOMY project (Vienna, Austria)	Jean and Dianne
<b>14 December</b>	IMI Networking event – Pharma meets Academia (Dudelange, Luxembourg)	Chris

## CONFERENCES

Date	Meeting	Place
<b>14-15 December 2018</b>	EDUKAL 2018 – Fourth educational conference on Alzheimer's disease, <a href="https://www.edukal.alzheimer.hr">https://www.edukal.alzheimer.hr</a>	Zagreb, Croatia
<b>16-18 January 2019</b>	13 <sup>th</sup> Human Amyloid Imaging, <a href="http://www.worldeventsforum.com/hai/">http://www.worldeventsforum.com/hai/</a>	Miami, Florida
<b>6-7 February</b>	3 <sup>rd</sup> HBP Student Conference on Interdisciplinary Brain Research, <a href="https://education.humanbrainproject.eu">https://education.humanbrainproject.eu</a>	Ghent, Belgium
<b>14-17 February</b>	11 <sup>th</sup> Panhellenic Conference on Alzheimer's Disease and Related Disorders, <a href="http://www.alzheimer-conference.gr">http://www.alzheimer-conference.gr</a>	Thessaloniki, Greece
<b>19-20 March</b>	2019 Alzheimer's Research UK, <a href="https://www.alzheimersresearchuk.org">https://www.alzheimersresearchuk.org</a>	Harrogate, UK
<b>20-23 March</b>	13 <sup>th</sup> Göttingen Meeting of the German Neuroscience Society, <a href="https://www.nwg-goettingen.de/">https://www.nwg-goettingen.de/</a>	Göttingen, Germany
<b>26-31 March</b>	The 14 <sup>th</sup> international conference on Alzheimer's & Parkinson's diseases, <a href="https://bit.ly/2Jyvw3t">https://bit.ly/2Jyvw3t</a>	Lisbon, Portugal
<b>4-7 April</b>	13 <sup>th</sup> World Congress on Controversies in Neurology, <a href="http://www.comtecmed.com">http://www.comtecmed.com</a>	Madrid, Spain
<b>14-17 April</b>	BNA2019 - Festival of Neuroscience, <a href="http://meetings.bna.org.uk/bna2019/">http://meetings.bna.org.uk/bna2019/</a>	Dublin Ireland
<b>15-18 May</b>	World Psychiatric Association and Psychiatric Association of Macedonia Thematic Congress, <a href="http://wpadementia2019.com">wpadementia2019.com</a>	Ohrid, Macedonia
<b>20-21 May</b>	8 <sup>th</sup> European Conference on Clinical Neuroimaging, <a href="https://www.euroccn.com/">https://www.euroccn.com/</a>	Brussels, Belgium
<b>21-22 May</b>	Alzheimer's Society Annual Conference, <a href="https://www.alzheimers.org.uk">https://www.alzheimers.org.uk</a>	London, UK
<b>29 June-2 July</b>	5 <sup>th</sup> Congress of the European Academy of Neurology (EAN), Congress, <a href="https://www.eanpages.org/event/5th-ean-congress-in-oslo-norway-norges-varemesse">https://www.eanpages.org/event/5th-ean-congress-in-oslo-norway-norges-varemesse</a>	Oslo, Norway
<b>1-4 July</b>	Royal College of Psychiatrists' International Conference, <a href="https://www.rcpsych.ac.uk">https://www.rcpsych.ac.uk</a>	London, UK
<b>19-20 September</b>	International MinD Conference 2019, <a href="http://designingfordementia.eu">http://designingfordementia.eu</a>	Dresden, Germany
<b>22-25 October</b>	29 <sup>th</sup> Alzheimer Europe Conference "Making valuable connections"	The Hague, Netherlands
<b>4-7 December</b>	Clinical Trials in Alzheimer's Disease, <a href="http://www.ctad-alzheimer.com/ctad-2019">http://www.ctad-alzheimer.com/ctad-2019</a>	San Diego, USA

# 29<sup>th</sup> Alzheimer Europe Conference

## Making valuable connections

### The Hague, Netherlands

#### 23–25 October 2019

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

 #29AEC

