2020 began with the publication of an article we co-authored with the European Working Group of People with Dementia, on Patient and Public Involvement in research. “Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia” appears in Volume 19, Issue 1 of the journal Dementia. Overall, our paper shows that involving people with dementia and their supporters in dementia research is a win-win for everyone but that, while progress has been made, certain areas of collaboration still need some work.

We are also delighted to announce our involvement in 3 new projects. RECOGNISED (Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia) is a 4-year project and PRIME (Prevention and Remediation of Insulin Multimorbidity in Europe) will run for 5 years. Both are funded by the EU’s Horizon 2020 research and innovation programme. The ADAIR project, which aims to provide crucial mechanistic insight about the effects of air pollutants on the brain in humans and discover biomarkers for air pollution and Alzheimer’s disease (AD) risk-prediction, is a 2-year JPND-funded project.

Supporting and helping to further all aspects of dementia research at the European level is hugely important to us and we are proud to be so actively involved in these and all other EU projects in which we are currently partnering/collaborating.

Talking of EU collaboration, we are delighted to announce two Vice-chairs for the European Alzheimer’s Alliance (EAA), MEPs Marisa Matias (Portugal) and Hilde Vautmans (Belgium). They join their colleagues, Chairperson Sirpa Pietikäinen MEP (Finland) and Vice-chair Christophe Hansen MEP (Luxembourg) in taking leading roles in the EAA for the 2019-2024 term. We look forward to continuing our work with them, for example at our February 2020 lunch debate. We also thank Vice-chair Christophe Hansen MEP, in advance, for hosting this debate on “Advancing Alzheimer’s research through private-public partnerships”.

Sadly, this month, we also had to say goodbye to all six UK members of the EAA, as they and their colleagues depart the European Parliament following the UK’s formal exit from the European Union on 31 January 2020. We thank them for their support and important contributions to making dementia a European priority.

On a more positive note, the European Commissioner for Equality, Helena Dalli, has announced that there will be a new European Disability Equality Strategy for 2021.

Lastly, I would like to invite you to already mark the dates of the 30th Alzheimer Europe Conference #30AEC, which will take place in Bucharest from 20-22 October. You can already find some details about the event on our website and the call for abstracts will be launched in the coming weeks.

Jean Georges
Executive Director
ALZHEIMER EUROPE

8 January: Members of the EWGPWD and Alzheimer Europe publish article reflecting on Patient and Public Involvement in research

An article, entitled “Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia”, has been published in Volume 19, Issue 1 of the journal Dementia.

In 2017, Alzheimer Europe developed a position on Patient and Public Involvement, in collaboration with INTERDEM and the EWGPWD. In this article, Chris Roberts and Helen Rochford Brennan, who both have dementia, as well as Jayne Goodrick, Chris’s supporter, provide further reflection on three of the seven key issues addressed in the position paper, namely in relation to:

- recognition and acknowledgement of the contribution made by people with dementia,
- promoting and protecting the rights and well-being of people with dementia,
- training and support.

The authors reflect on their personal and ongoing experience of PPI and how this relates to the position paper which they helped develop. They conclude that involving people with dementia and their supporters in dementia research is a win-win for everyone involved and that although a lot of progress has been made, certain areas need to be further explored in collaboration with people with dementia and their supporters.

For more information, contact Dianne Gove, Director for Projects: dianne.gove@alzheimer-europe.org

The article can be found, here:
https://doi.org/10.1177/1471301219876402

Dementia is an international peer-reviewed journal that acts as a forum for social research aiming to improve quality of life and care for people with dementia and their families.

27 January: Information about important dates, accommodation and travel for 30th Alzheimer Europe Conference now on website

The 30th Alzheimer Europe Conference (#30AEC), “Building bridges”, will take place in Bucharest, Romania from 20-22 October 2020. Information about important dates, accommodation and travel are already available on our website, as is a preliminary programme.

The call for abstracts, as well as registration information, will be available in the coming month. Watch this space!

https://www.alzheimer-europe.org/Conferences/Bucharest-2020

Alzheimer Europe networking

On 10 February (Brussels, Belgium) Ana and Dianne attended the WP4 Paradigm meeting.

On 13 to 15 January (Frankfurt, Germany), Angela attended the launch of the PRIME project.

On 15 and 16 January (Prague, Czech Republic), Jean attended the launch of the ADAIR project.

On 20 January (Brussels, Belgium), Angela attended a DataSavesLives meeting at the European Patients’ Forum offices.

On 21 January (Brussels, Belgium), Jean met with the EFPIA task force on Alzheimer’s disease.

On 21 January (Brussels, Belgium), Jean met with Alzheimer Belgique.

On 27 January (Paris, France), Jean met with France Alzheimer.

On 27 January (Barcelona, Spain), Angela attended the launch of the RECOGNISED project.

On 28 January (Madrid, Spain), Jean and Chris attended the Scientific Coordination Board meeting of the Neuronet project.
JANUARY 2020

EU PROJECTS

6 January: EPAD project publishes paper on prescreening of Alzheimer’s disease risk factors

On 6 January, an international team of researchers from the European Prevention of Alzheimer’s Dementia (EPAD) project published a scientific article in the journal Alzheimer’s Research & Therapy. In the published paper, scientists investigated whether common Alzheimer’s disease (AD)-related factors predict trial-ready cohort participation and amyloid status across different prescreen settings. The analysis included participants from four cohorts linked to the EPAD Registry (i.e. 16,877 participants with an average age of 64 years). The open access publication is available here: https://doi.org/10.1186/s13195-019-0576-y

More information about the project and the availability of the data can be found at: ep-ad.org/

13-15 January: Investigating connections between metabolic disorders, compulsivity and cognitive impairment: PRIME project holds kick-off meeting in Frankfurt

From 13-15 January, the kick-off meeting of the Prevention and Remediation of Insulin Multimorbidity in Europe (PRIME) project took place in Frankfurt, Germany. PRIME is a 5-year long project which aims to explore the mechanisms that link obesity and diabetes to brain disorders such as obsessive-compulsive disorder and Alzheimer’s disease.

The PRIME project was developed in response to a Horizon 2020 call on “understanding causative mechanisms in co- and multimorbidities combining mental and non-mental disorders” and is led by Professor Barbara Franke, Chair of Molecular Psychiatry at Radboud University in Nijmegen. PRIME brings together a multidisciplinary team that includes academic institutions in Italy, Spain and Germany as well as SMEs, NGOs and patient organisations.

Insulin, a hormone produced by the pancreas, is responsible for regulating the metabolism of carbohydrates (including sugars), fats and proteins. Insulin dysregulation is a key feature of metabolic disorders such as type 1 and type 2 diabetes, and has also been implicated in obesity. More recently, studies have shown an association between insulin dysregulation and dementia, as well as mental illnesses characterised by compulsive behaviours. The PRIME project was founded on the hypothesis that insulin dysregulation underlies the multimorbidity associated with major mental and somatic diseases.

The PRIME project has three key goals: 1) to extend our understanding of insulin multimorbidity across the lifespan, 2) to understand the causal mechanisms linking somatic and mental insulin-related illnesses, and 3) to develop tools for early diagnosis, improved clinical care and prevention of insulin-related lifespan multimorbidity. To achieve these goals, PRIME will use existing clinical registry, cohort and population datasets to explore the links between insulin dysfunction and compulsivity disorders or dementia. Potential mechanisms will be validated and refined using animal and cell models of disease, providing proof-of-concept for drug, dietary and lifestyle intervention approaches. Insulin-related mechanisms will be further tested and refined using clinical genetic and genomic datasets. In addition to increased mechanistic understanding, the PRIME project aims to outline new directions for research and clinical care, including medication and lifestyle interventions.

The PRIME kick-off meeting brought together representatives of the 17 partnering organisations in PRIME. Three patient organisations were represented, including Alzheimer Europe, as well as members of the external Scientific and Ethical Advisory Board. Over the course of the kick-off meeting, all 8 work packages were presented and discussed in detail. The meeting finished with an open discussion on how best to disseminate the activities and learnings of the PRIME project to academic, industry, public and patient stakeholders.

Project Officer Angela Bradshaw represented Alzheimer Europe at this meeting.
14 January: VirtualBrainCloud project launches its website

The VirtualBrainCloud project aims to develop and validate a decision support system that provides access to high quality multi-disciplinary data for clinical practice. The result will be a cloud-based brain simulation platform to support personalised diagnostics and treatments for neurodegenerative diseases. The project is pleased to announce it has launched its new website:

https://virtualbraincloud-2020.eu

14 January: AMYPAD passes the mark of 1000 research participants for its clinical studies

The Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) project recently hit a major milestone with the recruitment of the 1000th research participant. This collaborative research initiative to improve the understanding, diagnosis and management of Alzheimer’s disease (AD) through the utilisation of β-amyloid PET imaging has two main clinical studies.

The AMYPAD Prognostic and Natural History Study (PNHS) wants to follow up and understand the natural history of AD in order to define the optimal window of opportunity for secondary prevention of AD through β-amyloid PET imaging. As of 14 January, 400 participants have consented to participate in the study. Of those, 316 have been scanned so far. To date, there are eight sites actively recruiting participants into the PNHS in Amsterdam, Edinburgh, Toulouse, Barcelona, Geneva, Tayside, Montpellier and Paris. The AMYPAD PNHS aims at recruiting 2,000 individuals suspected of possible Alzheimer’s disease with a particular focus on those with emerging amyloid pathology.

The second component is the AMYPAD Diagnostic and Patient Management Study (DPMS), which aims to investigate the clinical utility of amyloid-PET in a controlled but realistic clinical setting of patients with subjective cognitive decline, mild cognitive impairment and dementia possibly due to AD. Over 600 of the expected 900 patients have already been recruited at eight sites across Europe. The DPMS is fully activated in Geneva, Amsterdam, Toulouse, Barcelona, London, Stockholm, Cologne and Lausanne, with a total of 653 patients and almost 450 amyloid PET scans performed.

15 January: EPAD has recruited its 2000th participant

On 15 January, the members of the European Prevention of Alzheimer’s Dementia (EPAD) research initiative announced the recruitment of the 2,000th research participant in its Longitudinal Cohort Study (LCS).

EPAD is a Europe-wide collaboration aiming to improve the understanding of the early stages of Alzheimer’s disease. EPAD is set up to recruit from existing cohort studies as well as clinics across Europe. EPAD has established the first pan-European register including research participants aged 50 or over across the dementia risk spectrum. From this register, individuals who do not have dementia are invited to join the EPAD LCS, involving standardised tests and follow-up over several years. Currently, EPAD has 29 study sites up and running across 9 European countries (i.e. Belgium, France, Greece, Italy, Netherlands, Spain, Switzerland, Sweden, UK).

16 January: ADAIR project holds kick-off meeting in Prague

The ADAIR project (2020-2022) held its kick-off meeting in Prague, Czech Republic, on 16 January 2020. A growing body of evidence from epidemiological and animal studies shows that exposure to air pollutants can impair the brain. The ADAIR project therefore aims to provide crucial mechanistic insight about the effects of air pollutants on the brain in humans and discover biomarkers for air pollution and Alzheimer’s disease (AD) risk-prediction. The ultimate goal is to develop strategies for early identification of people at risk of AD, and to discover novel targets for preventive strategies in AD.

ADAIR is a multi-national collaboration between neuroscientists, environmental scientists, clinicians,
epidemiologists, informaticians, and non-profit organisations. Results from the project will be actively and regularly communicated to the scientific community, the public, the media, patient organisations and key governing bodies in Europe via scientific and non-scientific publications through traditional and digital media outlets, and via discussions with stakeholder groups.

Alzheimer Europe is an external collaborator in this project and Executive Director Jean Georges attended the kick-off meeting. The ADAIR project is funded by the JPND, for a duration of 36 months. It will conclude in December 2022.

20 January: AETIONOMY project finalises sustainability agreement for knowledge base, data and sample sharing

AETIONOMY (Organising Mechanistic Knowledge about Neurodegenerative Diseases for the Improvement of Drug Development and Therapy) was an Innovative Medicines Initiative-funded consortium project that ran between January 2014 and December 2018. Aiming to develop a mechanism-based taxonomy for Alzheimer’s and Parkinson’s disease (PD), AETIONOMY systematically captured and represented existing knowledge on neurodegenerative disease in a computable format, which could then be analysed using algorithms. In addition, AETIONOMY applied a computational approach to existing and new clinical datasets in order to more accurately model disease progression, mapping disease events to specific biological mechanisms. Finally, AETIONOMY validated its approach for mechanism-based patient stratification by performing a clinical study that recruited over 400 people living with PD, and by using existing samples and data from ongoing Alzheimer’s disease (AD) cohort studies.

At the end of 2019, partners of the AETIONOMY project (including Alzheimer Europe) agreed the terms of a Sustainability Agreement, which covers the ongoing maintenance of the AETIONOMY knowledge base (KB) and lays out provisions for managing storage of and access to clinical samples and data generated by the project. This agreement will ensure that the AD and PD research communities can continue to benefit from the valuable assets developed by the AETIONOMY project.

Under the terms of the Sustainability Agreement, ELIXIR (the European Life-Science Infrastructure for Biological Information) will maintain and host the AETIONOMY KB. Access to all AETIONOMY data and samples will be governed by a Sustainability Committee, which includes (amongst others) the Academic Coordinator of AETIONOMY, Martin Hofmann-Apitius, and Dianne Gove, Director for Projects at Alzheimer Europe. Data and sample access requests should be addressed to Jean-Christophe Corvol of the Institut du Cerveau et de la Moelle Epinière, Principal Investigator of the AETIONOMY clinical study.

22 January: AD Detect and Prevent introduces its video blogs

The AD Detect and Prevent project has launched a web-page with video blogs in which the various partners discuss their work in the context of the project. As well as regular project partner updates, videos about Alzheimer’s disease and dementia, and video presentations from conferences will be made available here.

In keeping up with recent changes in the conceptualisation of and terminology related to Alzheimer’s disease (AD), AD Detect and Prevent is pursuing the ambitious aim of developing a digital tool to improve the early detection of AD prior to the possible onset of AD dementia. It is combining this with programmes for reducing lifestyle risk factors.

https://www.addp.eu/blog/

27 January: DISTINCT project launches its website

DISTINCT stands for “dementia: intersectorial strategy for training and innovation network for current technology”. The main aim of DISTINCT is to develop a premier quality multi-disciplinary, multi-professional and intersectorial education and training research framework for Europe.

The project is pleased to announce it has launched its website: www.dementiadistinct.com

DISTINCT also has a Twitter account @DTdementia which you can follow to keep up to date with the project’s activities.

27 January: “The eye as a window to the brain” – RECOGNISED holds its kick-off meeting in Barcelona

On 27 January, the RECOGNISED project (Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia) held its kick-off meeting in Barcelona, Spain. RECOGNISED is a 4-year consortium project funded by
the European Union though its Horizon 2020 Research and Innovation framework programme. Coordinated by Professor Rafael Simo from the Vall d’Hebron Research Institute (VHIR) in Barcelona, RECOGNISED brings together 21 project partners from academia, SMEs and patient organisations, including Alzheimer Europe and the International Diabetes Federation – Europe (IDFE).

In recent years, several studies have shown that type 2 diabetes (T2DM) is associated with cognitive impairment and dementia. For example, people with T2DM have a 2-fold higher risk of developing Alzheimer’s disease (AD) when compared to their nondiabetic peers. Recent studies also suggest that T2DM can act as an accelerator of dementia in people with mild cognitive impairment (MCI). Alongside, growing evidence has shown that neurodegeneration of the retina is an early event in the development of diabetic retinopathy, a clinical complication of diabetes that leads to vision loss. Interestingly, researchers have also shown that people with MCI or dementia have detectably different retinas, with fewer retinal blood vessels than their unaffected peers. The RECOGNISED project has been designed to build on these findings, aiming to evaluate whether non-invasive retinal tests could be used to identify T2DM patients who are at a higher risk of developing MCI and dementia.

To achieve this goal, the RECOGNISED consortium has set out two key project objectives: firstly, to investigate the common mechanisms that cause diabetic retinopathy and cognitive impairment in T2DM; and secondly, to use the retina as a tool to identify individuals with T2DM at a higher risk of developing cognitive decline or dementia. Using mouse models of T2DM and AD, RECOGNISED partners will dissect the biological mechanisms that drive retinal dysfunction in these comorbid conditions, using advanced molecular techniques to study the diverse range of cell types that make up the retina and its neurovasculature. Using this knowledge, RECOGNISED will undertake detailed clinical studies to assess retinal structure and function alongside neuropsychological and brain imaging tests, aiming to stratify the risk and severity of cognitive decline in the T2DM population. RECOGNISED will also use previously collected data and samples from registries, cohorts and biobanks to extend these observations to the wider population, aiming to guide new clinical recommendations and open up new therapeutic strategies.

Angela Bradshaw represented Alzheimer Europe at the RECOGNISED project kick-off meeting.

Link: https://cordis.europa.eu/project/id/847749

28 January: Neuronet convenes third Scientific Coordination Board meeting in Madrid

On 28 January (Madrid, Spain), the Neuronet project convened its 3rd Scientific Coordination Board meeting.

The Board is formed of 16 leaders from the Innovative Medicines Initiative projects within the area of neurodegeneration research. It is responsible for Neuronet’s strategic decision-making.

The day started with an outline of achievements throughout 2019. The project Coordinator Carlos Diaz (SYNAPSE Research Management Partners) provided an overview of Neuronet’s Governance bodies (SCB as well as four Working Groups). He then showed the attendees a prototype asset map which he explained aims to provide a high-level overview of the main assets created by the projects so far.

After that, the attendees were updated on the progress regarding the development of Neuronet’s Knowledge Base, which aims to serve as an accessible overview of information on the projects and their activities. Neuronet is currently also finalising the setup of an online Forum that aims to promote dialogue and participation across projects.

The attendees then discussed the main achievements in Neuronet’s communication efforts. This included the setup of a community of communication representatives from all projects, the Neuronet project website, quarterly newsletter, an annual social media campaign as well as Neuronet’s participation at the Alzheimer Europe Conference and Lunch Debate.

The afternoon focused on gaps as well as opportunities within Neuronet. It revolved around a discussion on key needs at the portfolio level, as well as a lively discussion on the possibilities for future research. These topics will be elaborated upon further in the coming weeks, based on the discussions at the meeting.

Concluding, the Project Leader Lennert Steukers (Janssen) recapitulated the main conclusions, confirmed the next steps and wrapped up the meeting.

www.imi-neuronet.org
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 are:

- **AD Detect and Prevent** - grant agreement 820636
- **AETIONOMY** - grant agreement 115568
- **AMYPAD** - grant agreement 115568
- **EPAD** - grant agreement 115736
- **Neuronet** - grant agreement 821513
- **PRIME** - grant agreement 847879
- **RECOGNISED** - grant agreement 847749
- **VirtualBrainCloud** - grant agreement 826421

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 91, representing 26 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 (EAA):

- **Austria**: Monika Vana (Greens/EFA)
- **Belgium**: Petra de Sutter (Greens/EFA); Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe)
- **Bulgaria**: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsetselina Penkova (S&D); Sergei Stanichev (S&D)
- **Finland**: Heidi Hautala (Greens/EFA); Mapietra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP)
- **France**: François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjou (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeuex (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP)
- **Germany**: Alexandra Geese (Greens/EFA); Erik Markwardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA)
- **Greece**: Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraki (EPP); Elissavet Vozemberg (ECOGNISED)
- **Ireland**: Matt Carthy (GUE/NGL); Ciaraan Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ’Ming’ Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O’Sullivan (Greens/EFA)
- **Italy**: Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D)
- **Lithuania**: Vilija Blinkevičiute (S&D)
- **Luxembourg**: Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); Isabel Wiselr-Lima (EPP)
- **Malta**: Roberta Metsola (EPP); Alfred Sant (S&D)
- **Netherlands**: Jeroen Lenaers (EPP); Annie Schreijer (S&D); Pierrefrancesco Majorino (S&D)
- **Poland**: Elżbieta Łukacijewska (EPP)
- **Portugal**: Sara Cerdas (S&D); Jorge Guma S (GUE/NGL); Maria Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D); Romana Tomc (EPP); Romania: Cristian Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP)
- **Slovakia**: Ivan Stefanec (EPP)
- **Spain**: Isakun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens-EFA)
- **Sweden**: Ytje Guteland (S&D); Peter Lundgren (ECR)

EUROPEAN ALZHEIMER’S ALLIANCE

27 January: European Alzheimer’s Alliance welcomes Vice-chairs

Alzheimer Europe is delighted to announce that MEPs Marisa Matias (GUE/NGL, Portugal) and Hilde Vautmans (Renew Europe, Belgium) have agreed to serve as Vice-chairs of the European Alzheimer’s Alliance (EAA).

These members join Chairperson Sirpa Pietikäinen MEP (EPP, Finland) and Vice-chair Christophe Hansen MEP (EPP, Luxembourg) in undertaking these roles within the EAA. We look forward to working with them to help ensure that dementia remains a European priority.

31 January: Alzheimer Europe pays tribute to departing UK EAA members

Alzheimer Europe has paid tribute to the work of its UK members of the European Alzheimer’s Alliance (EAA), as they
Alzheimer Europe has written to each of the UK EAA members thanking them for their contribution and helping to make dementia a European priority in the preceding years. The letter also wished them well in their future endeavours, whilst encouraging them to remain supportive of our member organisations in the UK, Alzheimer’s Society and Alzheimer Scotland.

The departing UK members of the EAA are:
- Martina Anderson (GUE-NGL)
- Theresa Griffin (S&D)
- Jude Kirton-Darling (S&D)
- Claude Moraes (S&D)
- Rory Palmer (S&D)
- Alyn Smith (EFA-Greens)
- Julie Ward (S&D).

**EU DEVELOPMENTS**

7 January: JPND launches transnational call for novel imaging and brain stimulation methods and technologies related to neurodegenerative diseases

The EU Joint Programme – Neurodegenerative Disease Research (JPND) has launched a transnational call, inviting proposals for ambitious, innovative, multinational and multidisciplinary collaborative research projects aimed at the development of novel and the advanced use of existing cutting-edge imaging and brain stimulation technologies related to neurodegenerative diseases.

The total made available for this call is about EUR 18 million. Pre-proposals must be submitted by 6 March 2020.

https://www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/jpnd-open-call-2020/open-calls/

16 January: Expert group issues statement on 10 years of work on de-institutionalisation

As part of its conference, the European Expert Group (EEG) on the Transition from Institutional to Community-based Care has issued a statement marking 10 years of coordinated EU action on deinstitutionalisation, taking stock of past achievements and setting out a common vision for the future.

The EEG advocates for replacing institutions with family and community-based support, promoting person-centred, quality and empowering models of services, with formal and informal care that fully complies with the human rights of children and adults.

The statement highlights that awareness of the issue has been raised in different European contexts, with examples such as the Špidla Report, the EEG Guidelines and Toolkit, and changes to the ESIF Regulations highlighted as particular areas of progress.

However, the statement also notes that EU policies and funding have not always been aligned and that institutionalisation remains a problem in Europe. It highlights that over 1 million people in the EU still live in institutions, segregating them from society and denying them control over their lives.

The statement also advocates for further funding to help Member States change their rules, procedures and practices, with a focus on changing the social protection and welfare systems, putting individuals' needs at the centre.

The statement concludes by calling on the EU to support the transition from institutionalisation to family and community-based support in all of its relevant legislative, policy and funding instruments. You can read the full statement at:

www.deinstitutionalisation.com/2020/01/16/10-years-towards-inclusion/

20 January: EU Commissioner commits to new European disability equality strategy

The European Commissioner for Equality, Helena Dalli, has announced that there will be another European Disability Equality Strategy.

Speaking at “Towards Inclusion 2020”, an event marking 10 years of the European Expert Group on Transition from Institutional to Community-based care, Commissioner Dalli indicated that the Commission had committed to a new European Disability Equality Strategy for 2021. Ms Dalli said:
“I have already set up a Task Force for Equality, to make sure equal treatment and inclusion will be paramount in all Commission policies.

Independent living is a pre-condition, for equal treatment, and a cornerstone of our equality agenda.

We will make sure that independent living features in all our present and future work:

- In the strengthened disability strategy, that we will build following the evaluation of the present strategy.
- In our Action Plan to implement the European Pillar of Social Rights.
- In our country reports and policy recommendations in the European Semester, which we will link more closely with the Sustainable Development Goals.”

The full speech can be read at: http://bit.ly/37FLHID

20 January: European Social Catalyst Fund formally launched

The European Social Catalyst Fund (ESCF), a new initiative to support the development of detailed implementation plans to scale proven social innovations, has been launched. The objective of the ESCF is to bring together public and private resources to improve social services to enable people who need support to live as valued and participating members of their communities.

It is envisaged that the fund will act as a catalyst to unlock public and private resources (e.g. philanthropy and social investment) to achieve improved outcomes for disadvantaged and vulnerable people, so they may live as participating and valued members of society. Phase 1 of ESCF will be funded by a combination of the European Commission and philanthropy.

The aim of Phase 1 will be to support a range of robust implementation plans for at least five initiatives that, if implemented, will contribute to meeting or reducing key social challenges at national levels and have the potential for shared learning, application and spread across borders.

More information can be found at: www.euscf.eu/about

MEMBERS’ NEWS

1 January: Alzheimer’s Association of Israel (EMDA) announces new Chairman

EMDA – the Alzheimer’s Association of Israel – has announced a new Chairman of the Board of Directors, Boaz Weiss. Mr Weiss was preceded by Yona Eliad, who was the chair of the association for fourteen years. EMDA is grateful to Mr Eliad for his leadership and hugely important contribution to the growth of the association. EMDA is a non-profit organisation founded in 1988 by family members of people with Alzheimer’s disease and other forms of dementia.

7 January: Alzheimer’s Society works with NHS England and others to make dementia care in England as personalised as possible

The Dementia Choices Action Network (DCAN) is a collaboration to make dementia care in England as personalised as possible. The initiative was created to determine how Universal Personalised Care can benefit people
affected by dementia from diagnosis to end of life and is a joint collaboration between Alzheimer’s Society, the National Health Service (NHS) England, Improvement and the Coalition for Collaborative Care.

DCAN offers an approach rooted in personalisation and integration, delivered by six components of a Comprehensive Model of Personalised Care:

- Shared Decision Making
- Personalised Care and Support Planning
- Social Prescribing and community development
- Enabling Choice
- Supported Self-Management
- Personal Health Budgets.

The initiative plans to learn from a wide range of stakeholders via an open network of organisations and individuals interested in making personalised care the default experience of everyone diagnosed with dementia.

A key task for the DCAN network is to increase awareness and knowledge amongst people affected by dementia, and to give them opportunities to shape, direct and co-produce changes that will have most impact following a diagnosis of dementia.

On 7 January 2020, over 80 stakeholders including clinicians, commissioners, people with dementia, carers, researchers and charities, attended the first DCAN Assembly and started exploring what good personalised care for people with dementia and their carers looks like and how to make this a reality.

The day was interactive with opportunities for discussion and ideas. All six areas of the Comprehensive Model for Personalised Care were examined. This Assembly allowed everyone to hear about the good practice and innovation work already taking place and practical examples of how personalised care has worked for people with dementia, including stories from people with lived experiences.

All learning from the DCAN is being used to inform a National Dementia Plan for Universal Personalised Care 2021-25. Follow #DCAN #DementiaCan on Twitter to find out more and keep up to date.

20 January: The Alzheimer Society of Ireland demands that the new Irish Government finally “Deliver on Dementia”

A general election will be held in the Republic of Ireland on Saturday, 8 February 2020. The Alzheimer Society of Ireland (ASI)’s slogan for this election campaign is: “Deliver on Dementia – Time to End the Crisis”.

The ASI is demanding that dementia must be included in the new “Programme for Government” and is calling on the assistance of the Irish public to make this happen.

The Irish public is being encouraged to ask local governmental candidates in Election 2020 to make a pledge to “Deliver on Dementia” in the next Programme for Government to ensure:

- Full implementation of the Irish National Dementia Strategy
- Home care for everybody with dementia
- Dementia is included in the Chronic Disease Management Programme.

The Alzheimer Society of Ireland is the main voice for those people with dementia and their families, who are currently under a massive emotional and financial strain, as there are just too many black holes across the country where people are forced to put up with inadequate services and supports. For more information on The ASI’s General Election campaign, go to: www.alzheimer.ie

21 January: Association of Alzheimer’s disease of Heraklion develops an innovative model of integrated care for healthy older people

In Greece, scientists from the Association of Alzheimer’s disease of Heraklion “ALLILEGI”, in Crete, backed by generous funding from the TIMA Charitable Foundation, have developed an innovative model of integrated care for healthy older people.

The programme promoted active and healthy ageing. 100 individuals were involved, aged between 64-90 years old, both men and women, with an average education of 12 years, and with very mild cognitive impairment due to factors related to ageing. Participants were submitted to a neuropsychological assessment before and after the trial programme. They attended twice a week for three-hour sessions of cognitive training, relaxation techniques, psychological support, and music therapy. They also participated in cultural, social and leisure activities such as movies, speeches, excursions, museums, theatre, traditional feasts, coffee meetings, local festivals with the cooperation of the local community, and intergenerational activities with primary school children, as well as dinners with live music. Furthermore, they had the
opportunities to learn how to use PC programmes (Skype, Facebook, email, Internet Explorer), and how to speak a foreign language (Italian). They also created their own choir. The ultimate aim of the programme was the improvement of their mental health, mood and attitude towards life after retirement, in addition to assisted adjustment in changes due to ageing; assisted socialisation and the improvement of personal relationships.

The first results from the pilot study were impressive. The participants’ own evaluations are very touching and coincide with the objective neuropsychological data. The original aims of the programme are completely fulfilled. These healthy, older participants felt regenerated and active, with new attitudes towards ageing well. They have better relationships, they socialise more, and they feel mentally and physically healthier. Their common wish was that the programme would continue the following year because they felt that it was an exceptional benefit in their lives. Eventually, the aim is to develop this programme into an integrated model of elderly care with a biopsychosocial approach with proved effectiveness and benefits.

22 January: Alzheimer’s Society leads the combined effort to “Bring Dementia Out”

There are over 850,000 people in the UK living with dementia. Some of these people are lesbian, gay, bisexual and transgender (LGBT+), yet many aren’t getting the support they need.

Everyone’s experience of dementia is unique, but there are many additional challenges that LGBT+ people affected by dementia face, such as:

- LGBT+ people with dementia may experience past memories more vividly than recent ones. They might believe they are living in a time in which being LGBT+ is still illegal and fear repercussions.
- Trans people with dementia may also experience stronger memories of the time before they transitioned. This can make day-to-day activities, such as dressing and using the bathroom, confusing and distressing.
- Some LGBT+ people may experience stigma, and fear discrimination when sharing information with health and social care providers.

Alzheimer’s Society worked together with people affected by dementia, national and local organisations and LGBT+ communities in the development of the Bring Dementia Out innovation in 2018 to 2019. The aim of Bring Dementia Out was to help LGBT+ people affected by dementia feel more comfortable in coming forward to access the information and support they need. A number of resources were developed and tested over a two-month period in Brighton and Hove and in Greater Manchester. This included a video sharing people’s experiences, a booklet and webpage with steps on how best to support people and signposting to useful organisations and information.

Bring Dementia Out saw great results thanks to the dedicated working group, which included volunteers with lived experience of dementia, Alzheimer’s Society colleagues and the partner organisations. Together, they reached LGBT+ people affected by dementia and helped to increase awareness and understanding of the challenges faced within the communities and amongst health and social care professionals.

One of the biggest achievements of this initiative is that the key organisations involved are now taking this innovation forward to lead on scaling it at a wider level. This includes LGBT Foundation, the National Dementia Action Alliance, The Guinness Partnership, the National LGB&T Partnership and Switchboard.

If you want to find out more about Bring Dementia Out, please contact the Bring Dementia Out Programme Coordinator, Claire Days, on claire.days@lgbt.foundation

24 January: Alzheimer Larissa recently organised a day trip to the Annual Open Air Force exhibition in the City of Larissa

Continuing their aim to promote awareness of and reduce stigma against dementia through common activities, Alzheimer Larissa organised a field trip on 7 November 2019, bringing together locals, mobile residents of the Municipal Elderly Care Home and community dwelling older people living with dementia.

The group all travelled together to the Annual Open Air Force exhibition. They strolled around the exhibition panels, which were dedicated to showing the history of the Air Force, their daily training, as well as their involvement in the city’s social
life. Residents of the Municipal Elderly Care Home discovered that “their home” was on display, depicting a previous visit of Air Force officers during festivities. It was a pleasant coincidence, which gave the residents the confidence to interact with the staff and enquire further about the exhibits. The group chatted to both the pilots and the ground personnel, discussing the velocity of the aircrafts, how long they could fly for, whether fighter jets have one seat or may accommodate multiple persons, and whether they can use them to fly to the Greek islands, to visit their relatives. They also met one of the world’s few fighter model-makers, who talked enthusiastically about his passion for flight, and about how he builds replicas from scratch.

It was a hot sunny day, and many waited under the gazebos for the air show to start. Some were attracted by the planes on sight and were brave enough to climb the stairs and enjoy a close look at the pilot seat together with the numerous children that visited the show. Others wandered around the rescue or firefighting aircrafts, or waited under the ground control stations of unmanned aircraft vehicles. Although some had arranged to leave early for lunch, the sound of plane engines kept them motivated. The visit was a huge success. Everyone really enjoyed the air show. The staff was also kind enough to provide the group with a bus for their belated departure, as well as arranging for commemorative photos to be taken.

24 January: Bosnian Alzheimer association presents new website and updates its YouTube channel

The Bosnian Alzheimer association (Udruženje AiR) now has new website and has also added two new videos to its YouTube channel.

See new website, here: https://youtu.be/urTx9pmOlKM
See the videos, here: https://www.youtube.com/channel/UCQFX4tfrkul360FGzJ_DgZa

SCIENCE WATCH

23 December 2019: Study in mice shows potential sex differences in responses to tau pathology

On 23 December, researchers from the USA published an article on sex-specific responses to tau pathology that are mediated by microglial miRNAs in the journal Nature Neuroscience.

The new study reports that male and female microglia expressed different sets of microRNAs at baseline and in response to tau pathology (which has been previously linked to Alzheimer’s disease). In addition, the researchers found that removal of microRNAs, exacerbated tau aggregates in male but not in female tauopathy mice.

https://www.nature.com/articles/s41593-019-0560-7

POLICY WATCH

11 December 2019: OECD publishes report into the use of neurotechnology

The Organisation for Economic Cooperation and Development (OECD) has published a “Recommendation on Responsible Innovation in Neurotechnology”, which, for the first time, sets out international standards in this domain. It aims to guide governments and innovators to anticipate and address the ethical, legal and social challenges raised by novel neurotechnologies while promoting innovation in the field.

The report notes that such governance issues surrounding neurotechnology have implication throughout the duration of the innovation process, from fundamental brain research, cognitive neuroscience, and other brain-inspired sciences through to questions of commercialisation and marketing. The document specifically addresses issues such as (brain) data privacy, the prospects of human enhancement, the regulation and marketing of direct-to-consumer devices, the vulnerability of cognitive patterns for commercial or political manipulation, and further inequalities in use and access.

The Recommendation embodies nine principles, which focus on:

- Promoting responsible innovation
- Prioritising safety assessment
- Promoting inclusivity
- Fostering scientific collaboration
- Enabling societal deliberation
- Enabling capacity of oversight and advisory bodies
- Safeguarding personal brain data and other information
- Promoting cultures of stewardship and trust across the public and private sector
- Anticipating and monitoring potential unintended use and/or misuse.

The full text of the recommendations can be found at: www.legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0457
To confirm the results of this study, more large-scale investigations involving additional disease stages and longer follow-up durations are now required.

https://stm.sciencemag.org/content/12/524/eaau5732

6 January: Biohaven Pharmaceutical reports successful completion of an interim futility analysis for its Phase II/III T2 Protect AD study

Biohaven Pharmaceutical, a clinical-stage biopharmaceutical company with a portfolio of innovative candidates targeting neurological diseases, has recently received notification from the independent Data Safety Monitoring Board (DSMB) to continue its T2 Protect AD clinical trial of troriluzole for the treatment of mild to moderate Alzheimer’s disease (AD). This experimental drug modulates glutamate, the dysfunction of which is known to be implicated in AD.

The Phase II/III study is a randomised, double-blind and placebo-controlled trial evaluating the efficacy and safety of troriluzole in people with mild to moderate AD. In this trial, which recently completed enrolment, US research participants received oral capsules (280 mg of troriluzole or placebo) once daily for 48 weeks.

The independent DSMB reported that the trial successfully completed its pre-planned interim futility analysis. The experimental drug has passed the futility review based on pre-specified criteria for the interim analysis, which evaluated cognitive function and hippocampal volume.

"We are very pleased the interim futility analysis supports continuation of the T2 Protect AD Study, and we are hopeful that the trial will demonstrate at its completion that troriluzole ameliorates the symptoms of Alzheimer’s disease”, said Dr Howard Feldman, Principal Investigator of the T2 Protect AD study.


7 January: New study investigates the prevalence of Mild Cognitive Impairment in the elderly population in Greece

On 7 January, an international team of scientists from Greece, Cyprus and New York published an article on the prevalence of Mild Cognitive Impairment (MCI) in the journal Alzheimer Disease & Associated Disorders.

MCI refers to a state in which people experience cognitive impairment(s) but can still carry out activities of daily living. To date, there exist only a small number of large population-based studies that investigate how common (prevalent) this condition is.

In order to estimate the prevalence rates of MCI in people aged 65 and over, the researchers randomly selected 1960 individuals who participated in the Hellenic Epidemiological Longitudinal Investigation of Aging and Diet (HELiad) study. The participants of this study all underwent a comprehensive

1 January: PET study shows superiority of Tau imaging in predicting brain atrophy in early Alzheimer’s disease

On 1 January, Dr Renaud La Joie and colleagues published a paper in Science Translational Medicine, showing that tau-PET imaging is a more accurate predictor than amyloid-PET imaging of subsequent brain atrophy in early Alzheimer’s disease (AD).

Positron emission tomography (PET) uses radioactive dyes (also known as tracers) that stick to specific molecules in the body, revealing their presence on PET scans. For example, amyloid tracers such as [18F] Florbetapir can be used to detect the presence and extent of amyloid plaques in the brain, facilitating a more accurate diagnosis of AD. However, amyloid-PET studies have shown little association between amyloid burden and the clinical severity of dementia. It is not yet known whether Tau-PET can more accurately predict neurodegeneration in people with AD, as Tau-PET imaging is a relatively novel technique.

To answer this question, Dr La Joie and colleagues undertook a PET imaging study in a group of 32 people with early symptomatic AD, comparing the ability of amyloid-PET or Tau-PET to predict brain atrophy as measured by structural MRI (magnetic resonance imaging). Using the imaging data from PET and MRI scans, they generated 3D maps showing the topography of brain atrophy in relation to amyloid-PET or Tau-PET signals. Looking at baseline levels of Tau-PET, they found a strong association with subsequent brain atrophy, suggesting that aggregation of Tau in neurofibrillary tangles is a good predictor of future neurodegeneration. In comparison, amyloid-PET performed poorly, showing a low association of amyloid accumulation with brain atrophy.

The researchers also evaluated whether age at baseline was associated with the quantity of amyloid or Tau detected on PET scans. They observed that individuals who were diagnosed at an older age tended to have less Tau accumulation – and slower rates of brain atrophy. Conversely, earlier onset of AD was associated with a higher baseline Tau burden, and more rapid atrophy.

To confirm the results of this study, more large-scale investigations involving additional disease stages and longer follow-up durations are now required.

https://stm.sciencemag.org/content/12/524/eaau5732
neurological as well as neuropsychological assessment. The diagnosis of MCI was based on the Petersen criteria.

After standardising their sample for age and sex, the team found that 13.11% of the population had MCI.

Concluding, the scientists underlined that their results indicated that MCI prevalence in the elderly population in Greece is on par with previously reported rates. The researchers also highlighted that there is a great need for prospective studies that use a robust methodology in order to improve our understanding of the dementia continuum.

https://journals.lww.com/alzheimerjournal/Abstract/publishahead/Prevalence_of_Mild_Cognitive_Impairment_in_the.99316.aspx

8 January: Study in Nature points to a role for the adaptive immune system in Alzheimer’s disease

On 8 January, Dr David Gate and colleagues published a paper in Nature, showing for the first time that clonally-expanded T cells are present in cerebrospinal fluid and brain samples from people with Alzheimer’s disease (AD). Our immune systems protect our bodies using two different approaches. The first approach, termed “innate immunity”, involves immune cells such as macrophages, scavenger cells that indiscriminately destroy a broad range of pathogens, such as bacteria. The second type of immune response, termed “adaptive immunity”, involves cells called “leukocytes”, immune footsoldiers which only recognise specific pathogens. When T leukocytes, also known as “T cells”, encounter and recognise a specific pathogen (for example, a measles virus), they undergo clonal expansion, proliferating extensively to generate thousands or even millions of identical T cells that can track down and destroy the pathogen in question. Unlike the innate immune system, the adaptive immune system can create long-lasting immunological memories. Immunological memory is at the heart of most vaccination strategies, which rely on the fact that the adaptive immune system “remembers” what specific pathogens look like, and can mount a protective response to them before they do any damage.

Although many studies have now shown that the innate immune system goes off-track in AD, causing neuroinflammation, little is known about the adaptive immune response. Do T cells enter the brain and, if so, what do they do while they’re there? To answer this question, Dr Gate and colleagues first studied blood samples from groups of people with AD, mild cognitive impairment (MCI) or healthy controls. They observed that people with AD or MCI had a higher abundance of CD8+ TEMRA cells, which are also known as cytotoxic or “killer” T cells due to their ability to trigger the death cascade in target cells. In a separate cohort of individuals, the researchers assessed the relationship between cognition and the presence of different T cell subtypes. They identified a negative correlation between TEMRA cells and cognition in people with AD & MCI: in other words, the presence of these cells is associated with cognitive impairment. Interestingly, they noted that TEMRA cells from people with AD and MCI showed signs of antigenic stimulation, suggestive of prior activation in response to a pathogen.

Next, the researchers asked whether these CD8+ T cells were present in the brains and CSF of people with AD. Using a small number of post-mortem brain samples, they localised T cells to amyloid plaques and AD-affected areas of the hippocampus. Importantly, using state-of-the-art sequencing technology they showed that CSF from a small number of people with MCI or AD contained higher numbers of clonally-expanded CD8+ T cells compared to CSF from healthy individuals. As this was indicative of an adaptive immune response to a pathogen, the researchers then performed further studies to assess the antigen specificity of the CD8+ T cells in CSF from people with AD. Although there was some variation between individuals, there was a shared antigen motif for a protein that belongs to the Epstein-Barr virus (EBV), an extremely common virus that can cause infectious mononucleosis.

Together, these results are a first demonstration that there is an adaptive immune response in AD, associated with neurodegeneration and cognitive impairment – although researchers caution that there is no evidence of a causal link between EBV and AD, stating that several different antigens may be responsible for T cell activation in people with AD. To confirm the results of this study, more large-scale investigations involving additional disease stages and longer follow-up durations are now required.

https://www.nature.com/articles/d41586-019-03892-8

8 January: Research study suggests that a class of antibiotics may help treat frontotemporal dementia

On 8 January, US researchers from the University of California, San Francisco, and the University of Kentucky, Lexington, published a paper showing that a class of antibiotics called aminoglycosides may help treat frontotemporal dementia (FTD). Findings were published in the journal Human Molecular Genetics.

FTD is the most common type of early onset dementia that mainly affects the frontal and temporal lobes of the brain and causes behaviour and language changes. Several genetic mutations have been described that cause FTD including a mutation in the genes that regulate the production of a protein called progranulin.
In the published study, scientists used cell cultures to test whether several aminoglycoside antibiotics, added to the cells exhibiting these mutations, can restore progranulin expression. They found that G418 and gentamicin B1 rescued the expression of progranulin to approximately 50% and less than 10% respectively. The effect detected was dose and time-dependent.

Authors plan future research including studies in mouse models and the development of new compounds that could be more effective with lower toxicity.

8 January: Clinical study shows that an active lifestyle can slow cognitive decline in people with inherited forms of frontotemporal dementia

On 8 January, Kaitlin Casaletto and colleagues published a paper in the Alzheimer’s and Dementia journal, identifying a link between active lifestyles and reduced cognitive decline in people living with inherited forms of frontotemporal dementia (FTD).

Approximately 40% of people with FTD have a family history of disease, with 10% of individuals possessing autosomal dominant mutations in genes such as C9orf72 and MAPT. The autosomal dominant mode of inheritance means that a single mutated copy of these genes can cause a particular trait — in this case, the development of FTD. Previously, the DIAN Study of individuals with autosomal dominant forms of Alzheimer’s disease showed that higher levels of physical activity were associated with better cognitive and functional outcomes. Kaitlin Casaletto and colleagues therefore set out to evaluate the relationship between physical activity and brain health outcomes in a cohort of individuals with inherited, autosomal dominant FTD.

The researchers recruited 105 FTD mutation carriers and 69 non-carriers to the study, analysing their physical and cognitive activities over a period of 3 years based on self-reported measures called the PASE (Physical Activity Scale for the Elderly) and CAS (Cognitive Activity Scale). MRI scans were also performed. Greater physical and cognitive activities were associated with a substantial reduction in clinical decline per year in FTD mutation carriers. This was in spite of continued frontotemporal atrophy: even among participants who showed signs of brain atrophy, those that were physically and cognitively active showed sustained improvement on cognitive tests compared to their counterparts who were the least physically and cognitively active.

Together, these results suggest that an active lifestyle — both physically and cognitively — may confer clinical resilience to cognitive decline in autosomal dominant FTD. However, the researchers cautioned that further studies that experimentally manipulate physical and/or cognitive activities are required in order to validate this hypothesis.

8 January: Research suggests that the assessment of walking speed improves predictive ability to detect dementia

On 8 January, a team of Swedish and Italian scientists published an article on cognitive and physical markers of prodromal dementia in the journal Alzheimer’s & Dementia.

The study draws on the Swedish SNAC-K study, including data on 2546 people who underwent a series of tests.

The researchers grouped these people into one of four profiles:

- healthy
- cognitive impairment, no dementia
- slow walking speed
- cognitive impairment, slow walking speed.

In order to find out whether the assessment of walking speed helps to find out whether a person is at a higher risk of developing dementia, the researchers then looked at the results from a follow-up assessment.

Out of the 2546 initial participants, 193 had developed dementia after 4 to 12 years, with an additional 117 cases of people who had developed dementia and died.

The statistical analyses of the team suggested that especially those people who experienced cognitive impairments as well as slow walking speed at the initial assessment, were at the highest likelihood to develop dementia in future.

The team therefore concluded that adding a measurement of physical function (in this case walking speed) to standard cognitive test batteries is advisable to help clinicians identify people who are at a higher risk of developing dementia.

13 January: Biogen acquires Pfizer’s experimental drug PF-05251749 for neurological diseases

On 13 January, the global biotechnology company Biogen announced an agreement to acquire the investigational therapy PF-05251749 from Pfizer for treating neurological...
A timely and accurate diagnosis of Alzheimer’s disease (AD) is important for proper treatment. Scientists can pinpoint the disease during life, by testing for the arrival of AD proteins in the cerebrospinal fluid (CSF), so current guidelines recommend the use of these protein markers in practice. The guidelines are, however, difficult to translate into the daily work of doctors and researchers.

Determining the protein markers costs money, and a lumbar puncture - which can be painful and carries its own risks - is required to obtain the CSF. Moreover, the protein marker measurements do not always provide a clear diagnosis. So, doctors are faced with a daily dilemma: For whom is it “worth” doing a lumbar puncture and for whom is it better to omit the procedure?

Hanneke Rhoudius-Meester (pictured), a clinical geriatrician and researcher at the Alzheimer Center Amsterdam, together with colleagues from across Europe, set out to find a way to help doctors decide which patients would most benefit from a CSF test. Using data from the PredictND project (2014-2018) in which Hanneke Rhoudius-Meester was a consortium member, and together with Combinostics, a company that develops software to assist doctors in the diagnosis of dementia, they developed a computer tool to help doctors to make this choice.

The researchers used simulated CSF protein marker values in the computer tool, based on data collected from 535 participants in clinical studies on dementia. By combining these with other diagnostic tests (brain scan and cognitive tests), the tool predicts which participants’ CSF markers would improve the reliability of diagnosis. The computer tool identified 140 out of 535 participants who would benefit from CSF marker tests, reaching a confident diagnosis for 71% of the included participants. Together, these results indicate that computerised decision support tools could be helpful in guiding doctors to decide whether or not a patient should have CSF testing.

Their results were published in the journal PLOS ONE on 15 January 2020. Read the paper, here: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0226784

### 15 January: Computer tool created to help doctors identify which patients would benefit from CSF tests during diagnostic process for AD

A timely and accurate diagnosis of Alzheimer’s disease (AD) is important for proper treatment. Scientists can pinpoint the disease during life, by testing for the arrival of AD proteins in the cerebrospinal fluid (CSF), so current guidelines recommend the use of these protein markers in practice. The guidelines are, however, difficult to translate into the daily work of doctors and researchers.

Determining the protein markers costs money, and a lumbar puncture - which can be painful and carries its own risks - is required to obtain the CSF. Moreover, the protein marker measurements do not always provide a clear diagnosis. So, doctors are faced with a daily dilemma: For whom is it “worth” doing a lumbar puncture and for whom is it better to omit the procedure?

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Their results were published in the journal PLOS ONE on 15 January 2020. Read the paper, here: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0226784

### 21 January: Study in AD rats reveals functional benefit of lithium microdosing at later stages of amyloid pathology

On 21 January, Dr Edward Wilson and colleagues published a paper in the Journal of Alzheimer’s Disease, showing that lithium microdosing can have functional benefits in Alzheimer’s disease (AD) rats with established amyloid pathology.

Lithium is often prescribed as a mood stabiliser for people with bipolar disorder, acting via multiple mechanisms that regulate neurotransmission. Interestingly, animal studies suggest that lithium may have additional neuroprotective benefits, decreasing amyloid deposition and improving cognition in mouse models of AD. However, clinical evidence supporting a therapeutic role for lithium in AD is more nuanced; while a 2017 Danish epidemiological study linked high lithium concentrations in drinking water with a reduced incidence of dementia, a 2018 US study suggested that this difference may be due to regional socioeconomic and healthcare disparities. A further issue to consider is the risk profile of Lithium: at sustained, high doses it can cause nausea, diarrhoea and muscle weakness, which can lead to discontinuation of treatment.

Against this nuanced backdrop, Dr Wilson and colleagues aimed to investigate the effect of lithium microdosing on AD pathology in preclinical models of disease. Could microdoses of lithium be equally effective in mitigating cognitive decline, without the undesirable side-effects of conventional, high-dose lithium? To answer this question, the researchers tested the effects of NPO3 on cognition, amyloid plaque pathology
and neuroinflammation in a rat model of AD. NPO3 is a new formulation of lithium that has much higher bioavailability than conventional lithium formulations, and has proved to be safe in a Phase I clinical trial for Huntington’s disease. First, Dr Wilson and colleagues administered NPO3 to transgenic AD rats and littermate controls for a period of 12 weeks, performing working memory tests to evaluate the effect of NPO3 on cognition. AD rats treated with NPO3 performed as well as their healthy counterparts, with diminished cholinergic bouton loss compared to AD rats that did not receive NPO3. In addition, NPO3 treatment reduced levels of soluble and aggregated amyloid beta in the brains and blood plasma of AD rats, also reducing markers of oxidative stress and neuroinflammation. Together, these results suggest that NPO3 effectively crosses the blood-brain barrier in rat models of AD, with therapeutic benefits in terms of cognition and markers of AD pathology. Link to article: https://content.iospress.com/articles/journal-of-alzheimers-disease/jad190862

22 January: Neurotrope reports results from its Phase II trial of Bryostatin-1 for moderate to severe AD

On 22 January, Neurotrope, a clinical-stage biopharmaceutical company focused on developing novel therapies to treat neurodegenerative diseases including Alzheimer’s disease (AD), announced new results from its Phase II study of Bryostatin-1 for moderate to severe AD. The Phase II study is a randomised, double-blind and placebo-controlled clinical trial evaluating the safety, tolerability and efficacy of Bryostatin-1 for the treatment of moderate to severe AD in US participants not receiving memantine treatment. Research participants received 7 doses of study drug over 12 weeks. Top-line results released last September showed that the Phase II study of Bryostatin-1 failed to meet its primary endpoint. The company conducted then a full review and provided this month its corporate update. Following completion of data analysis, the company said that the study showed improvement in cognitive function based on the change from baseline to week 13 in the Severe Impairment Battery (SIB) total score, which is the primary endpoint, in the bryostatin-1 treatment group of 32 research participants. In the placebo group of 33 research participants, there was also an increase from baseline in the mean SIB at week 13.

The company added that it has been awarded a USD 2.7 million grant from the National Institute of Health to support an additional Phase II clinical trial for people with advanced AD. Study link: https://prn.to/2vJDDU

23 January: Clinical study finds no association between herpesvirus and Alzheimer’s disease

On 23 January, Dr Mary Allnutt and colleagues published a paper in Neuron, showing no differences in herpesvirus detection in brain samples from people with Alzheimer’s disease (AD) and their unaffected peers.

Several studies have previously linked herpesviruses such as HHV-6A, HHV-6B and HSV-1 with the development of AD. HHV-6 (which causes the common childhood infection, roseola) and HSV-1 are known to infect cells of the central nervous system, and are linked to conditions such as multiple sclerosis, encephalitis and epilepsy. In animal models of AD, scientists have shown that amyloid plaque formation can be stimulated by the presence of HHV-6 or HSV-1. Using genetic sequencing techniques to analyse post mortem brain samples for the presence of herpesvirus, two recent publications have shown an increase in viral DNA in the brains from people with AD compared to unaffected controls. However, the genetic sequencing techniques and statistical analyses used in these papers have been criticised by some scientists in the AD field. To clarify and extend the results of these and other studies investigating the link between herpesvirus and AD, Dr Allnutt and colleagues set out to re-analyse the large genetic datasets used in the previous studies. Using RNA-sequencing data from the Mount Sinai Brain Bank (MSBB) and Religious Orders Study/Memory and Aging Project (ROSMAP) studies, they were able to screen post mortem brain samples from over 900 individuals, looking for HHV-6 sequences. To perform this large-scale bioinformatics analysis they used PathSeq, a new screening tool that was developed by the Broad Institute to detect the presence of over 100 different types of virus. Unlike previous studies, PathSeq did not detect any significant association between the presence of HHV-6 and AD. For example, of the 177 people in the MSBB cohort with definite or probable AD, only 4 showed any evidence of HHV-6 infection in brain samples – and only at very low levels. The research team then moved on to directly test post mortem brain samples for the presence of herpesvirus DNA, using a highly-sensitive analysis technique called digital droplet PCR (ddPCR). This technique can provide a measurement of viral load in samples, expressed as the number of virions per million cells analysed. Here, the researchers extended their analyses to include samples from MSBB and a further brain bank (the JHBRC), assessing a total of 708 post mortem brain samples, 510 of which came from people with AD. When they
evaluated the HHV-6 viral load across the two brain banks, they observed no significant differences between people with AD and healthy controls. In other words, people with AD do not have substantially higher levels of HHV-6 in their brains when compared to unaffected individuals.

Together, these results appear to contradict the results of previous studies showing an association between herpesvirus and AD. However, Dr Allnutt and colleagues cautioned that while their study found no link between HHV-6 and AD, it does not necessarily rule out an association. An acknowledged limitation of studies based on genetic sequencing analyses is that they are dependent on complex mathematical algorithms, applied using high-performance computers. Small modifications in these algorithms and the way they are applied can lead to substantial differences in the results. Consequently, the researchers are now looking at even larger cohorts and brain banks, to extend the study and validate its results.


28 January: Biogen receives approval from FDA to relaunch a Phase III clinical trial of Aducanumab

The biotechnology company Biogen has recently received approval from the US Food and Drug Administration (FDA) to re-dose the research participants formerly enrolled in its ENGAGE and EMERGE Phase III studies of Aducanumab in Alzheimer’s disease (AD).

Around 2,400 participants are eligible to participate in the new Phase III study expected to start in March 2020. This Phase IIIb trial is an open-label and multicentre study evaluating the safety and tolerability of Aducanumab in US participants with AD who had previously participated in the Aducanumab studies. In this new trial, all participants will receive monthly intravenous infusions of Aducanumab (10mg/kg) for a total duration of 100 weeks.

The EMERGE and ENGAGE Phase III studies were discontinued in March 2019 following a futility analysis of data, which reported that the trials were unlikely to meet their primary endpoint. As a result of this decision, the EVOLVE Phase II safety study and the PRIME Phase Ib long-term extension study of Aducanumab were also discontinued. However, in October, Biogen announced its plans to seek regulatory approval for Aducanumab, based on a new analysis of a larger dataset from its EMERGE and ENGAGE Phase III studies. The new analysis revealed that the Phase III EMERGE study had met its primary endpoint, showing a significant reduction in clinical decline following administration of Aducanumab to participants with mild cognitive impairment due to AD and mild AD dementia.

https://www.beingpatient.com/fda-approves-aducanumab-redosing-trial/

DEMENTIA IN SOCIETY

21 January: Monty Python star Terry Jones dies with a variant of frontotemporal dementia

Terry Jones, one of the original members of British surreal comedy group Monty Python, passed away on 21 January, four years after contracting a variant of frontotemporal dementia. The Welsh actor and writer played a variety of characters in the group’s Flying Circus television series, and directed several of their films, including Life of Brian (1979).

A statement from his family said:

"Terry passed away on the evening of 21 January 2020 at the age of 77 with his wife Anna Soderstrom by his side after a long, extremely brave but always good humoured battle with a rare form of dementia, FTD.

"His work with Monty Python, his books, films, television programmes, poems and other work will live on forever, a fitting legacy to a true polymath."

Terry Gilliam, with whom he directed The Holy Grail (1975), described him as a "brilliant, constantly questioning, iconoclastic, righteously argumentative and angry but outrageously funny and generous and kind human being".

Sir Michael Palin paid an emotional tribute to him in an interview with the BBC:


Our thoughts are with the Jones family, at this sad time.

Pictured: Monty Python, with Terry Jones in the centre.

30 January: Critically acclaimed Dutch-German film about dementia – “Romy’s Salon” - is out in cinemas

“Romy’s Salon” revolves around a young girl, Romy, who spends time at her grandmother’s hair salon after school. Romy notices changes in her grandmother’s behaviour, due to the onset of Alzheimer’s dementia. The film follows Grandma Stine as her dementia progresses, and highlights the
LIVING WITH DEMENTIA

22 January: Helen Rochford-Brennan, Chairperson of the EWGPWD, asks “What matters to me … Who am I?”

“What matters to me?” is a question that people living with dementia are often asked to consider when speaking at conferences or taking part in research. But such consideration is not as common in a healthcare setting.

I have been a patient a number of times in the last few years and my experience has not always been positive. On one occasion there was no consideration taken of my dementia diagnosis and I was moved within a hospital five times. A new environment and new staff contributed to my confusion. Every healthcare professional should know and must know who I am. Who am I when I present to the hospital with dementia and/or delirium? Who am I when I attend my GP, who am I when I meet the community nurse and require services at home? Who am I if an ambulance is called to my home?

The Irish Health Information and Quality Authority (HIQA) have recently undertaken work on a human rights based approach to care and the foundation of this is “knowing” the person. The Irish health service are finally looking at how to implement “What matters to me” which is a great step forward.

People living with dementia and their families must be empowered to give clear information on what matters to the person and health care systems must hear our voices. But systems are made up of people; so while we need robust systems and policies we also need the human beings to uphold our human rights.

I saw with interest and joy the #HelloMyNameIs campaign, which encourages healthcare professionals to introduce themselves. This is very important and I support the campaign. However, in any conversation just one introduction is not enough and if the doctor introduces him or herself, then the person with dementia must also be given the time to introduce themselves in return.

In modern Ireland today, the health service is in crisis: insufficient staff, home-care chronically underfunded and too many older people on trolleys in hospital emergency departments. It is a stressful environment for both the patients and the medical professionals. However, if healthcare teams just ask the simple question of “what matters to me”, they can already improve my experience and mitigate the terrible environment.

From a human rights based approach, I call on all healthcare staff across Europe to find out who they are really treating. Do you know the person’s medical needs, emotional needs, spiritual needs and social needs? Do you know and understand what brings them comfort and joy? Do you involve people living with dementia in care decisions and look out for non-verbal signals if they cannot speak? To others like me living with dementia, I want to remind you that you matter and you are important. Speak up and be heard.

NEW PUBLICATIONS AND RESOURCES

21 January: New US resource of family caregiver interventions launched online

“Best Practice Caregiving” is a free online database of dementia interventions for family caregivers. The programmes featured on the site have all been evaluated and are currently being delivered in the US.

The information and support database is searchable and interactive, and should help healthcare and community-based organisations, as well as funders and policy makers to discover and share vetted interventions and programmes. Find out more at: https://bpc.caregiver.org

On 30 January 2020, it went on general release in German cinemas. You can watch the trailer, here: https://youtu.be/1En9N7_RXZM
The Flanders Centre of Expertise on Dementia is happy to present its new webpage for international visitors. The page contains information on the mission and main projects of the Centre, as well as new publications and news.

https://www.dementie.be/the-flanders-centre-of-expertise-on-dementia-for-the-international-audience/

**JOB OPPORTUNITIES**

**27 January: UK Dementia Research Institute seeks Research Fellow**

The UK Dementia Research Institute at University College London (UCL) is looking for a highly motivated Research Fellow to join the lab of Dr Tim Bartels. Dr Bartels specialises in synuclein misfolding and lipidomics associated with Parkinson’s disease. The deadline for applications is 13 March 2020.

For more information and to apply, see: https://bit.ly/3aBiU9T

**28 January: Alzheimer’s Society seeks new Head of Research**

Alzheimer’s Society (UK) is looking for an experienced individual to join its ranks, as Head of Research - a key role within the Research and Development directorate. The successful applicant will have oversight of the research grants activity, research communications and patient and public engagement (through the Research Network of Volunteers). They will also be the subject matter expert on neuroscience for the organisation.

Leading the Alzheimer’s Society’s research programme, specific research initiatives and projects - all in accordance with the organisation’s policy of public and patient engagement and best practice in research management - involves building close collaborative relationships with the scientific, clinical and social research communities, individual researchers at all levels and university administrations. Additionally, the post holder will work closely with other directorates and with external contacts in umbrella organisations, government and other charitable funding bodies. The deadline for applications is 17.00 on 6 February 2020.

For more information about the role, and how to apply, visit:

http://bit.ly/30XdDFm

**EDUCATION**

**15 January: University of Stirling organises conference about living with dementia, aimed at people with a learning disability**

A free conference for people with a learning disability who want to learn more about living well with dementia will be held by the University of Stirling, on 10 March 2020, at the Stirling Court Hotel (on University of Stirling campus).

The day will focus on findings from a study at the University of Stirling, funded by the Alzheimer’s Society and led by an inclusive research team, including co-researchers with a learning disability. Those attending will have the opportunity to hear from the team and try some of the positive ways in which people with a learning disability and dementia were supported.

Please note that the event is for people with a learning disability and a supporter, as required. It is free to attend, but booking is essential.

Find out more about the programme, and book a place, via: http://bit.ly/35nfjt8

**22 January: Oxford University and Alzheimer’s Research UK organise free talks on dementia**

Free talks on Alzheimer’s, dementia, current treatments and the latest research are organised, on an annual basis, by the University of Oxford, as part of the Alzheimer’s Research UK Thames Valley network centre.

The 2020 event is taking place on the morning of 14 March. As well as being free, it is open to the public. Please do register your attendance, however, so that the organisers can have an idea of expected numbers.

To view last years’ presentations, visit: www.oxdare.ox.ac.uk/openday2019

For further information about the event, please email aruk.administrator@dpag.ox.ac.uk or telephone (+44) 01865 282358.

http://bit.ly/3aROvUX

**24 January: NIHR supports workshops for Early Career Researchers to write, lead and submit their first grant in the field of dementia**

Join a series of NIHR supported workshops for Early Career Researcher (ECR) academics in writing, leading and submitting their first grant in the field of dementia. A small number of funded places are still available.
The NIHR Portfolio Development group is supporting a number of workshops developed and coordinated by Dr Katie Featherstone to enable a cohort of Early Career Researchers working in the field of Dementia to write and submit their first significant grant as PI aimed at NIHR/MRC/Alzheimer’s Society/Alzheimer’s Research UK funding streams. This is an opportunity to understand the process including finding your narrative, meet other researchers in a similar situation, and learning the craft of successful grant writing from experienced NIHR and NHS researchers who have been through the process successfully.

Submitting a large grant proposal can be a daunting prospect; these workshops aim to support and provide mentorship to a cohort of Early Career Researchers to develop clinical interdisciplinary research ideas, foster collegiate working practices, and ultimately submit a high-quality research proposal.

Workshop 1: How to identify clinically relevant research questions
Workshop 2: Developing research that meets the needs of people living with dementia
Workshop 3: Cohesion of story and achieving methodological congruence
Workshop 4: Designing and delivering dissemination and impact.

As at 24 January 2020, there were still a couple of funded places left on this year’s series of workshops to be hosted in London.

Please email megan.calvert-ohare@nihr.ac.uk for more information on how to apply. The deadline for applications is 7 February 2020.

29 January: Ligue Nationale Alzheimer Liga organises trainings on various aspects of dementia for healthcare professionals and carers

The Belgian Alzheimer association, Ligue Nationale Alzheimer Liga is organising a number of training days (in French) for people with an interest in learning more about dementia. These will take place in the first half of 2020 and are mainly aimed at healthcare professionals and carers of people with dementia.

- “Personne ressource démence” will take place on 6 February, 5 March, 2 April and 7 May 2020, in Liège.
- “Sensibilisation à la pathologie démentielle en général et à la maladie d’Alzheimer en particulier” will take place on 13 February 2020, in Liège.
- “Concilier l’intérêt du patient et de son accompagnement” will take place on 18 June, in Liège.

If you are interested, visit: https://alzheimer.be/nos-activites/formations/

29 January: Interdem Academy invites applications for its upcoming masterclass on Social Cognition and Technology

The next 3-day Interdem Academy masterclass, on “Social Cognition and Technology”, will take place from 11-13 March 2020 in Prague, Czech Republic. In total, 10 Interdem Academy members can participate in the 3-day masterclass (the group will include about 35 early stage career researchers, in all). Interdem encourages people from outside the Academy to participate, new Academy members are more than welcome.

For more information and registration, see http://bit.ly/INTERDEMmasterclass, or send an email to the executive office of the Academy: interdem-masterclass@maastrichtuniversity.nl

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

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### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>4 February</td>
<td>EPAD Sustainability meeting (Barcelona, Spain)</td>
<td>Jean</td>
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<tr>
<td>10 February</td>
<td>WP4 Paradigm meeting (Brussels, Belgium)</td>
<td>Ana and Dianne</td>
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<tr>
<td>12 February</td>
<td>Association Luxembourg Alzheimer Ethics Committee (Luxembourg, Luxembourg)</td>
<td>Jean</td>
</tr>
<tr>
<td>17-18 February</td>
<td>Alzheimer Europe Board (Brussels, Belgium)</td>
<td>AE Board, Jean and Cindy</td>
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<tr>
<td>17 February</td>
<td>Board of Alzheimer Europe Foundation (Brussels, Belgium)</td>
<td>AEF Board, Jean</td>
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<tr>
<td>18 February</td>
<td>European Parliament lunch debate (Brussels, Belgium)</td>
<td>AE Board, members, sponsors and staff</td>
</tr>
<tr>
<td>18 February</td>
<td>Company round table meeting (Brussels, Belgium)</td>
<td>AE Board, members, sponsors and staff</td>
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<tr>
<td>18 February</td>
<td>Biogen Information meeting (Brussels, Belgium)</td>
<td>Ana and Dianne</td>
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<tr>
<td>18-20 February</td>
<td>EWGPWD meeting (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<tr>
<td>19 February</td>
<td>Public Affairs meeting (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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### CONFERENCES

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>27 February</td>
<td>Dementia &amp; rights; from principles to practice (webinar)</td>
<td>Adelaide, Sydney</td>
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<tr>
<td>2-3 March</td>
<td>9th European Conference On Clinical Neuroimaging [<a href="https://www.euroccn.com/">https://www.euroccn.com/</a>]</td>
<td>Paris, France</td>
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<tr>
<td>19-21 March</td>
<td>34th International Conference of ADR &quot;Hope in the age of dementia&quot; [<a href="https://adi2020.org/">https://adi2020.org/</a>]</td>
<td>Singapore</td>
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<tr>
<td>26-29 March</td>
<td>14th World Congress on Controversies in Neurology (CONy), [<a href="http://cony.comtecmned.com/">http://cony.comtecmned.com/</a>]</td>
<td>London, UK</td>
</tr>
<tr>
<td>2-5 April</td>
<td>International Conference on Alzheimer’s and Parkinson’s Diseases and related neurological disorders (AD/PD), [<a href="https://aap-adp-jenica.com/general-information/">https://aap-adp-jenica.com/general-information/</a>]</td>
<td>Vienna, Austria</td>
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<tr>
<td>11-12 June</td>
<td>Care in the Age of Outrage, [dementiaconference.com]</td>
<td>Sydney, Australia</td>
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<tr>
<td>26-30 July</td>
<td>Alzheimer’s Association International Conference (AAIC), [<a href="https://www.alt.org/">https://www.alt.org/</a>]</td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>20-22 October</td>
<td>30th Alzheimer Europe Conference “Building bridges” [<a href="https://www.alt.org/">https://www.alt.org/</a>]</td>
<td>Bucharest, Romania</td>
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<tr>
<td>11-13 October 2021</td>
<td>31st Alzheimer Europe Conference</td>
<td>Helsinki, Finland</td>
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The Alzheimer Europe newsletter received funding under an operating grant from the European Union’s Health Programme (2014-2020). The content of this newsletter represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.