ALZHEIMER EUROPE NEWSLETTER

WELCOME

Despite being the shortest month of the year, February has managed to be jam-packed with news. We started the month by simultaneously opening the call for abstracts and the registrations for the 29th Alzheimer Europe Conference #29AEC. Make sure you submit your abstracts before the deadline, 30 April 2019, and take advantage of the Early Bird registration fees, available until 30 June.

We are also delighted to announce three new Alzheimer Europe publications this month: Our 2018 Yearbook, comparing national dementia strategies in Europe; our Ethics report, examining experiences of people from minority ethnic backgrounds with dementia; and our latest Dementia in Europe magazine, which covers a number of our own activities, as well as recent policy news relevant to people with dementia, both at European and national level. There is also a special section looking back at our 2018 conference in Barcelona.

The flurry of activity continues as the month reaches its close, with a series of Alzheimer Europe meetings in Brussels: Our Board is meeting on 25-26 February and we have organised a lunch debate on the topic of “Dementia as a European research priority”, a company round table with our corporate sponsors and a public affairs meeting with our members. We are looking forward to the exchanges with policymakers, sponsors and member organisations, all of which will be reported in next month’s newsletter.

Jean Georges
Executive Director
ALZHEIMER EUROPE

1 February: Call for abstracts and registrations open for 29th Alzheimer Europe Conference

Alzheimer Europe and Alzheimer Nederland are pleased to announce that registrations and the call for abstracts are both open for the 29th Alzheimer Europe Conference (#29AEC). The conference will take place in The Hague, Netherlands from 23 to 25 October 2019.

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

**Societal perspectives:**
- Awareness and policy campaigns
- (Inter) National dementia strategies
- Inclusion of people with dementia
- Connecting with minority groups
- Early onset dementia
- Legal and ethical issues
- New housing concepts
- Technology
- Socio-economic aspects of dementia
- Risk factors and prevention

**Care and services:**
- Needs and experiences of people with dementia and their family caregivers
- Training and education of care professionals
- Memory clinics and centres
- Post-diagnostic support
- Psychosocial interventions
- Acute and hospital care
- Respite care
- Volunteers and care in the community
- Home and residential care
- Palliative care approaches

Please read the abstract submission guidelines carefully before submitting an abstract. The submissions deadline is 30 April 2019: https://www.alzheimer-europe.org/Conferences/The-Hague-2019/Call-for-abstracts


22 February: 29th edition of Dementia in Europe magazine published

We are pleased to present the 29th edition of our “Dementia in Europe” magazine. It details some of our recent efforts to ensure dementia remains a European priority, including our December 2018 European Parliament lunch debate on “Dementia as a priority of the EU health programme”; the first meeting of the newly-convened Governmental Expert Group on Dementia, an exciting new initiative aiming to fill the void created when a similar European Commission group was disbanded, mid-2018; the 4th edition of our Alzheimer’s Association Academy; and our 2018 publications - a yearbook on comparing dementia strategies across Europe and the 2018 and an ethics report promoting intercultural dementia care and support in Europe.

With the May 2019 European elections just around the corner, we asked MEPs in the European Alzheimer’s Alliance about their hopes and plans for the future of the EU. Readers can also learn about our 2019 European Dementia Pledge election campaign, aiming to ensure as many MEPs as possible support us and our members in making dementia a public health priority.

We provide an update on the European Accessibility Act and Marianne Thyssen, EU Commissioner for Employment, Skills, Social Affairs and Labour Mobility, tells us more about the Work Life Balance provisions associated with the European Social Pillar. Representatives of the Innovative Medicines Initiative (IMI), which celebrated its 10th anniversary in 2018, also spoke to us about some achievements to date and about Alzheimer Europe’s involvement in IMI projects.
Other topic areas in this issue include the upcoming German dementia strategy; an interview with Helga Rohra, a founding member and the first Chairperson of the European Working Group of People with Dementia (EWGPWD), who recently left the group; public opinion on France’s controversial decision to stop reimbursing anti-dementia drugs; and recent headlines about Artificial Intelligence (AI) and its ability to predict Alzheimer’s disease.

Finally, the “spotlight” section takes a looks back at the success of the 28th Alzheimer Europe Conference (#28AEC), in Barcelona. Key presentations at the opening ceremony and the plenary sessions are covered and we also highlight the contributions of people with dementia at the conference.

You can buy the magazine via our E-shop: http://alzheimer-europe.org/Publications/E-Shop
Past issues can be freely downloaded here: http://alzheimer-europe.org/Publications/Dementia-in-Europe-magazines

22 February: Alzheimer Europe publishes 2018 Yearbook comparing national dementia strategies

At the 24th Alzheimer Europe Conference in Glasgow in 2014, The Glasgow Declaration was launched, calling for the creation of a European Dementia Strategy and for the development of national strategies in every European country. Since then, a considerable number of national governments have published national dementia strategies.

Almost five years on from the Glasgow Declaration, our 2018 Yearbook has been published, comparing 21 dementia strategies (or national plans) and two neurodegenerative strategies across European countries, with a specific view to providing a comparative overview of the priorities and areas of focus. Doing so has allowed us to establish not only what areas of dementia policy and practice are being prioritised by national governments, but also the diversity of approaches to these issues. The main body of the report is broken down into five main headings, which are then further subdivided into specific subject areas. The five main headings are:

- Development and implementation of strategies.
- Human rights and legal matters.
- Diagnosis, post diagnostic sport, care and treatment.
- Informal carers.
- Research.

These headings reflect the most frequently recurring themes across all of the strategies reviewed, regardless of differences in terms of population size, economic status or healthcare systems.

Specifically, considering the commitments and policies contained within the strategies, it is apparent that the greatest number relate to the provision of health and social care services for people with dementia. This includes a focus on care coordination, diagnosis, treatment and the training of health and social care practitioners. Aside from these service-focused commitments, awareness raising amongst the public and improved infrastructure and resources for research were also areas of significant focus for many of the strategies.

The analysis of the policies and commitments within the national dementia strategies are done so at face value; with the exception of where strategies have had mid-point reviews or evaluation, this report does not focus on the implementation or progress of commitments or policies within the strategies. As such, where a country or strategy is not included under a certain section or subsection of the report, it should not be inferred that the country is not carrying out work in this area – it simply reflects that there was a lack of reference to this area within the country’s strategy. Equally, the inclusion of commitments or action points within the report are not a guarantee that they have, or will be, implemented.

The report also contains person contributions from the European Working Group of People with Dementia (EWGPWD), sharing their personal views and experiences in relation to specific themes identified within the strategies. The report has now been published in English and copies can be ordered from:

https://www.alzheimer-europe.org/Publications

22 February: AE examines experiences of people from minority ethnic backgrounds with dementia, in 2018 ethics report

An increasing number of people from minority ethnic groups are reaching an age at which the risk of developing dementia is higher and this trend is predicted to continue in the next few decades. At the same time, people from minority ethnic groups tend to use fewer services than their counterparts from the majority ethnic groups in different countries. This applies to most forms of support and care but is particularly noticeable in the context of residential care. It is clear from the literature that there are several factors which may contribute towards the low uptake of services and support. Moreover, it is sometimes assumed that people from minority ethnic groups don’t need support, based on the assumption that “they look after their own”. This is a stereotype which needs to be challenged and different approaches to care and support explored, together with people from different ethnic groups, in order to develop support which is culturally appropriate and acceptable.

In 2018, Alzheimer Europe (AE) set up an expert working group, chaired by Director for Projects Dianne Gove, to write a comprehensive report aimed at improving the situation of people with dementia, their carers and professional carers.
from minority ethnic backgrounds through the identification and promotion of intercultural care and support. Members of the working group, with different expertise and experience in the field and from a range of ethnic groups, worked together to produce the report. The key sections of the report cover issues related to the prevalence, assessment and diagnosis of dementia in minority ethnic groups, interpreter-mediated dementia assessments of people from minority ethnic groups; working with and involving local minority ethnic groups in the development of intercultural care and support, live-in/migrant carers for people with dementia and challenges encountered by professional and informal carers.

The report has now been published in English and will soon be available in French and German.

AE would like to thank the members of the working group, who donated their time, expertise and personal experience in the field. The members of the group were (in alphabetical order): Jean Georges (Luxembourg), Michal Herz (Israel), Siiri Jaakson (Finland), Ripaljeet Kaur (United Kingdom), Debi Lahav (Israel), T. Rune Nielsen (Denmark), Sahdia Parveen (United Kingdom), Charlotte Plejert (Sweden), Mohammed Akhlak Rauf (United Kingdom), Daphna Golan Shemesh (Israel) and Carolien Smits (Netherlands).

The report “The development of intercultural care and support for people with dementia from minority ethnic groups” received funding under an operating grant from the European Union’s Health Programme (2014–2020) and from the Robert Bosch Stiftung.

Information can be found, and copies purchased from March onwards, via:

https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Alzheimer Europe networking

On 30 and 31 January (London, UK) Ana and Dianne attended the kick-off meeting of the RADAR-AD project.

On 4 and 5 February (Berlin, Germany) Cindy attended the EPAD Investigator meeting and the PoC kick-off meeting.

On 6 February, Ana attended a PARADIGM Webinar about gap analysis in patient engagement in the development of medicines.

On 14 February (Luxembourg, Luxembourg), Jean met with representatives of Roche for an exchange of views.

On 15 February (Amsterdam, Netherlands), Jean participated in a F2F Executive Committee meeting of AMYPAD.

On 19 and 20 February (Edinburgh, UK), Jean attended the Programme Board meeting of the 2nd Joint Action on Dementia.

On 21 February (Luxembourg, Luxembourg) Gwladys met with Lufthansa Group to discuss sponsorship of #29AEC.

EU PROJECTS

24 January: MinD design evaluation stage begins

January saw the start of an important phase in the EU project MinD, which aims to improve the quality of life of people in the early stages of dementia. In mid-January, colleagues from University of Twente, Netherlands, worked with colleagues from Alexianer Hospital in Berlin, Germany, to begin evaluating the Good Life Kit, one of the two designs the project has developed. Dr Geke Ludden, project lead for University of Twente said:

“We want to support people with dementia by helping them to think about how they can lead a mindful and meaningful life.”

The kit invites people diagnosed with dementia to think together with their loved ones in a playful way about what they hold most important in their lives what the diagnosis of dementia means to them, and what they can and want to do to live life well. 16 prototypes in four languages have been produced of the Good Life Kit by the University’s DesignLab DreamTeam – an interdisciplinary team of students.

The kits have been produced in four languages for evaluation with people with dementia in The Netherlands, Germany, Spain and The UK. People with dementia have been involved through Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) and the Public and Patient Involvement (PPI) group in Nottingham (UK), as well as through MinD care partners Zorggroep Sint Maarten (Netherlands), Alexianer Klinik (Germany) and Intras (Spain).

The evaluation of the Good Life Kit in The Netherlands began on 24 January, where the University of Twente (the Human Centred Design and Interaction Design groups) is working together with MinD partner Zorggroep Sint Maarten. Case managers Ilse Diersehius and Christel Weusthof:

“We are of the opinion that the Good Life Kit can be a useful supplement in the guidance that we, as case managers at Zorggroep Sint Maarten, offer to our clients and to those around them. It is also very much in line with our own vision, ‘Share your life’, and with how we look at and treat our clients.”

https://designingfordementia.eu/

30-31 January: RADAR-AD holds its kick-off meeting in London

The RADAR-AD (Remote Assessment of Disease and Relapse – Alzheimer’s Disease)
The ultimate goal of the project is the development and validation of technology-enabled, quantitative and sensitive measures of functional decline in people with early stage AD. Dianne and Ana attended and took part in the work package discussions related to Public and Patient Involvement, ethics and dissemination and in discussions with researchers involved in other work packages. The European Working Group of People with Dementia will be playing a key role as the Patient Advisory Group within this project. They will inform the research partners about their perspectives and experience throughout the whole project and this will guide the development of appropriate materials and procedures. The EWGPWD will commence their role at the next EWGPWD meeting in Luxembourg in March where they will be commenting on the research protocol and contributing towards the development of focus group discussions at national level. AE will be working closely with researchers from King’s College London, the University of Oxford, Lygature and Takeda Development Centre Europe Ltd.

**18 February: INDUCT project is developing technology for dementia care planning in nursing homes**

Early Stage Researcher (ESR) Kate Shiells tells us about her work for the Interdisciplinary Network Using Current Technology in Dementia (INDUCT) project:

As an Early Stage Researcher now in the final year of the INDUCT project, I am currently in the process of analysing results. For my research, I have been exploring how electronic patient records (EPR) are helping or hindering care staff to plan care for people living with dementia in nursing homes. To do so, I have interviewed nursing home staff in Belgium, Czech Republic and Spain. One of the many questions I asked was, “what is most important for you to know about individuals with dementia you care for?” Common answers to this question included: being aware of what their routines were like before they moved into the home; knowing their previous occupation; and finding out who the most important family members or friends are in their lives.

I also wanted to explore the needs of people with dementia in nursing homes through a review of the literature. Much of the literature in this field has involved investigating their needs through proxy accounts. In other words, asking family members and formal carers. Research has shown, however, that proxy accounts can often be unreliable. Therefore, I only included studies that explored the self-reported needs of people with dementia in my review.

Participants commonly described their lives as boring and wished for social interaction and activities to counteract this boredom. A number of participants also said that helping others in the home provided a means of occupation, be it simply listening to other residents’ problems. Furthermore, people with dementia overwhelmingly want to be able to access the outdoor environment, and often feel trapped inside the home due to inaccessible outdoor spaces, or simply because there are not enough staff to assist them to go outside.

I hope to use this information to guide developers of EPR systems to design electronic assessment forms and care plans that allow staff to collect the types of information they need to know about people with dementia, and which also prompt them to address the relevant needs of people with dementia they are caring for. For more information:

https://www.dementiainduct.eu/project/esr13/

**21 February: AD Detect and Prevent project aims to create innovative digital healthcare solution**

Detecting Alzheimer’s disease (AD) during the presymptomatic phase - before people themselves or their relatives become aware of any problems, is extremely challenging. In most cases, AD is only discovered when clear cognitive symptoms emerge, at which point the disease progression has already caused irreversible damage to the brain and may have begun to impair quality of life. Timely detection could allow for more effective healthcare interventions and is therefore of paramount importance.

The AD Detect and Prevent project, funded through the EU’s Horizon 2020 programme, aims to exploit the synergies of its cross-disciplinary consortium of patient organisations, start-ups and academics, to effectively address this issue.

The project will integrate a novel cognitive assessment method, developed by researchers connected to the University of Oxford, into a digital cognitive training and rehabilitation platform by the digital therapeutics company, Brain+. This method could identify subtle AD-specific cognitive symptoms at the presymptomatic phase. Subsequently, the platform will offer a personalised intervention programme aimed to reduce the risk of AD.

Researchers at the University of Oxford, Aarhus University and the University of Nottingham will examine the sensitivity, specificity and effectiveness of the digital solution via vigorous behavioural and neuroimaging studies. Alzheimer Europe and the European Brain Council will explore target user needs.

As such, the project hopes to arrive at a novel and scientifically-tested digital tool allowing for presymptomatic detection of AD and enabling early interventions to reduce the risk of AD.

The project aims to launch this innovative healthcare solution, which can be accessed through mobile applications and computers, in the Danish and UK markets in 2020, with the ambition to expand the final tool to other European countries.
The kick-off meeting of the AD Detect and Prevent project was held in late 2018 (23 November). On this occasion, all members of the consortium shared their perspectives on the anticipated milestones, reviewed the overall objectives of the project and agreed on the next steps. Researchers at the University of Oxford and Brain+ are currently developing and testing different prototypes to gain insights on which format provides the best user experience while remaining a consistent and accurate tool for detecting presymptomatic cognitive signs of AD before clinical trials of the software begins.

The project coordinator is Brain+

Website: http://www.brain-plus.com/

Twitter: https://twitter.com/thebrainplus

Facebook: https://www.facebook.com/brain.plus.training/

**EU project acknowledgement**

A number of the projects in which Alzheimer Europe is a 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:

- **AD Detect and Prevent** - grant agreement 820636
- **RADAR-AD** - grant agreement 806999

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

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

- **Austria**: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).
- **Belgium**: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Julie Flahaut (EPP); Catherine Stihler (S&D).
- **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); Claudia Hagerup (S&D).
- **Estonia**: Urmas Paet (ALDE); Finland: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Merja Kyllonen (GUE/NGL); Sirpa Pietikäinen (EPP).
- **France**: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Barbara Hendrich (EPP); Christophe Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Víctor Belda (ECR).
- **Germany**: Angelika Niebler (EPP); Udo Voigt (NI); Greece: Kostas Chrysochosogous (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Elissavet Vozenberg (GUE/NGL).
- **Greece**: Kostas Chrysochosogous (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Elissavet Vozenberg (GUE/NGL). (S&D).
- **Ireland**: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Danny Healy-Rae (S&D); Dan Boyle (S&D); Danny Healy-Rae (S&D); Danny Healy-Rae (S&D).
- **Italy**: Costas Mavrides (S&D); Eleni Theocharous (EPP).
- **Lithuania**: Vilija Blinkyte (S&D); Matt Curry (GUE/NGL); Nessa Childers (S&D); Damiano Zoffoli (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**: Ebliza Lukaciewska (S&D); 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 Sârbu (S&D); Claudia Ciprian Tanaseacu (S&D); Renate Weber (EPP).
- **Slovakia**: Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborská (ECP).
- **Slovenia**: Franc Bogovič (EPP); Tanja Fajon (S&D); Aljoz 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 Zaba Bidegain (EPP).
- **Sweden**: Yvette Goulard (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECP); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Nancynicole McCallan (S&D); Torsten Sinkfield (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).

**EUROPEAN ALZHEIMER’S ALLIANCE**

13 February: European Alzheimer’s Alliance member to host exhibition on accessibility in EP

Marek Plura MEP (Poland), a member of the European Alzheimer’s Alliance (EAA) is to host an exhibition entitled “Europe without barriers” in the European Parliament, highlighting the barriers people with disabilities experience around Europe.

The exhibition will open by screening some of the films which were shown as part of the 2018 “European Film Festival Integration, You and Me”, a festival which focuses on promoting the inclusion of people with disabilities.

The films include real life dramas and biographies of people with disabilities, demonstrating the experiences and
challenges they face in everyday life, as well as exploring other issues such as poverty, immigration, sport etc.

As part of his work around disabilities and accessibility, Mr Plura also recently spoke at a European Economic and Social Committee (EESC) hearing into people with disabilities and voting, exploring the legal and practical barriers which often prevent people from voting. You can read his comments and those of others, here: https://bit.ly/2UYcfOG

If you would like to attend the exhibition, please contact: marek.plura-office@europarl.europa.eu

22 February: Members of the European Alzheimer’s Alliance reflect on making dementia a European priority

The current political and policy context means there will be a lot of significant developments in a short space of time, including changes to the Commissioners, the ongoing negotiations on the Multiannual Financial Framework (MFF) which determines the future budgets of the EU (including the place of health) and the future Horizon Europe (2021-2027) research programme. This provides both opportunities and challenges for dementia as a European priority.

With the European elections approaching in May 2019 and the Commission entering its final year, Alzheimer Europe has reflected on the progress made at a European level over the past 5 years and invited members of the European Alzheimer’s Alliance (EAA) to reflect and share their thoughts on:

- What they considered as the key achievements at an EU level in the recognition of dementia as a European priority.
- What they believed the European Union could do to further support people with dementia and their carers in future health, research and social programmes.
- What they saw as the greatest achievement/contribution of the EAA over the past five years.

In total, 10 Members of the European Parliament (MEPs) shared their thoughts, including Vice Chair of the EAA, Sirpa Pietikäinen. Members highlighted progress in a number of areas, including highlighting specific areas of work to date, including the dementia-specific funding as part of Horizon2020, the Work Life Balance initiative and the EU Joint Action on Dementia. Looking to the future, members also identified the need for a greater focus on dementia as part of Horizon Europe, as well as fostering collaboration across policy, health, social and research disciplines.

You can read the full comments from members in the February edition of the Dementia in Europe magazine, available at: https://www.alzheimer-europe.org/Publications/Dementia-in-Europe-magazines

EU DEVELOPMENTS

23 January: EAN and EFNA co-organise meeting on “Lifting the Burden of Neurological Diseases” at European Parliament

On 23 January 2019, the European Academy of Neurology (EAN) and the European Federation of Neurological Associations (EFNA) organised a meeting on “Lifting the Burden of Neurological Diseases”. It was hosted in the European Parliament by Karin Kadenbach, MEP.

The meeting aimed to present the latest data showing the growing burden of neurological ill health, both at the European and global level. This has been illustrated by the new data from a project run by EAN: Neurocare. EAN President Prof. F. Fazekas and Past President Prof. G. Deuschl explained that Neurocare aims at understanding the burden of neurology and neurological care, as well as its disparities in Europe and is based on data from the Global Burden of Disease (GBD) study.

Based on DALY’s, neurological diseases amount to 28% of the overall disease burden in Europe. Globally this figure is 23%. This, added to the total number of neurological diagnoses in these countries, leads to the conclusion that more or less every second European has a brain disorder (although neurological multi-morbidities have to be taken into account here).

The project is collecting data at country level and also allows for a deeper qualitative study of care provision in six of the main neurological diseases (Parkinson’s, epilepsy, MS, headaches, stroke, and dementia/Alzheimer’s). In particular, stroke and epilepsy were discussed, respectively by Prof. F. Fazekas and Prof. E. Beghi (International League against Epilepsy). 45.9 million people had epilepsy in 2016, with 1.4m people being newly diagnosed that year. Both disorders constitute a major cause of death and disability and contribute to excess mortality, lost years of quality living, lost work force and excess spending for long-term patient care.

Chair of the meeting J. Bowis said that, while several decades ago neurology was not present on the political agenda, this has now significantly changed. He asked all present to come up with a plan of action for politicians. We should propose solutions and their implementation, rather than waiting for politicians to do so. A panel of experts then provided advice on how stakeholders can work together to advocate for increased priority for neurological disorders at the global, EU and Member States level.

S. Hogan, Head of Sector Neuroscience at the Commission’s DG Research emphasised that EUR 2.4 billion has gone to
neurological disorders under the current EU Research Framework Programme (FP), including both basic and translational research. Importantly, a new project has recently been launched - European Brain Research Area (EBRA), led by the European Brain Council (EBC).

EBC Executive Director F. Destrebecq mentioned the Value of Treatment for Brain disorders study (VoT) in which treatment gaps were described through various case studies. Effective clinical interventions were identified for cost-saving solutions for governments. It deserves to be completed by studies such as Neurocare.

Prof. G. Waldemar, representing the BioMed Alliance emphasised a need to make health research a top priority in Horizon Europe and create a European Council for Health Research as well as a Steering Board for Health to create more synergies and promote patient and societal engagement and to provide scientific advice.

Prof. K. Sipido, chair of the Scientific Panel for Health (SPH), emphasised the importance of engaging with policy makers. A cardiologist by training, she pointed to comorbidities that show we have to work together across disciplines, and also across different structures and organisations. The SPH - an expert group within the Commission, introduced in to Horizon 2020 with support of the European Parliament - consists of individuals selected for their expertise. They provide foresight and recommendations involving consultation with stakeholders. She emphasised, here, that a proper engagement with patients into research and implementation is necessary. Prof. Sipido recommended to include health among the missions and stressed the importance of collaborative research across national borders and made a call to address the challenges for health research more adequately.

C. Tănăsescu, MEP concluded by saying that data presented here, showed that there is no doubt that we need to develop new treatments, although there is still a long road ahead.

EFNA President J. Jaarsma closed by mentioning one of EFNA initiatives - the MEP Interest Group on Brain, Mind and Pain that focuses on addressing policy issues of relevance to patients. Many of the points discussed at the current meeting will be included in EFNA’s newly updated policy documents.

Jean Georges, Executive Director of Alzheimer Europe attended the meeting.

Read the full meeting report and access the presentations, here:


5 February: The European Medicines Agency has a new address in Amsterdam

The European Medicines Agency (EMA) will leave its London premises on 1 March 2019 and relocate to Amsterdam. From 4 March 2019 (from 1-4 March, it will operate remotely), the official address of the EMA will be that of its permanent building in Amsterdam Zuidas:

European Medicines Agency, Domenico Scarlattilaan 6, 1083 HS Amsterdam, Netherlands.

The EMA will not physically occupy its permanent building until the latter part of 2019. For further details about temporary arrangements during 2019, visit:


7 February: Alzheimer Europe signs EU4Health response to EU’s Sustainable Development Goals reflection paper

In September 2015, the 17 Sustainable Development Goals (SDGs) of the 2030 Agenda for Sustainable Development were adopted by world leaders at the UN. EU Member States and the EU Commission have committed themselves to achieving the global goals. As part of the debate on the future of Europe launched in March 2017, the Commission published a reflection paper: “Towards a Sustainable Europe by 2030” on 30 January 2019.

The reflection paper puts forward three scenarios to stimulate the discussion on how best to deliver the SDGs within the EU. The paper also notes that the scenarios are only illustrative in nature and intend to promote discussion. The three scenarios are:

- An overarching EU SDGs strategy guiding the actions of the EU and its Member States.
- A continued mainstreaming of the SDGs in all relevant EU policies by the Commission but not enforcing Member States’ action.
- An enhanced focus on external action while consolidating current sustainability ambition at EU level.

Following this publication, Alzheimer Europe signed a letter as part of the EU4Health group, welcoming the paper, whilst expressing disappointment at the lack of progress towards an implementation plan or measurable goals. The response additionally identifies issues such as underfunding of healthcare systems, alongside increasing demand, inaccessibility of medicines and cuts in social protections, as detrimental to positive health outcomes for EU citizens.

The EU4Health response identifies and supports scenario 1 as the best option to prioritise the issue for the next President of the European Commission, as well as being the only scenario to support Member States achieve their commitments. The response calls for an ambitious and urgent political response
to achieve sustainable and patient-centred universal access to healthcare and a reduction of increasing health inequalities. The response concludes by noting that ensuring the future sustainability of health systems is fundamental to the attainment of most SDGs, particularly those related to the reduction of inequalities, gender equality and elimination of poverty. Health must therefore be regarded as a cross-cutting dimension of the 2030 Agenda and should be addressed as such.

You can read the EU Commission Reflection Paper here: https://bit.ly/2sXp3I5
You can read the full EU4Health response here: https://bit.ly/2BzcP7V

8 February: European disability organisations campaign on voting rights for people with disabilities

Two European disability organisations, the European Disability Forum (EDF) and Inclusion Europe, are running campaigns encouraging people with disabilities to vote and for legal and physical barriers to voting for people with disabilities to be removed.

As part of its campaign, the EDF have published quotes from people with different disabilities sharing their experiences of trying to vote, as well as providing online good practice information on how to make print, audio and video materials more accessible. Additionally, the organisation has launched a “European elections for all” petition, urging political leaders and electoral commission to ensure that people with disabilities are able to vote.

The Inclusion Europe campaign also provides resources explaining the importance of the European elections, how to make election more accessible and how people with disabilities and their supporters can engage in the election. Their campaign on voting primarily focuses on legal barriers faced by persons with disabilities, highlighting examples such as persons subject to guardianship being unable to vote in some countries.

Included below, Alzheimer Europe have provided some links to some of the resources and information related to the campaigns:

- A video outlining Inclusion Europe’s campaign can be viewed here: https://bit.ly/2Bmv1ru
- The EDF petition can be viewed and signed here: https://bit.ly/2Auc5B8
- The Fundamental Rights Agency has an interactive map, showing which countries place voting restrictions on people who are deemed to lack capacity. This can be accessed at: https://bit.ly/2SB3yMC

12 February: UK upper house releases report into EU-funded research in the event of “no-deal” Brexit

The EU Home Affairs Sub-Committee of the House of Lords (the UK’s upper chamber), has published “Brexit: the Erasmus and Horizon programmes”, which examines the implications for UK research in the event of a “no deal” scenario on 29 March 2019.

The report considers immediate effects on the Erasmus+ and Horizon 2020 programmes, as well as the potential effect on future collaboration in the future Horizon Europe research programme.

Page 45 of the report explicitly notes the benefit to dementia research as a result of existing arrangements including developments in analyses of amyloid plaques, the Innovative Medicines Initiative (IMI), as well as Dementia Research Institute’s use of the EU’s competitive application process.

Other key findings from the report include:

- The UK is a world leader in research with an exceptionally strong science base, which results in the UK receiving substantial amounts of funding, access to professional networks, and opportunities to connect and collaborate with European partners built over decades of cooperation.
- The Withdrawal Agreement would ensure that UK participation in Erasmus+ and Horizon 2020 could continue largely unchanged but only until the end of the current Multiannual Financial Framework period, at the end of 2020.
- In a “no deal” scenario, the UK Government has committed to underwrite funding from Erasmus+ and Horizon 2020 until the end of 2020. However, there is an urgent need for greater clarity on how this guarantee would work in practice, including who will disburse the funding and what terms and conditions will apply.
- Significant Horizon 2020 funding streams, including the European Research Council and Marie Skłodowska-Curie “Actions”, are not open to third country participation and therefore are not covered by the underwrite guarantee. The UK Government should confirm how it intends to replace this funding as soon as possible.
- It is in the UK and the EU’s mutual interest to preserve current levels of cooperation on research and innovation and educational mobility; as such, the UK should seek full participation in the Erasmus and Horizon Europe programmes as an “associated third country”.
- If the UK Government is unable or unwilling to secure association to the forthcoming Erasmus and Horizon programmes, it will be incredibly difficult to try to replicate a similar scheme at a national level.

You can read the full report at: https://bit.ly/2DvM3MV
13 February: European Economic and Social Committee (EESC) holds hearing on voting and disabilities in Europe

A European Economic and Social Committee (EESC) hearing has highlighted that about 800,000 EU citizens from may be deprived of their right to vote in the upcoming European elections as a result of their disability, as well as facing other barriers to voting.

The hearing also heard that despite the existing international legal framework for protecting the rights of persons with disabilities, legal and technical barriers persist in all EU Member States that may prevent or make it difficult for many Europeans with disabilities to cast their vote or run for office. As many as 16 Member States have national policies and legislation which can deprive the person of their right to vote on the basis of their disability or mental health.

Physical barriers also exist, including polling stations that are poorly adapted to individual needs, as well as electoral information and campaigns that are often inaccessible to deaf or blind people.

Marek Plura MEP (Poland), who is also a member of European Alzheimer’s Alliance, highlighted that the EU and all Member States have ratified the UN Convention on the Rights of Person with Disabilities (UNCRPD) which clearly articulates civic and political rights. This means that the EU as a whole and individual Member States have an obligation to ensure that persons with disabilities are able to vote and to participate in the elections.

A new information report compiled on behalf of the EESC is expected to be presented at the plenary in March 2019, outlining around 200 examples relating to legal and technical barriers faced by persons with disabilities who want to exercise the right to vote.

You can read further detail about the event at: https://bit.ly/2UYcfOG

1 February: Jersey announces a new support group for carers

The Jersey Alzheimer’s Association (JAA) is launching a new carers’ information and support programme, for people currently caring for someone with dementia.

Guest speakers will share their expert knowledge on a range of subjects relevant to the role of caring. The programme also provides an opportunity for informal care-givers to engage in a friendly and supportive environment with others in a similar situation.

Sessions will take place either the third or fourth Thursday of every month at The Monterey Hotel, starting from 21 February.

Each session will run as follows:
- 6.00pm – 6.30pm Meet and greet and refreshments
- 6.30pm – 7.00pm Topic talk
- 7.00pm – 7.15pm Q&A session
- 7.15pm – 7.45pm Group reflection
- 7.45pm – 8.00pm Round up and farewell.

For more information please contact Michala: michala@jerseyalzheimers.com

The JAA is pleased to announce that the States of Jersey Police, the Occupational Therapy Department, Jersey Library and Jersey Heritage will join them, to help raise awareness, reach out to the community and enhance the lives of those affected by dementia.

The Dementia Friends programme aims to change the way people think, act and talk about dementia. Specially trained Dementia Champions will deliver face-to-face awareness sessions to small groups, schools and in the workplace aimed to help people learn about what it is like to live with dementia and asks them to turn that understanding into action.

Since its inception the global Dementia Friends network has seen over 2.8 million people attend dementia awareness sessions and the JAA is delighted to be leading the programme in Jersey, which is now the 48th country to join what has become a huge, international initiative to change perceptions and experiences of dementia. For more information please contact:

michala@jerseyalzheimers.com or wendy@jerseyalzheimers.com

29 January: Jersey launches Dementia Friends programme

29 January saw the launch of the Jersey Alzheimer’s Association (JAA) Dementia Friends programme. Over the next 12 months, in connection with the Dementia Friends programme, as well as its Parish Pursuit programme, the JAA will visit all 12 of Jersey’s parishes, to showcase its own services and activities, as well as those offered by its community partners.

The Dementia Carers Campaign Network (DCCN) is a group of people who have experience caring for a loved one with dementia. The Network aims to be a voice of and for dementia carers in Ireland and to raise
awareness of issues affecting families living with dementia. The group is facilitated by The Alzheimer Society of Ireland. At the beginning of February, an election was held at a Committee Meeting in Dublin for the roles of Chair and Vice-chair of the DCCN, as the past two-year term had concluded. Judy Williams was re-elected as Chair, having successfully proven herself to be passionate, effective and committed in this role. Ray Cregan, a dedicated and hard-working committee member was elected as Vice-chair.

The DCCN has exciting plans for 2019. Currently, members are engaging with health care professionals in Ireland to promote the video “The Experience of a Dementia Diagnosis”, which is a joint campaign with the Irish Dementia Working Group. The video shares personal stories of diagnosis, from people with dementia, family carers and Dr Tony Foley, with the aim of improving the critical moment of diagnosis.

If you would like to find out more about the work of the DCCN please follow the group on twitter @DCCNIRL or email Laura.Reid@alzheimer.ie

Pictured: Judy Williams and Ray Cregan

5-6 February: Federazione Alzheimer Italia brings together 18 Italian Dementia Friendly Communities

During the first week-end of February, in Milan, Federazione Alzheimer Italia brought together the 18 Italian Dementia Friendly Communities: two days full of interesting ideas to bring together and highlight the collective work done so far, allowing for an exchange of information and strategies.

Almost exactly three years after the launch of the Abbiategrasso pilot project, which started in February 2016, the network has expanded to include 18 communities throughout Italy. The network is strengthened by the sharing of a common idea, an internationally recognisable logo and a great number of initiatives for people with dementia.

The two days were used to discuss, in the light of the international scene, the results achieved, but above all to explore the limits and how to overcome them, starting from a fundamental feature of the Dementia Friendly Communities: measurement through an annual self-assessment questionnaire. A day of training has allowed the participants to investigate issues related to communication, design of the interventions, measurement of the effectiveness and satisfaction of the initiatives but also, and above all, an enriching moment for comparison, exchange of views, experiences, stories and emotions.

What emerged shows that the Dementia Friendly Communities can only be successful if: They always listen to the needs of people with dementia, ensuring the people themselves are the leading figures in the planning of activities; if they involve younger generations; and if they increase awareness about dementia among the wider population.

Many shared projects have been explored so far: From training; to local police; to the creation of preferential lanes in supermarkets; to the environmental adaptation of libraries; to the involvement of schools. These are the tangible results of these communities, thanks to which it is possible to make a difference in the lives of people with dementia.

6 February: England’s National Dementia Action Alliance focuses on impact and engagement at Annual Conference

The National Dementia Action Alliance (NDAA) Annual Conference took place on 6 February at the Royal College of Nursing in London with more than 100 NDAA member attendees from across the dementia care and research sector. The NDAA is an alliance of over 125 health and social care organisations across England that takes action on dementia through collaboration, engagement, sharing best practice and influencing. All activity undertaken is in partnership and informed by people living with dementia and carers. Whilst the NDAA operates independently, it is hosted by the Alzheimer’s Society.

The theme of the day was “Dementia Support and Research: The Power and Impact of Meaningful Engagement”. As a result, a key focus of the day was learning from the experiences of people living with dementia and carers. A panel consisting of those with a diagnosis and carers shared their positive experiences of the healthcare, research, care home and leisure sectors. The session also lent itself to discussions around some of the challenges the panel members had faced in these areas. Furthermore, people living with dementia and carers provided details of the projects they had contributed to and on which they had partnered with a selection of NDAA members. This lived experience of dementia was central to the success of the conference and attendees left feeling inspired and motivated to create their own change.

The agenda also featured a session on working with national and local Government, an update on the 2020 Dementia Challenge and a series of workshops looking at the IDEAL and Pri-Dem research studies and the Meeting Centres initiative. The conference was sponsored by Housing & Care 21, who, alongside the Alzheimer’s Society, were instrumental in creating the Dementia Friendly Housing Charter.

The NDAA will be hosting a stand at this year’s Alzheimer’s Society’s Annual Conference. The Alzheimer’s Society has announced the programme for its annual conference, taking place in London, 21-22 May 2019. Keynote speakers include:
the UK Secretary of State for Health and Social Care; leaders in research; medical professionals; and people affected by dementia. The Alzheimer's Society welcomes delegates from European sister organisations with a 10% discount code (ASAC19GENTEN).

To read more about the NDAA Annual Conference here: https://www.dementiaaction.org.uk/news/29424_ndaa_annual_conference_report_now_available

7 February: First dementia training for first responders takes place in Croatia

As part of the programme through which the City of Zagreb is becoming a Dementia Friendly Community, the first basic training session on dementia was delivered to Zagreb police officers, firefighters and tram drivers, on 7 February 2019. This event marked the beginning of the City of Zagreb Health Office’s educational programme, which will further include municipal police, municipal utility companies and their call centres and members of emergency technical interventions. By the end of the year, the programme will extend to social workers and carers in homes for the elderly owned by the City of Zagreb.

This first session, on 7 February, was carried out by Alzheimer Croatia and included topics related to dementia, its symptoms and ways of recognising it, as well as a workshop to help improve participants’ interaction and communication with people with dementia.

The thirty participants evaluated the knowledge gained as extremely useful and expressed the conviction that they would be able to put what they had learned immediately into practice. At the end of the session, most of the participants joined Croatia’s Dementia Friends initiative.

12 February: Spominčica reports on opening of ‘nursing oasis’ for people with dementia in Slovenia

On 12 February, Spominčica-Alzheimer Slovenia attended the opening of a ‘nursing oasis’ for people with advanced dementia, at the Nursing home Laško, part of SPA Thermana Laško. Stefania L. Zlobec, president of Spominčica, welcomed this improvement in services, still rare in Slovenia but important for the wellbeing of people with dementia.

With the rapid increase in the number of individuals with dementia - the estimated number in Slovenia is around 33,000 - the development of a nursing oasis offers a new approach to advanced care planning. These kinds of investments can significantly enhance quality of life and contribute to new care facilities and services for people with advanced dementia. One of the primary aims of a nursing oasis is to provide patients with support and help ensure dignity at end of life.

Many people with advanced dementia have mobility problems, difficulties in communicating and continence problems. Sometimes the only indicator medical staff have, of the wishes and needs of patients with advanced dementia, is non-verbal communication. However, they are clearly able to sense external stimuli, such as colours, light, touch, smells and sounds, and repeated activities can help to prolong their ability to distinguish between objects, textures, materials, senses and stimuli.

The nursing oasis is a big sensory room, following modern concepts of care, which focus on the importance of respecting the individual. The interior of the room consists of five beds and furnishings that encourage residents to feel comfortable and safe. The furniture in room is mostly made of natural materials, in warm colours and each resident has their own private space. The beds are separated by decorative moving panels, illustrated with motifs from nature and landscapes. The wellbeing of residents is further enhanced with ambient lighting and aromatherapy.

The concept of the nursing oasis is now in some Slovenian nursing homes, but in some other countries it is already an example of good practice. Some of the reported positive results of such care are: reduced restlessness; better awareness of own body; and improvements in the immune system.

12 February: Alzheimer’s Society and Sport England launch first dementia-friendly sport and physical activity guide

Alzheimer’s Society and Sport England have joined forces to call on the sport and physical activity sector to commit to becoming dementia friendly and reduce the barriers that prevent many people affected by dementia from taking part in sport and physical activity.

The appeal was issued as the Alzheimer’s Society launched its first dementia-friendly sport and physical activity guide at the Kia Oval cricket ground in London on 12 February.

The guide has been developed in partnership with input from across the sports sector and people living with dementia, with National Lottery funding from Sport England. It is designed to help the sport and physical activity sector to support - and empower - people who are living with dementia to lead active lives and remain independent for as long as possible.

The practical guide aims to inform and educate individuals and organisations so they have a better knowledge of dementia
and how it affects people. It also provides tools and guidance so that the sector can help more people affected by dementia enjoy the benefits of staying active in a caring and understanding environment.

And by becoming dementia-friendly, leisure centres, sports clubs and gyms can reap the benefits of improved customer experiences and increased revenue.

Jeremy Hughes, Chief Executive Officer at Alzheimer’s Society, said:

“Dementia can devastate lives and it is vital that people with dementia are enabled and empowered to live the life they want in their community.

“Visiting a gym, sports centre or favourite leisure facility to take part in physical activity can be daunting for people with dementia, loved ones and friends – but with support and adjustments from sport and physical activity providers, they will remain active.

“We need the whole sector to unite against dementia by committing to the actions outlined in the guide and make employees Dementia Friends, so no one has to face dementia alone.” For more information visit: https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-sports

13 February: Memory-friendliness was on the agenda of the first ever Memory Parliament in Finland

The first “Memory Parliament” was held in Finland on 13 February. The Parliament gave people with memory-related diseases and their family members the chance to ask Members of the Finnish Parliament questions.

The audience wanted to know, for example, about support for children with a parent who has early onset memory-related disease and how support and services could be provided equally in all parts of Finland. The panel answering questions consisted of four Members of Parliament, all from different political parties.

The Minister of Family Affairs and Social Services, Annika Saarikko gave the opening speech. She highlighted the importance of recent discussions in Finland about the quality of care for elderly people: “We have to listen to the people with memory-related issues when discussing their care”, she said.

Several lectures covering different issues about memory-friendliness in Finland were also given.

The Memory Parliament was organised by the “Memory Club” in the Finnish Parliament, the Alzheimer Society of Finland (Muistiliitto) and its partners.

14 February: Alzheimer Hellas presents REMEDES for Alzheimer (R4Alz): A new diagnostic psychometric tool for the diagnosis of minor & major neurocognitive disorders

REMEDES constitutes a system oriented towards high precision measuring and recording of reflexes via optical and/or auditory stimuli. The system is suitable for detecting and quantifying a person’s proprioception/kinaesthesia, since it is based on the fundamental human action-reaction phenomenon, involving seeing and/or hearing an event, and reacting through the myoskeletal system. It comprises a number of portable wireless devices that can be placed in arbitrary places and be configured accordingly, this way setting up and performing new types of reflex measuring exercises. Although several tools are available in literature for detecting healthy cognitive aging from Subjective Cognitive Impairment (SCI), SCI from Mild Cognitive Impairment (MCI) and MCI from dementia, there is not yet a common accepted neuropsychological tool capable enough to differentiate between the clinical spectrum of ageing and especially from SCI to MCI. Cognitive control abilities such as inhibition and working memory are correlated with cognitive decline and dementia. As a result, Alzheimer Hellas in collaboration with the School of Electrical and Computer Engineering, School of Psychology and Medicine School of Aristotelian University of Thessaloniki (AUTH) designed a new cognitive control test. The R4Alz test is a new psychometric tool used for the assessment of abilities of cognitive control and attention control, which, does not seem to require language skills, in order to minimise the influence from the patient’s educational level. The first tasks are assessing abilities such as working memory storage, working memory processing and working memory updating, enriched by episodic buffer recruitment; while the next tasks are assessing attention control and specifically selective attention, sustained attention and divided attention. The last tasks are assessing inhibition, switching of attention, and cognitive flexibility. Every task includes seven pads. Every pad is followed by a specific colour, sound or figure depending on the task. The subtest’s instructions are both verbal and nonverbal. The battery’s duration is almost an hour, while it’s administration is quite simple. The validation study is in progress and the pilot results will be announced very soon.

For more information please contact Mrs Poptsi Elena: epoptsi@gmail.com
18 February: Alzheimer Athens participates in European Programme E-Lily: Medical information search via the Internet

The use of the Internet makes it easier to seek help and medical information for all of us, but especially for people in isolated areas, where access to health services and psychological support is limited. In these cases, the internet can be a lifeline for seeking help. At the same time, however, its use is undermined by many risks: Which medical information to trust; where to search; what to watch out for when we look for such serious information on the internet. For all these reasons, knowledge about proper use of the Internet to find medical information is of the utmost importance for caregivers.

Since November 2018, Alzheimer Athens has been involved in a European Erasmus+ programme, in cooperation with four other organisations. The project is coordinated by Szczecinska Szkoła Wyzsza Collegium Balticum (Poland); Cyprus Technology University is responsible for developing the comparative report on health literacy and the training methodology; Anziani e non solo (Italy) will undertake the online platform creation and the dissemination of the project; Alzheimer Bulgaria is engaged in the implementation of the programme in Bulgaria; and finally, Alzheimer Athens (Greece) is responsible for creating the trainer’s guide and for the evaluation of the entire programme.

The aim of this programme is to educate caregivers of people with dementia about how to use the Internet more effectively and safely, to find medical information and psychological support. Forms will be created for training caregivers in the use of computers and how to search for and retrieve reliable information via the Internet. Furthermore, an online platform with all the necessary information will be created to allow even the most isolated caregivers to be trained. Finally, the whole effort will be tested in groups of caregivers in order test its usefulness.

The first meeting of the group involved in this Erasmus+ programme took place from 12 to 15 December 2018 in Athens, hosted by Alzheimer Athens.

POLICY WATCH

19 February: Bulgaria is making progress on social care, but needs a national dementia strategy, Foundation Compassion Alzheimer Bulgaria tells the UN

Foundation Compassion Alzheimer Bulgaria (FCAB) has just submitted a report to the UN Committee on Economic, Social and Cultural Rights (CESCR). The report, the 6th of its kind that the FCAB has submitted, was completed prior to the 65th session of the CESCR and gives the NGO’s perspective concerning the implementation of the country’s national long-term care strategy. It advises that there are important gaps in implementation, and that the need for a dementia-specific strategy is clear. Here are some of the points included in the report:

Approximately 100,000 people in Bulgaria are currently living with dementia (50,000 of them with Alzheimer’s disease). While the country has demonstrated a genuine commitment to improving social services, including those for older people and people living with dementia - for example by adopting a national strategy on long-term care and an action plan for 2018-2021 for the implementation of this strategy – there is still much to do and many promises that are, as yet, undelivered. A national strategy/plan for coping with challenges related to dementia and to the health and social care and services is still lacking and would be of huge benefit to the fast-growing number of people with dementia and their families and carers.

According to the Implementation Plan of the National Strategy for long-term care, 100 new social services for more than 2,000 users are planned, including:

- 6 day care centres for people with different forms of dementia and their families,
- 16 day care centres for people with disabilities, including with severe multiple disabilities,
- 10 centres for ‘social rehabilitation and integration for persons with mental disorders’,
- 68 care centres for people with disabilities and older people who need care.

There is no database yet, nor data on the real scope of people affected by Alzheimer’s disease and dementia, and on the different types of the disease. There is, however, annual statistical data on the number of people with dementia who have been under medical supervision (2,307 people for 2015). FCAB hopes its report will be taken into consideration by the UN CESCR and that it will have the Committee’s support in calling for further implementation of the long-term care plan and for a dementia-specific strategy in the near future. You can read the report here:


SCIENCE WATCH

28 January: Researchers investigate association between antiepileptic drug use and risk of dementia

On 28 January, French and German researchers published a research paper analysing the potential association...
between the use of antiepileptic drug and the dementia risk in the journal of Alzheimer’s disease.

In the published report, scientists performed a case-control study using data from the Disease Analyzer database. They analysed data from 101,150 individuals followed by general practitioners and neuropsychiatrists in Germany between 2013 and 2017. The study population included 50,575 people with dementia and 50,575 controls without dementia with a mean age of 81 years old. Overall, they described no significant association between antiepileptic drug use and dementia risk. However, levetiracetam generic drugs were found to be associated with an increased dementia risk. Researchers also pointed out several limitations of the study and recommended further analysis.

https://content.iospress.com/articles/journal-of-alzheimers-disease/jad181194

4 February: Researchers investigate sex differences in Alzheimer’s disease

JAMA Neurology

On 4 February, an international group of researchers published an article on the differences in global amyloid and regional tau disposition between men and women in the journal JAMA Neurology. Although there is a wide consensus that both amyloid and tau disposition are tied to neurodegeneration, the influence of sex differences in early Alzheimer’s disease (AD) progression are yet to be made clear. Therefore, the team aimed to find out to what scale sex differences exist in tau disposition of clinically healthy older adults by the use of a brain imaging technique (positron-emission tomography).

The researchers analysed scans of 296, drawn from 2 independent cross-sectional cohorts. The scientists reported that interestingly their results showed that especially women with higher amyloid burden had greater entorhinal cortical tau signal as compared to male participants with higher amyloid burden. Although the team reported that due to issues with follow up and limited power in the analyses, they concluded that their findings potentially support the growing evidence base of biological differences in risk of AD and warrant further research in this area.

https://jamanetwork.com/journals/jamaneurology/article-abstract/2722842

4 February: Scientists publish findings on region-specific brain changes in AD

Communications Biology

On 4 February, an international group of researchers published analyses of Alzheimer’s disease (AD)-related brain region specific protein expression changes in the journal Communications Biology. Although considered a growing field of interest for the development of disease modifying treatments, region-specific brain changes throughout progression of AD are still poorly modelled.

In order to gain new insights into how AD develops and to help find possible new targets for interventions, the authors looked at protein expression changes in six different brain regions, applying a series of spatial proteomics analyses using mass spectrometry.

The brain regions were selected based on their differences in being affected by the disease. They encompassed three heavily affected regions; hippocampus (HP), entorhinal cortex and cingulate gyrus, two lightly affected regions; sensory cortex and motor cortex as well as one relatively “spared” region, the cerebellum. Overall, the studied brain samples encompassed nine cases of AD and nine asymptomatic controls donated for research by patients at the New Zealand Brain Bank in Auckland.

In their publication, the team reported, that they identified a total of 128 protein changes, present in five out of the six studied brain areas. Based on evidence in the literature, the team concluded that at least 44 protein changes had previously not been associated with AD. Furthermore, the researchers reported, that they found a possible protective protein expression profile in the cerebellum. Data of this study is open access and can be freely used for further research: https://doi.org/10.17605/OSF.IO/6BQKQ.

The article is available here: https://www.nature.com/articles/s42003-018-0254-9

6 February: Study reports a link between mid-life inflammation and cognitive decline in old age

On 6 February, US researchers from the University of Mississippi Medical Center published a report examining the association between systemic inflammation measured during midlife and later cognitive decline in the journal Neurology.

In the published study, scientists analysed five known inflammatory biomarkers in blood samples from a total of 12,336 people participating in the Atherosclerosis Risk in Communities Study (ARIC), which is a prospective epidemiologic study conducted in four US communities. The participants were then followed for approximately 20 years. Cognitive assessments (memory, executive function and language) were evaluated over three visits at the beginning, six to nine years later and at the end of the study. They found that people with high levels of inflammatory markers measured in midlife had steeper cognitive decline over the next 20 years compared to those with low inflammatory biomarkers.

http://n.neurology.org/content/early/2019/02/13/WNL.0000000000007094

7 February: Recent study reports that a hormone produced during exercise might protect against AD

On 7 January, an international group of researchers reported that the hormone released into the circulation during physical exercise called irisin could prevent...
cognitive decline in Alzheimer’s disease (AD).

In the study published in the journal Nature Medicine, scientists studied a gene called FNDC5, which is known to regulate the formation of irisin. Using tissue samples from US brain biobanks, researchers showed that irisin was present in the human brains of people with no cognitively impairments and that this level was reduced in the brains of people with late AD. Similar findings were described in AD experimental mouse models. Then, they genetically modified the mouse models to inactivate the FNDC5 gene and found that the mice had impairment in synaptic plasticity and memory. Conversely, overexpression of FNDC5/irisin restored brain function including memory defects in AD mouse models. In addition, scientists performed a protocol of daily swimming and looked at the effect of exercise on irisin and the brain of mouse models. They found that this exercise could prevent memory deficits and the reduction of FNDC5/irisin levels in the brain of mouse models.

Together with these findings, researchers suggested that boosting irisin, either pharmacologically or through exercise, may constitute a potential strategy for therapeutic intervention in AD.

https://www.nature.com/articles/s41591-018-0275-4

11 February: Scientists aim to understand reasons for reduced blood flow and subsequent cognitive impairment in AD

On 11 February, an international group of researchers published a study on Alzheimer’s disease (AD) mouse models in the journal nature neuroscience. Their aim was to provide insights into the underlying mechanisms of impaired blood flow within the brain.

Previous evidence has shown reductions in brain blood flow in people with AD as well as AD mouse models that were accompanied by cognitive impairment. In the pursuit of a better understanding of the underlying disease mechanism, the scientists looked at differences between APP/PS1 and 5xFAD mouse models and wild-type mice and found that so-called neutrophils (a common form of white blood cells) were stuck in cortical capillaries, mainly contributing to the constricted blood flow.

Building on previous research, the team administered antibodies that deplete neutrophils and observed immediate improved blood flow as well as improved cognitive function after one month of treatment.

Based on these results and findings from other teams, the researchers concluded that the approach of improving brain blood flow through interventions that interfere with stuck neutrophils would be an area of interest for future research.

https://www.nature.com/articles/s41593-018-0329-4

13 February: GeneMatch programme reports on feasibility of online recruitment registry for AD research

On 13 February, researchers from the United States of America (USA) reported on the feasibility of the GeneMatch programme in the journal Alzheimer’s and Dementia.

Recent research focuses more and more on possibilities to bring eligible study participants and trials together. Launched at the end of 2016, GeneMatch’s aim is to recruit participants for Alzheimer’s disease (AD) prevention studies. The programme is led by the Banner Alzheimer’s Institute and receives funding from the National Institute of Aging, National Institutes of Health, Alzheimer’s Association, GHR Foundation as well as other organisations. A main feature is that interested people aged 55-75 from the USA can enrol online (or at a partner healthcare site) and will be provided a cheek swab kit for DNA extraction and apolipoprotein E (APOE) genotyping.

In this recent publication, the researchers reported that the programme was joined by over 75,000 participants. Nearly 30% of participants have one APOE4 allele (a variation which is associated with an increased risk of AD), and approximately 3% have two APOE4 alleles (associated with a higher risk of developing AD).

Interestingly, the authors report that although the programme uses a variety of recruitment strategies, that there is a gender disparity and participants are predominantly female (although social media advertisements specifically targeting men were launched in October 2017).

More information on the program, aspects of ethical considerations as well as a detailed enrolment funnel comparison and the authors’ ideas on future directions can be found here:

https://www.alzheimersanddementia.com/article/S1552-5260(18)33624-0/fulltext

18 February: Alzheimer’s Research UK funds Phase II clinical trial for agitation in AD

On 18 February, the dementia research charity Alzheimer’s Research UK announced funding of a phase II clinical trial to assess the feasibility of a cannabis-based medicine to treat agitation in people with Alzheimer’s disease (AD).

The trial aims to recruit 60 volunteers with AD between 55 and 90 years and also involve a placebo group. The cannabis-based medicine will be administered through a mouth spray already approved for people with multiple sclerosis.

At the same time, the charity called for caution about self-medicalisation, stressing that people should not take cannabis in an uncontrolled setting as; “there is no good evidence that using cannabis in an uncontrolled setting could benefit people
living with dementia, and... that the drug can involve risks such as short-term memory and thinking problems, coordination difficulties and anxiety”.

The trial will be led by King’s College London and shed light into the question whether it is practical to give a person with dementia a drug using a mouth spray, who is experiencing a certain level of distress and discomfort.


18 February: Study finds ethnoracial differences in AD

On 18 February, a team of Mayo Clinic researchers reported ethnoracial differences in Alzheimer’s disease (AD) in a scientific paper published in Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association.

The research team examined 1,625 brain tissue samples from a cohort of donated brain tissues. They looked at demographic and AD clinicopathologic features across an ethnoracially diverse group of people including Hispanic/Latino, black/African American and white/European American.

Scientists found differences among the ethnoracial groups. Hispanic decedents had lower years of education (13 years) compared to black and white decedents (14 years). Findings also showed that Hispanic decedents had dementia symptoms at an average age of 70, a year earlier than black decedents and two years earlier than white decedents. Hispanic decedents also had a higher frequency of family history of cognitive impairment compared with the other ethnoracial groups. The disease duration differed across the groups with 12 years for Hispanic decedents, 9 years for non-Hispanic whites and 8 years for African-Americans. https://www.alzheimersanddementia.com/article/S1552-5260(18)33630-6/fulltext

20 February: The University of Dundee Drug Discovery Unit announces partnership with Takeda to develop new treatments for tau pathology

On 20 February, the University of Dundee Drug Discovery Unit, an integrated drug discovery group translating world-class biology research into novel drug targets and candidate drugs, announced its partnership with the Japan’s largest pharmaceutical company Takeda to develop new treatments for tau pathology including Alzheimer’s disease (AD). This partnership is expected to accelerate the progression towards clinical development of experimental drugs that prevent tau misfolding.

“Our mission is to bridge the gap between innovative life science research and drug development in areas of unmet clinical need, and Alzheimer’s disease is at the top of the list”, said Dr David Gray, head of innovative targets at the Drug Discovery Unit.


LIVING WITH DEMENTIA

5 February: Idalina Aguiar tells us about meeting the President of the Republic of Portugal with the National Association of Informal Caregivers

Prior to my Alzheimer’s diagnosis, I was my husband’s carer for 25 years. He became totally dependent on me following an accident. Now, I need care myself and in my country, formal support for carers does not exist. I am part of a group of carers who defend, clarify and fight for the rights of informal caregivers and wants their roles to be recognised. I am a member of Alzheimer Portugal and the National Association of Informal Caregivers (ANCI) and have previously participated in several initiatives, awareness actions, demonstrations and vigils, with both associations.

On 5 February, the ANCI was received by the President of the Republic of Portugal, Marcelo Rebelo de Sousa, at the Palácio de Belém. MEP Marisa Matias, member of the European Alzheimer’s Alliance, was also present. President Rebelo de Sousa reaffirmed his support for the recognition of the Statute of the Informal Carer and renewed our hope that steps would be taken by the Governing. The next day, there was a decision by the Council of Ministers to approve a legislative act with measures to protect informal carers. On my island, the autonomous region of Madeira, the Regional Government submitted a proposal for a regional legislative decree in parliament, so that the Informal Carer Statute can be recognised in the region.

I am delighted to see that significant steps are being taken at regional and national levels. Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English. https://bit.ly/2X7NJfP

13 February: Kevin Quaid shares his experience of diagnosis and his shift in perspective since joining the Irish Dementia Working Group

I was diagnosed with Lewy Body Dementia in 2017, aged 53. From the beginning I chose to be open about my diagnosis. Because of this decision my personal story has gradually become a communal journey; speaking publicly about living with dementia has brought me an international community of understanding. I want to challenge the stigma of dementia and encourage other people to be open.
As part of this work I self-published a book – “Lewy Body Dementia Survival and Me”. To my delight and surprise I am overwhelmed by the worldwide response from people who have read it and said that it was such a help to them. After diagnosis I would never have thought I would be an author. But this achievement has given me savage hope.

I joined the Irish Dementia Working Group, supported by The Alzheimer Society of Ireland, in early 2018. I enjoy the work, but what is really wonderful is that you meet other people living with dementia who want to advocate for change. We understand each other so well and there is a special bond. It’s great to meet people who ‘get’ exactly how you feel.

We have different diagnoses – I live with Lewy Body Dementia so I do not have issues with short term memory like my colleagues with Alzheimer’s disease. But I have issues with hallucinations, fear and broken sleep. And we all face the challenge of stigma.

The main focus of our most recent meeting was Taking Journeys and Travelling with Dementia, and each and every member had wonderfully practical ideas. I was reminded again of the value of asking the experts – people living with dementia!

I always loved to travel and we lived in Australia for five years. We have just returned from a three-month holiday there, with some of our family who live there and it was a fantastic holiday.

The trip gave me a new fight and a new strength to make sure that I am back there again next year when my daughter is getting married. Twelve months ago I was very very ill and it seemed just like a pipe dream, that I would be in Australia to give my daughter away on her wedding day, it has now become a reality.

For both Helena my wife and myself the day that I was diagnosed with Lewy Body Dementia was probably one of the darkest days of our lives. But since becoming an advocate and joining the Irish Dementia Working Group I have a new focus and a new purpose in my life. There are still dark days but there are also many days when I feel I have a wonderful life despite my diagnosis. I try to live my life to the fullest each and every day and at the moment it is working!

For further information: www.alzheimer.ie

DEMENTIA IN SOCIETY

6 February: German football legend Rudi Assauer has died due to complications from Alzheimer’s disease

Former Schalke technical director and club legend Rudi Assauer, who spent 18 years with the German Bundesliga club, passed away on 6 February. Mr Assauer, who publicly revealed he had Alzheimer’s disease in 2012, was 74 years old.

He was already a well-known and respected footballer in his own right, having played 307 games as a defender for two clubs, Borussia Dortmund and Werder Bremen, between 1964 and 1976. He won the 1965 German Cup and the 1966 European Cup Winners’ Cup with Dortmund.

Mr Assauer was, however, better known for his more recent role at FC Schalke 04, AKA the “Royal Blues”. He held this position from 1981-1986 and from 1993-2006 and during his second stint, the club won three trophies: two German Cups and the 1997 UEFA Cup.

NEW PUBLICATIONS AND RESOURCES

6 January: Dementia Engagement and Empowerment Project (DEEP) launches new website

The Dementia Engagement and Empowerment Project (DEEP), has launched a new website. DEEP is:

• A UK-wide network – It connects groups to each other to magnify the views, hopes and intentions of people with dementia. It supports groups to share learning and skills and to increase confidence
• Independent – The network belongs to the groups themselves, not to any particular dementia service or organisation
• Diverse – It is made up of groups strongly rooted in their local communities, including some in care homes
• Rights based – It encourages groups to identify and speak out about the issues that are important to them (not only to be consulted about issues that are important to others).

Check out the website, here:

https://www.dementiavoices.org.uk/
7 February: New guide published by Alzheimer’s Society (UK) aims to help with challenges faced when caring

If you are the main person supporting someone with dementia, a new guide published by the Alzheimer’s Society (UK) may help. Caring for a person with dementia can be a rewarding experience. But can also be challenging at times. As dementia progresses, the person may show changes that carers have not previously experienced, or were not expecting.

“Caring for a person with dementia: A practical guide” contains information and advice on all aspects of supporting someone with dementia, including:

- When the person doesn’t accept their diagnosis
- Needing a break from caring
- The person’s behaviour changes
- The person’s personal care needs change
- Deciding where the person will live.

Throughout the guide you’ll also find a wealth of information on many other issues you may face when caring for a person with dementia along with details on where to go for further advice or support.

More than 140 carers contributed to this guide, as well as health and social care professionals and other experts with specialist knowledge and experience. Check out the guide, here: https://bit.ly/2UKV0jt

EDUCATION

1 February: Registrations now open for KU Leuven 2019 Summer Course on Ethics in Dementia Care

The 5th edition of KU Leuven’s “Summer Course on Ethics in Dementia Care”, will take place in Leuven, Belgium, from 2 to 5 July 2019. The objective of the course is to foster exchanges on foundational, clinical-ethical and organisational-ethical approaches to dementia care practices.

During the course, national and international experts will give presentations on various ethical topics in the domain of dementia care. Time will be provided for intensive discussion and interaction.

The course is of interest to participants from diverse professional backgrounds, such as medicine, nursing, psychology, social work, health care administration, philosophy and theology, and to PhD students undertaking courses of study in these areas.

The language of instruction will be English and the deadline for registration and payment is 14 June 2019. An early bird registration fee is also available, until 15 May 2019. You can find more information here:


7 February: New Dementia MSc offered by University College London (UCL)

Applications are open for UCL’s new Dementia MSc course. The course, “Dementia: Causes, Treatments and Research (Neuroscience)” is offered jointly by the UCL Institute of Neurology and the Division of Psychiatry.

The course will provide “research-oriented and cutting-edge training in the study of dementia and its scientific basis, led by international leaders in the science and practice of dementia.” Two specialised pathways, in neuroscience and in mental health, are offered.

The deadline for applications is 26 July 2019.

Find out more: https://bit.ly/2TApu7F

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Contact Alzheimer Europe:
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## AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
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<th>AE representative</th>
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<tr>
<td>6-7 March</td>
<td>SyDAD annual meeting (Bordeaux, France)</td>
<td>Cindy</td>
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<tr>
<td>7-8 March</td>
<td>PARADIGM WP1/2 Workshop (Oxford, UK)</td>
<td>Ana</td>
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<tr>
<td>11 March</td>
<td>Preventive neurology initiative (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>18-20 March</td>
<td>EWGPWD meeting (Luxembourg)</td>
<td>Ana, Dianne</td>
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<tr>
<td>20-22 March</td>
<td>NEURONET kick-off meeting (Madrid, Spain)</td>
<td>Jean and Chris</td>
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<tr>
<td>22 March</td>
<td>AD-Detect-Prevent launch meeting (Copenhagen, Denmark)</td>
<td>Jean and Dianne</td>
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<tr>
<td>26-31 March</td>
<td>AD/PD Conference (Lisbon, Portugal)</td>
<td>Jean</td>
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<tr>
<td>27 March</td>
<td>Meeting with Biogen (Lisbon, Portugal)</td>
<td>Jean</td>
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<tr>
<td>27-28 March</td>
<td>PARADIGM WP3 Workshop and PARADIGM WP4 Workshop (Berlin, Germany)</td>
<td>Ana</td>
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## CONFERENCES 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
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<tbody>
<tr>
<td>20-23 March</td>
<td>13th Göttingen Meeting of the German Neuroscience Society, <a href="https://www.nwg-goettingen.de/">https://www.nwg-goettingen.de/</a></td>
<td>Göttingen, Germany</td>
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<tr>
<td>4-7 April</td>
<td>13th World Congress on Controversies in Neurology, <a href="http://www.comtecm.com">http://www.comtecm.com</a></td>
<td>Madrid, Spain</td>
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<tr>
<td>5-8 May</td>
<td>Understanding and Targeting Alzheimer’s disease, <a href="https://www.fens.org/Meetings/The-Brain-Conferences/Understanding-and-targeting-Alzheimer-disease/">https://www.fens.org/Meetings/The-Brain-Conferences/Understanding-and-targeting-Alzheimer-disease/</a></td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>15-18 May</td>
<td>World Psychiatric Association and Psychiatric Association of Macedonia Thematic Congress, wpadementia2019.com</td>
<td>Ohrid, Former Yugoslav Republic of Macedonia</td>
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<tr>
<td>8-9 June</td>
<td>International Forum on Women’s Brain and Mental Health: the gateway to Precision Medicine, <a href="http://www.forum-wbp.com">http://www.forum-wbp.com</a></td>
<td>Zurich, Switzerland</td>
</tr>
<tr>
<td>1-4 July</td>
<td>Royal College of Psychiatrists’ International Conference, <a href="https://www.rcpsych.ac.uk">https://www.rcpsych.ac.uk</a></td>
<td>London, UK</td>
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<tr>
<td>22-25 October</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague, Netherlands</td>
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