I would like to kick off this edition of our monthly dementia newsletter with a big congratulations to all our member organisations for their hard work this September, also known as World Alzheimer’s Month, particularly their activities for World Alzheimer’s Day (21 September). September is always a particularly busy month for Alzheimer’s associations across Europe and around the world, and is marked in a variety of different ways, all of which help to raise the profile of dementia, to support and advocate for people with dementia and to raise funds for dementia care and research.

On the project front, we have good news from Germany, where Federal Health Minister Jens Spahn and Federal Family Minister Franziska Giffey have given the go-ahead for the development of a national dementia strategy, during the launch of the “Allianz for People with Dementia 2014-2018” report. Congratulations to our German friends at the Deutsche Alzheimer Gesellschaft – DAlzG, who have been campaigning for this outcome since 2011 and who be pushing to try to ensure funding is available for implementing the future strategy.

At a European level, I am delighted to welcome a new member to our European Alzheimer’s Alliance (EAA) this month. We look forward to collaborating with MEP Ana Miranda (Spain) and hope to see her at future Alzheimer Europe lunch debates in the European Parliament in Brussels.

On the policy front, we have signed an open letter calling for strengthened provisions to be included within the Disability Act, legislation which would govern accessibility of goods and services. Signed by 20 NGOs, it outlines the areas of the Act needing to be strengthened and calls specifically for an agreement between the European Parliament and Council on the Act.

Finally, the 28th Alzheimer Europe Conference (#28AEC) is fast approaching and registrations will close on 19 October, so make sure you book your place now to avoid disappointment!

Jean Georges
Executive Director
ALZHEIMER EUROPE

16 September: Helen Rochford Brennan features in biggest Sunday newspaper in Ireland

Helen Rochford Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD) and Board member of Alzheimer Europe, is the subject of a profile published in the Sunday Independent newspaper (Ireland), on 16 September. The feature, which has already been widely shared via social media channels, paints a picture of Helen’s life before and since being diagnosed with Alzheimer’s dementia in 2012. It showcases the amazing advocacy work she does and emphasises that “if disabilities are well managed and supported by the community, those living with them can continue to lead productive and meaningful lives.”

Helen, also a former chair of the Irish Dementia Working Group, tells readers about her many methods of staying organised, when preparing to travel to and present at a large number of international conferences, where she has addressed royalty, governments, the European Parliament, the World Health Organization, national and international Alzheimer associations and global pharma companies. No mean feat, but her incredible work ethic together with support from both The Alzheimer Society of Ireland and Alzheimer Europe make it possible.

In summary, Helen has this to say: “please do not lose your voice to dementia.” She certainly hasn’t.

https://bit.ly/2OGz4n0

20 September: Alzheimer Europe accredited by WHO Europe

During the 68th session of the WHO Regional Committee for Europe, which took place in Rome from 17 to 20 September, a resolution accrediting 19 regional non-State actors not in official relations with WHO to attend future Regional Committee sessions was unanimously adopted. Alzheimer Europe is delighted to be one of those accredited, allowing us to develop a closer collaboration with the Regional Committee and contribute more actively to the implementation of the global dementia plan at a European level.


26 September: Make sure you register for 28AEC before 19 October!

Delegates can register for the 28th Alzheimer Europe Conference (#28AEC) in Barcelona until 19 October. The conference, “Making dementia a European priority” will take place from 29 - 31 October.

The full conference registration fee includes:
- Admission to all scientific sessions
- Delegate bag and final programme including the abstract book
- Opening ceremony on 29 October
- Scheduled coffee breaks on 30 and 31 October
- Scheduled lunches on 30 and 31 October

Special rates are available for people with dementia, students, delegates from lower and middle-income countries and members of CEFA or Fundación Alzheimer España.

For more information on registrations: https://bit.ly/2lw80Va
For detailed programme and abstracts: https://bit.ly/2Qocr01
Download Attendify, our official mobile app and join the event community, event name “28th AE Conference”: https://attendify.com/app/iaa2wt/
For travel information: https://bit.ly/2Osi02z
Follow the event on Twitter: #28AEC

28th Alzheimer Europe Conference - Meet the speakers

Our 28th annual conference #28AEC is fast approaching and we are very much looking forward to seeing you all in Barcelona from 29 to 31 October.

The exciting programme, around the theme of “Making dementia a European priority”, includes 23 keynote speakers. They hail from 9 different European countries and cover a wide variety of specialisms including prevention, care, diagnosis, pharmacologic and non-pharmacologic treatments, geriatric psychiatry, mental health and dementia policy, psychosocial innovations, psychology, ethics and nursing science. You can find out who they are and learn more about each of them here: https://www.alzheimer-europe.org/Conferences/Barcelona-2018/Keynote-Speakers

To find out what each will present and when, please see our conference programme: https://www.alzheimer-europe.org/Conferences/Barcelona-2018/Detailed-programme-and-abstracts
Alzheimer Europe networking

On 6 September (Luxembourg), Ana gave a presentation in a PARADIGM webinar on patient engagement on medicines research and development.

On 9 September (Brussels, Belgium), Owen participated in the European Public Health Alliance (EPHA) Core Group Meeting.

On 12 and 13 September (Barcelona, Spain), Chris attended the 4th General Assembly meeting of the MOPEAD project.

On 13 and 14 September (Prague, Czech Republic), Jean gave a presentation on Alzheimer Europe’s Dementia Monitor and Yearbook on care standards in residential settings at the 1st Conference of the European Ageing Network (former E.D.E.-EAHSA).

On 19 September (Brussels, Belgium), Owen met with Irene Oldfather, a member of the European Economic and Social Council (EESC), to discuss potential collaboration between Alzheimer Europe and EESC.

On 25 September (London, United Kingdom), Jean participated in a meeting of the Patients’ and Consumers’ Working Party of the European Medicines Agency.

On 25 September (Luxembourg), Ana and Dianne presented a webinar on “PPI in Dementia Research: The example of the EWGPWD” in the context of the EPAD Academy.

On 26 September (Brussels, Belgium), Owen attended the European Federation of Pharmaceutical Industries and Associations (EFPIA) Patient Think Tank.


On 27 and 28 September (Toulouse, France), Jean and Cindy attended the General Assembly Meeting of the PRODEMOS project. From 27 to 29 September (Valencia, Spain), Gwladys attended the INDUCT School Venues European Client/Supplier Business Workshop.

Follow us on Twitter

EU PROJECTS

28 August: EPAD publishes a new paper in the Journal of Medical Ethics

A paper authored by the ethics group within the European Prevention of Alzheimer’s Dementia (EPAD) project was recently published in the Journal of Medical Ethics. The paper entitled “On the personal utility of Alzheimer’s disease-related biomarker testing in the research context” was led by the EPAD fellow Eline Bunnik from the department of medical ethics and philosophy of medicine, Erasmus MC in Rotterdam (The Netherlands).

In this paper, the claim that Alzheimer’s disease (AD) biomarkers have personal utility for asymptomatic individuals is critically assessed. It demonstrates that in the absence of clinical validity, AD biomarkers cannot have personal utility and do not serve research participants’ autonomy.

http://dx.doi.org/10.1136/medethics-2018-104772

31 August: Introducing the newest addition to the INDUCT project

Angie Alejandra Diaz is the new INDUCT Early Stage Researcher (ESR15). Alejandra is originally from Colombia and is a Neuropsychologist. Based in IDES/Spain, she will be evaluating the effectiveness of new technologies, such as the GRADIOR, for use in cognitive rehabilitation for people with mild dementia in Spain. The randomised clinical trial in which the GRADIOR will be tested, started in September and will recruit around 50 people with dementia. She will continue to perform neuropsychological evaluation at the University Hospital of Valladolid, with the aim of recruiting the sample for the randomised clinical trial.

Alejandra is currently writing her first INDUCT scientific paper entitled "Computer-based cognitive rehabilitation programs for mild dementia and MCI-GRADIOR. New features". She is excited to meet all the consortium members for the first time, in Prague this month, at the fourth INDUCT School at Charles University. For more information about Angie’s work, please contact adb@intras.es or alejadiaz93@usal.es http://www.dementiainduct.eu/

31 August: ROADMAP updates us on recent progress

As the end of ROADMAP Phase 1 approaches, the project teams have been busy over recent months. Here we report on their latest activities.

The Project Coordination team, has been managing the Data Cube, taking responsibility for data collection, the quality checking of these data, and the development of the relevant IT infrastructure. It has also been convening several meetings to be held in October – the final ROADMAP General Assembly Meeting in Madrid, ROADMAP presentations at the Clinical Trials in Alzheimer’s Disease (CTAD) Conference and the Alzheimer Europe Conference (#28AEC), both taking place in Barcelona.
Among its other activities, the Outcome Definition team, has also been involved in the development of the Data Cube, overseeing its disease outcome and disease-staging component. Alongside this, the team is developing three manuscripts including findings from its survey, Public Patient Involvement consultations as well as mixed methods analysis. The team also recently held a presentation at the Alzheimer’s Disease International conference in August, featuring in a panel debate entitled “Women in Dementia”.

The Real-World Evidence Identification team, has almost completed populating the Data Cube, having collected 71 data sets. In addition to this, they have ongoing requests for further data, relating to Quality of Life, Presymptomatic Alzheimer’s disease modelling, and Time to Institutionalisation modelling. The Disease Modelling and Simulation team, has generated the Mini-Mental Status Examination (MMSE) model for a variety of data sources, and for comparative purposes has also obtained the Kuşoğlu et al. project data from which the model was developed. In September, the team also shared the data of the pre-clinical model for validation with the ROADMAP Consortium.

A wide range of activities have been conducted by the Health Economics team. In June, they made a presentation at the 38th Spanish Health Economics Association Conference in Las Palmas (Spain), entitled “Health-related quality of life in people with dementia measured with preference-based instruments: a systematic literature review and meta-analysis”. They also finalised two manuscripts for peer-review, namely “Health-related quality of life in people with pre-dementia or dementia measured with preference-based instruments: a systematic literature review” and “Resource utilization and costs in pre-dementia and dementia - a systematic literature review”. In addition, the team has finalised the data extraction and quality assessment for their systematic literature review of economic models, and identified the necessary data sets for mapping Quality of Life in Alzheimer’s Disease (QoLAD) to the generic EQ-5D health status measurement instrument. Finally, the team has defined the structure of their proof-of-concept health economics model for Alzheimer’s disease.

The Regulatory and Health Technology Assessment team has been similarly busy. They convened a face-to-face meeting of the Expert Advisory Group (EXAG) in September, and they currently prepare for the next virtual meeting, which will be held in October. The team also circulated an EXAG questionnaire and already presented an outline of preliminary results at the Guidelines International Network (G-I-N) Conference during a poster presentation. In addition, the team has been assessing the main regulatory and health technology assessment considerations relevant to a disease-modifying drug in Alzheimer’s disease, findings are due to be submitted in form of a manuscript for peer review to CNS Drugs.

The Communications team, has been working with the Project Coordination team in organising a ROADMAP event, entitled “Real-world evidence in Alzheimer’s disease” at the 2018 Alzheimer Europe Conference. ROADMAP colleagues will be making a range of presentations throughout four parallel sessions and a plenary talk by Project Coordinator John Gallacher. In addition, the team is currently finalising a conference brochure for the event. The team has also been involved in the development of a video introducing the Big Data for Better Outcomes (BD4BO) programme. Its final report on dissemination activities is currently under review.

Finally, the Ethical, Legal, and Social Implications team has much to report. Brent Mittelstadt has replaced Andrew Turner as co-lead of the team on behalf of the University of Oxford, and the whole of ROADMAP extends their thanks to Andrew for his invaluable contribution to the project. The team also has updates for three papers. Their manuscript on patients’ attitudes towards data sharing is undergoing peer review, as is their manuscript about reviewing justifications for greater sharing, transparency, and access to clinical trial data. Their manuscript on the ethics of outcome prioritisation in Alzheimer’s disease recently underwent a final round of internal reviews by the Consortium and will be submitted for peer-review shortly.

https://roadmap-alzheimer.org/

6 September: PARADIGM organises a webinar on patient engagement

On 6 September, the four patient organisations involved in PARADIGM (EPF, EURORDIS, EATG and AE) and a research foundation working with children and young people organised a webinar in the topic of patient engagement in the process of developing medicines. The webinar was organised for patients, carers and representatives from patient organisations with an interest in the topic. It was attended by over 100 participants.

The presentations described the way different patient groups are working in this area and some of the challenges that still need to be addressed. The presentations and a video of the webinar are available at this link: https://imi-paradigm.eu/patient-engagement-webinar-06-09-2018/

13 September: PARADIGM and PREFER connect to make patient engagement in medicines R&D a greater reality

The two Innovative Medicines Initiative (IMI) consortia PARADIGM, Patients Active in Research and Dialogues for an Improved Generation of Medicine (co-led by the European Patients’ Forum and the European Federation of Pharmaceutical Industries and Associations) and PREFER, Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle (co-led by Uppsala University and Novartis) have established a Memorandum of Understanding aiming to enhance the cooperation and collaboration between the two projects. While PARADIGM is broadly focused on
patient engagement at three points in the R&D process, PREFER looks at how and when it is best to perform and include patient preferences in decision making during the medical product life cycle.


13 September: MOPEAD project holds 4th General Assembly Meeting in Barcelona

On 12-13 September (Barcelona, Spain), the Models of Patient Engagement for Alzheimer’s Disease (MOPEAD) project held its 4th General Assembly meeting. MOPEAD identified four models for the early identification of mild Alzheimer’s disease (AD) dementia and prodromal AD patients (online screenings, screenings during open house days at memory clinics, screenings at diabetologists offices and at general practitioner offices). These have now been established in five countries (the Netherlands, Slovenia, Sweden, Spain and Germany) and will be compared and contrasted at the end of the project. The meeting was hosted by Fundació ACE and chaired by Mercè Boada (Project Coordinator) and Laura Campo (Project Leader).

A main subject of discussions during the meeting focussed on the progress of screenings at each study-site. One of the main challenges encountered during the project was the participation of general practitioners in the study. The reasons that potentially hindered participation will be explored through surveys for general practitioners on their attitudes towards early diagnosis of Alzheimer’s disease.

Presentations during the first day of the meeting also displayed some of the other challenges encountered at each of the study-sites. At the same time, they provided a basis for exchange on how to overcome some of them including best practice advice. A main conclusion was that especially challenges encountered are very valuable and they should be compiled to develop a structured overview that can be made available to the scientific community.

Discussions during the second day focussed on outstanding questions on how to model the economic costs of each method as well as plans for the statistical modelling. After that, a representative from GMV gave insights into some technical aspects of the project such as the common protocol for evaluation progress overview and the implementation of the diagnostic protocol.

This was followed by feedback and recommendations from Lutz Frölich (External Advisor) and presentations on MOPEADs communication work, including a new introductory video that is being finalised as well as an overview of upcoming publications.

https://www.mopead.eu/

20 September: MinD project team works on design prototypes and prepares for evaluation

In September, the MinD team was working, once again, in Germany and in The Netherlands. Alexianer St Hedwig Hospital, Berlin, TU Dresden, U Twente, Zorggroep Sint Maarten and Panton Design are hosting researchers from the various partner countries and disciplines to work together.

Researchers continue to work on the realisation of the prototypes of two designs, and on preparing for their evaluation. Conceptual development and programming are rapidly progressing for the Social Engagement Map, an interactive platform, which aims to help people with dementia to stay active and socially engaged. The team is also working on the refinement of the Good Life Kit, which aims to support people with dementia in approaching everyday life confidently. Key, is the final improvement of the concept and translation into four languages (English, German, Dutch and Spanish). Dutch design students from the University of Twente, supported by partner Panton, are helping with the realisation of the prototypes.

The initial framework for evaluation of the Good Life Kit and the Social Engagement Map with people with dementia, which was developed in Luxembourg in July, is being revisited. Healthcare partners from the four countries (UK, Germany, Netherlands, Spain) are shaping it to accommodate their local situations.

Looking ahead, the MinD team is preparing for its first international conference MinD2019. The conference will be held on 19-20 September 2019 at the Technische Universität Dresden, and is supported by the Special Interest Groups on Design for Behaviour Change and on Wellbeing and Happiness of the Design Research Society. The conference will provide a trans-disciplinary forum for researchers, practitioners, end-users and policy makers from the design and health care professions to exchange and discuss new findings, approaches and methods for using design to improve dementia care and to support people with dementia and their carers.

www.mind4dementia.eu

21 September: EPAD recruits 1000th participant

On World Alzheimer’s Day, the European Prevention of Alzheimer’s Dementia (EPAD) project reached a new milestone, with the EPAD Cohort study having screened more than 1,000 research participants. To announce this great news, the EPAD project published a press release.

EPAD is one of the world leading dementia prevention studies, led from the University of Edinburgh. It is a Europe-wide collaboration aiming to improve the understanding of the early stages of Alzheimer’s disease. The EPAD project offers a unique platform for testing and developing preventative
treatments for Alzheimer’s dementia. “We want to stand with the young academics and researchers helping to find a cure or amelioration for dementia”, said a research participant in the EPAD study.

EPAD is set up to recruit from existing cohort studies as well as clinics across Europe. It has established the first pan-European register including more than 30,000 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 Cohort study, involving regular health checks, standardised tests and brain scans. All participants are followed up over several years. Many participants in the EPAD Cohort study may be invited to participate in the EPAD Proof of Concept Trial to test new treatments for the prevention of Alzheimer’s dementia.

“Recruiting from the EPAD Cohort allows us to select the right people for the drug studies who are most likely to benefit from them. We are very grateful to have reached 1,000 participants in this globally important project”, said Professor Craig Ritchie, EPAD Co-coordinator. Participants in the EPAD Cohort are contributing to the advancement of science around dementia prevention in 20 locations across 7 European countries (i.e. France, Italy, the Netherlands, Spain, Switzerland, Sweden and UK).

25 September: Alzheimer Europe participates in EPAD Academy Webinar

On 25 September, AE members of staff Dianne Gove and Ana Diaz, together with the Chair of the EWGPWD, Helen Rochford-Brennan, presented the work led by AE in PPI in dementia research. The webinar was part of a series of webinars organised by the EPAD Academy. It was attended by 20 members of EPAD, including some EPAD fellows.

The presentation provided information about the understandings and definition of PPI in research and addressed some of the challenges and opportunities of conducting PPI in the field of dementia. Presenters also provided concrete examples of involving people living with dementia in different European projects and research through PPI. The chair of the EWGPWD referred to the relevance of PPI from the perspective of a person living with dementia and to her own personal experience of being involved in PPI activities.

EU project acknowledgement

A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.

The projects in this newsletter with EU funding are:

- EPAD – grant agreement 115736
- MOPEAD - grant agreement 115985
- PARADIGM - grant agreement 777450
- ROADMAP - grant agreement 116020

Members of the European Alzheimer’s Alliance

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

- Austria: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP).
- Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (ALDE).
- Bulgaria: Andrey Kovatchev (EPP).
- Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).
- Cyprus: Costas Mavrides (S&D); Eleni Theocharous (EPP).
- Czech Republic: Olga Sahnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovsky (EPP).
- Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D).
- Estonia: Urmas Paet (ALDE); Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE).
- Finland: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miepetra Kumpula-Natvi (S&D); Merja Kyllöne (GUE/NGL); Sirpa Pietikäinen (EPP).
- France: Dominique Bilde (EFN); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D).
- Germany: Angelika Niebler (EPP); Udo Voigt (Ni).
- Greece: Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL);
- Hungary: Ádám Kósza (EPP); Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE).
- Italy: Brando Benifei (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Remo Sernagiotto (EPP);
- Latvia: Vija Bliknevičute (S&D);
- Lithuania: Vilija Bliknevičute (S&D);
- Luxembourg: Georges Bach (EPP); Frank Engel (EPP);
- Malta: Roberta Metsola (EPP); Alfred Sant (S&D).
- Netherlands: Gerben-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP)
- Poland: Elżbieta Łukacijewska (EPP); Kryzyna Łybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP). Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL);
- Romania: Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP); Daciana Octavia Sârbu (S&D); Claudeu Ciprian Tanasescu (S&D); Renate Weber (EPP).
- Slovakia: Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborska (EPP); Jana Žitňanská (ECR).
- Slovenia: Nada Maric (S&D); Amel Niebler (EPP).
- Spain: Silviu Busoi, MEP (EPP); Marian Harkin (ALDE); Brian Hayes (EPP);
- Sweden: Kristina Gemperle (EPP); Annegret Kramp-Karrenbauer (CDU/CSU); Lena Adelsohn Liljeroth (S&D).
- Switzerland: Silviu Busoi, MEP (EPP); Roberta Metsola (EPP).
- United Kingdom: Paul Rübig (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI).
**EUROPEAN ALZHEIMER’S ALLIANCE**

*4 September: MEP Ana Miranda joins European Alzheimer’s Alliance*

Alzheimer Europe is delighted to announce that on 4 September, Ana Miranda, MEP (Spain) joined the European Alzheimer’s Alliance. Representing the Galician region of Spain, Ms Miranda presently sits on the Committee on Petitions and is a member of the Delegation for relations with the United States.

We look forward to working with her to make dementia a European priority in order to improve the lives of people with dementia, their families and carers.


**EU DEVELOPMENTS**

*1 September: European Parliament Committee proposes amendments to European Commission Work-Life Balance Directive*

The European Parliament Committee on Employment Committee on Employment and Social Affairs has published its report on the legislative proposals of the European Commission and Council for a directive in relation to parental and carers leave.

The Commission’s proposed directive is one of the first deliverables of the European Pillar for Social Rights and is based on the ‘New Start’ initiative aimed to address the work-life balance challenges faced by working parents and carers. The initiative aims to give effect to the objectives set out in the Treaty of equality between men and women with regard to labour market opportunities and equal treatment at work and the promotion of high level of employment in the EU.

The Committee’s Report is the culmination of extensive review of the proposed directive, including the opinions of both the Committee on Women’s Rights and Gender Equality, and the Committee on Legal Affairs.

Under the Commission’s existing legislative proposals, carers would be able to take up to five days per year, compensated at least half the level of sick pay within that country. The Committee’s Rapporteur, David Casa MEP, has proposed an amendment that, if adopted, would entitle to be paid at least equivalent to 75% of their gross wage, to ensure a greater consistency of income protection is across countries.

https://bit.ly/2MCn0q1

*7 September: EU Commission Appoints New Head of DG Sante*

The European Commission has appointed Anne Bucher, current chair of its Regulatory Scrutiny Board, to become the new Director-General of the department of health and food safety, DG SANTE.

Ms Bucher, a French economist, has worked for the Commission for 35 years, most recently having responsibility for preventing unnecessary and overly complicated EU legal proposals as part of the Commission’s ‘better regulation’ philosophy.

Ms Bucher takes her new post as of 1 October, replacing current head Xavier Prats Monné who has led the department since 2015.

*27 September: European Medicines Agency launches new website*

The European Medicines Agency (EMA) has launched a new version of its corporate website, aiming to further improve communication cooperation with partners and stakeholders and to support outreach to EU citizens.

The new website, updated in close collaboration with the European Commission (DG DIGIT), has cleaner display on mobile devices, simpler URLs, an updated visual design and an improved search function. The website content and structure remains unchanged and current URLs for every page and document will continue to work.

www.ema.europa.eu

*27 September: Alzheimer Europe signs open letter on Accessibility Act*

Alzheimer Europe has signed an open letter calling for strengthened provisions to be included within the Disability Act, legislation which would govern accessibility of goods and services.
Written by the European Disability Forum, the letter outlines the areas of the Act which we believe should be strengthened, including:

- Including Public Procurement, EU Funds, and TEN-T regulation within the Act.
- Inclusion of the Built environment (Many products and services would remain inaccessible even if they comply with the Accessibility Act).
- Enabling Necessity of Urban Transport in line with the United Nations Convention on the Rights of Persons with Disabilities. Many of the provisions of the Act (e.g. access to work, to education, to culture or to healthcare) depend on transportation.
- Including Emergency services to ensure universal accessibility of emergency services by using accessible call systems (e.g. real time text).
- Inclusion of micro-enterprises as around 93% of products and services are created by them.

We have encouraged member organisations to get in touch with their national Governments to ask them to support these strengthened provisions to ensure that people with dementia and other conditions can benefit from more accessible services and supports in their communities.


WORLD ALZHEIMER’S DAY

31 August: ADI launches awareness-raising documentary for World Alzheimer’s Month

To mark the start of World Alzheimer’s Month (September), Alzheimer’s Disease International (ADI) has launched a documentary called “Every 3 Seconds”, so-named because every three seconds someone around the world develops dementia. The documentary aims to raise awareness of the impact of dementia, to highlight the need for a more concerted global response to this challenge and to work towards reducing stigma.

The film was created in association with a range of academic, research and care organisations from around the world, to chart the human, social and economic impact of dementia globally around the condition.

www.alz.co.uk/everythreeseconds

6 September: CEFA presents its World Alzheimer’s Day activities

Cheles Cantabrana, the Spanish Alzheimer’s Confederation President, and María del Carmen Orte, IMSERSO General Director, spoke at the presentation of the World Alzheimer’s Day on 6 September. They presented CEFA’s activities for World Alzheimer’s Day on 21 September.

“Alzheimer’s Social Awareness”:

“In CEFA, we believe this message should serve to claim the necessary awareness that must exist to ensure an adequate comprehensive approach to Alzheimer’s disease that, in addition to confronting its socio-sanitary effects, put in the spotlight the observance of the affected people’s rights (patient-caregiver binomial), while respecting their dignity.”

“Dementias are the main cause of dependency and always involve both the dependent person and the person/persons who care for (binomial). Therefore, society, administrations, associative network ... must be aware of this reality and the socio-sanitary problems we face.”

For CEFA “it’s essential to consider Alzheimer’s and other dementias differently, so that the interests, needs, and above all, the affected people’s rights are correct, adequate and fully represented and defended. We must ensure to give legitimisation and own entity to certain areas that characterise people living with Alzheimer’s and other dementias.”

Speaking of “socio-sanitary integration”:

“It is necessary to address in a specific, particular and differentiated way the disease itself, but, above all, the effects it causes in the affected person: advanced ages, dementia feminisation, stigmatisation, social, psychological and health incidence in the caregiver... Therefore, we should consider the concept of socio-sanitary integration as a new care model, in which both the person with the disease and the binomial concerned patient-caregiver are the centre of attention.”

With the slogan “Alzheimer’s Social Awareness”, CEFA calls not only for the necessary awareness towards a comprehensive approach to Alzheimer’s disease but also wants to support any action or measure based on contrasted and testable evidence, while requiring a greater commitment to science, both biomedical and social or socio-sanitary, since it is the only resource to advance towards the eradication of the disease, as well as its consequences.”

Ms Cantabrana concluded by showing “CEFA’s commitment to support the National Alzheimer’s Plan that this country needs and that more than 4.8 million people demand and deserve.”

Pictured: left, Ms, Carmen Orte, General Directress of IMSERSO (Instituto de Mayores y Servicios Sociales); right, Ms. Cheles Cantabrana, President of CEFA
14 September: Federazione Alzheimer Italia reports on its conference and photo exhibition marking World Alzheimer’s Day

Being the voice of the persons with dementia is a priority for Federazione Alzheimer Italia (FAI). For this reason, to mark the 25th World Alzheimer’s Day and of the 7th World Alzheimer’s Month, FAI organised a special conference and exhibition in Milan on 14 September, dedicated to the theme of innovation at the service of the person with dementia, which means observing and listening to the persons with the disease, knowing their needs, their values, their interests. Only in this way is it possible to change the modality of assistance with an approach that starts from the person and not from the illness.

After the welcome greeting of President Salvini Porro, the tight schedule of the day included the intervention of special guest Kate Swaffer, present at the conference to concretely give a voice to people with dementia. Ms Swaffer specifically flew in from Australia to bring her testimony as a person living with dementia. Other speakers were Stefano Govoni, professor of Pharmacology at the University of Pavia; Carlo Defanti, scientific director of the FERB Alzheimer Center of Gazzaniga (Bergamo), who spoke about the European “RECAGE” project (Respectful Caring for the Agitated Elderly); Silvia Vitali, geriatrician and medical director of the Geriatric Institute Camillo Golgi of Abbiategrasso; Antonio Guaita, geriatrician and director the Golgi Cenci Foundation of Abbiategrasso, and Marco Fumagalli of Coop. Meridiana.

Other speakers were Stefano Govoni, professor of Pharmacology at the University of Pavia; Carlo Defanti, scientific director of the FERB Alzheimer Center of Gazzaniga (Bergamo), who spoke about the European “RECAGE” project (Respectful Caring for the Agitated Elderly); Silvia Vitali, geriatrician and medical director of the Geriatric Institute Camillo Golgi of Abbiategrasso; Antonio Guaita, geriatrician and director the Golgi Cenci Foundation of Abbiategrasso, and Marco Fumagalli of Coop. Meridiana.

The morning concluded with Mario Possenti, general secretary of FAI, who illustrated the initiative of the Dementia Friendly Communities at both national and international level, describing how it fits into the Global Plan for Dementia, adopted last year by the WHO.

The afternoon session was dedicated to the presentation of four “Dementia Friendly Communities”, in Albino (Bergamo), Cicala (Catanzaro), Cavedine (Trento) and Abbiategrasso (Milan).

Also on 14 September, in Palazzo Marino, FAI organised a photo exhibition on “Love, loss and laughter - Seeing Alzheimer’s differently” by American photographer Cathy Greenblat: 14 images (selected from the 100 pictures in her book of the same name) portraying people with dementia in everyday moments, with family members or care-givers. The goal is to show how, even after the diagnosis has been communicated, the person with dementia can continue to relate well to others and live a meaningful life.

The exhibition is also being simultaneously shown throughout the month of September in 34 cities across Italy.

www.alzheimer.it

17 September: Czech Alzheimer Society translates ADI booklet and creates infographic postcard to mark “Memory Week”

“10 Warning Signs”, a leaflet by Alzheimer’s Disease International (ADI), has come alive in Czech language and in a new infographic made by the Czech Alzheimer Society. The Society was pleased to release both during “Memory Week” 2018, observed in the Czech Republic from 17 to 23 of September.

“We already enjoy the public response, it seems that this way the issue of memory problem can draw more attention” said the Society. The Society also plans to display a 10 Warning Signs poster at various events.

An information campaign was held at 25 contact points (mostly residential social care providers) as well as “Mobile Counselling Centres” in 4 shopping malls, where dementia professional provided free consultancy (memory problems, early diagnosis, post-therapeutic support, information for carers etc.), and in more than 40 places around the Czech Republic, the Society provided free memory testing.

21 September: Flemish dementia centre launches SaniMemorix campaign on World Alzheimer’s Day

On World Alzheimer’s Day, 21 September, the Expertisecentrum Dementie Vlaanderen (Flanders Centre of Expertise on Dementia) launched a new campaign focusing on primary prevention of dementia. The SaniMemorix campaign was launched simultaneously in Flanders (Belgium), Norway, Germany, Luxembourg and the Netherlands.

The Expertisecentrum worked together with the Alzheimer Liga Vlaanderen (Alzheimer League Flanders) to distribute “vaccin boxes” at railway stations across Flanders.

A number of teaser films were also used to spread the word via social media channels and a press conference took place with the Flemish and the Brussels Ministers for Health and Welfare, who funded this campaign. The organisers also worked with Flemish and Brussels pharmacies, who provided
information to their customers, regarding dementia and prevention. The campaign film can be viewed here, in English:  
https://youtu.be/UY_LTaWEceU

21 September: ADI launches 2018 World Alzheimer Report on dementia research

This World Alzheimer’s Day, Alzheimer’s Disease International (ADI) released its World Alzheimer Report 2018 – “The state of the art of dementia research”. The report looks at where dementia research is globally, exploring stumbling blocks and looking at new work in the field. The report also underlines ADI’s call for increased dementia research funding.

https://www.alz.co.uk/media/180921

21 September: Federazione Alzheimer Italia presents “Jar of Memories” project

Anna Maria the elegant teacher, Enrico the polyglot engineer, Luigi the entrepreneur who loves sailing, Knut the German engineer passionate about golf. What do they have in common? All four of them are persons living with mild dementia. And they are the four protagonists of a new project by Federazione Alzheimer Italia (FAI), which seeks to offer people with dementia the opportunity to be real spokespersons for the complexities and difficulties of the disease, with the end goal of devising more effective strategies to support them and to fight their isolation.

Once a week, for almost a year, the four have been meeting at FAI headquarters in Milan to discuss various topics concerning the evolution of the disease, in the presence of a psychologist and an occupational therapist. Each of them openly shares his/her experiences, strategies put in place to cope with daily difficulties, doubts and fears, but also suggestions and messages that they would like to share outside the group context.

“In Italy there are over 1,200,000 persons affected by the disease, and this means that many families are also affected. There is no cure as yet, but there is still a lot that we can do,” declares Gabriella Salvini Porro, President of FAI. “Let’s move from an approach centred on the disease to an approach centred on the person: recognise that the person is not a passive object but an individual with his/her own history, identity, personality. Focus on the people: let them and their families speak, listen to their daily needs: this is our mission”.

During the last months Anna Maria, Enrico, Luigi and Knut have received a present: a tool which is a support in the group discussions and that is intended to help maintain important memories of their life. This is a jar, in which they are invited to store objects that remind them of their personal histories. A pair of gloves worn on someone’s wedding day, a black and white picture of someone’s sister, a worn out golf ball, a shell collected at the seaside: they are all placed in the “Jar of Memories”.

Meeting after meeting, the four contribute to defining the best possible uses of this jar. The project is in its initial phase and its real benefits still need to be verified, but it hopes to be a real support to people with dementia.

A video, made by creative agency Bitmama and launched on the occasion of the 25th World Alzheimer’s Day, 21 September, provides a visual description of the use of this special “Jar of Memories”: https://www.youtube.com/watch?v=9riy58oWFvg

www.ilvasodeiricordi.it

21 September: AMPA Monaco reports on its celebrations for World Alzheimer’s Day

To celebrate World Alzheimer’s Day, AMPA, Monegasque Association for research on Alzheimer’s disease organised 3 events.

On 17 September, AMPA published the Monegasque support booklet for family carers to help understand Alzheimer’s disease and accompany a person with a neurodegenerative disease. As the Professor Alain Pesce points out: “the family of those with neuro-degenerative diseases, the “carers”, are constantly looking for information and advice and that’s a good thing!” Based on this observation and upon AMPA’s initiative, the Monegasque geriatric service has put together a 60-page booklet for Monegasque families with detailed information on Alzheimer’s disease, its symptoms, risk factors, the situations to avoid and the right attitudes to adopt.

This booklet is instructive and covers the principal questions often asked by families. It describes behavioural issues, the evolution of the disease... and also encourages the public to go for a memory consultation in Monaco.

“I am convinced that it is possible to have a good quality of life despite having Alzheimer’s disease”, says Catherine Pastor. And this booklet aims to make this a reality: practical advice for carers, improving everyday life (morning routine, shower, meals, activities, night-time) and also anticipating certain situations like admission to an institution or wealth management. Other subjects, which are covered: the importance of maintaining social relations and communication and how to deal with “abnormal” behaviour. This booklet offers useful advice that can be used in a number of situations. This booklet also lists the specialised structures in Monaco, the available support, the different representatives and professionals who are likely to intervene in a home care situation.

This booklet is also part of psycho-educative programme for carers which will be available on AMPA’s website very shortly.
The booklet is available to download for free on AMPA's website.

On 20 September, as part of the 1st salon for domestic assistance and personal services in Monaco, AMPA organised a healthy aging morning for people with Alzheimer’s disease, their families and their carers. Everyone appreciated several activities and demonstrations of dance, Zumba and singing.

Also on 20 September, a Public Conference on “Alzheimer: The pathway of care and prevention” was given by the Professor Alain Pesce and Catherine Pastor, President of AMPA. http://ampa-monaco.com/pdf/AMPA_Brochure_Prog_Soutien_Hidants_web.pdf

21 September: Greece celebrates World Alzheimer’s Month

World Alzheimer’s Month (September) and especially World Alzheimer’s Day saw a calendar full of events that were open to the public and free of charge across Greece, organised by member associations of the Panhellenic Association of Alzheimer’s Disease and Related Disorders:

Athens
A march on the development of Friendly Communities (Athens Alzheimer Association), memory tests and training of Health Professionals (Mrs Parasiri Vasiliki, Board member), speeches on the first signs and the prevention of the disease as well as memory tests (Karelleio Alzheimer’s Institution) and a seminar on Dementia (by Nestor).

Thessaloniki
An all-day information stand on the waterfront in the city, where specialised personnel gave reliable information to the citizens about the disease, speeches all over the city, a theater play and an art exhibition as well as the launch of a children’s book on Alzheimer’s (Alzheimer Hellas). Alzheimer Hellas also participated in the 1st European Sport Event Forum that took place in Athens from 21 to 23 September.

Crete
The 6th Pan-Cretan Interdisciplinary Congress on Alzheimer’s Disease and Related Disorders as well as the 2nd Pan-Hellenic Congress on Active and Healthy Ageing took place from 27 to 30 September in Heraklion, Crete (Alzheimer’s Disease and Related Disorders Association of Heraklion Perfection “ALLILENGII”).

People of all ages ran and walked in the “Run-Walk For Memory” in Chania, Crete raising awareness of the disease (Chania Alzheimer Institute).

Elsewhere
Information seminars in Serres (by SOFPSI association), Patra (by Frontizo association) and Chalkida (by Alzheimer’s Disease and Related Disorders Association of Chalkida).

21 September: Alzheimer Switzerland organises a living library on dementia

On World Alzheimer’s Day, Alzheimer Suisse (Alzheimer Switzerland) organised a “living library” on the topic of dementia, in Bern.

Visitors to the library could “borrow” real people and learn about their professional or personal experiences with dementia. Readers were able to meet: a music therapist working closely with people with dementia; an experienced nurse; a doctor; and the wife of a man with a dementia with Lewy bodies. By providing a framework for conversation about issues on dementia, Alzheimer Switzerland aimed to help spread knowledge, overcome prejudices, raise awareness and strengthen the understanding of dementia in Switzerland.

The event was a pilot for two more living libraries in the Italian and French speaking parts of Switzerland.

21 September: Alzheimer Larissa Greece celebrates autumn and World Alzheimer’s Day

Alzheimer Larissa Greece (EENAA) celebrated World Alzheimer’s Day (WAD) under a new steering committee. Within the past year, the society has been working intensively to attract young and passionate volunteers and promote social bonding towards the promotion of mental health, a better understanding of patients’ needs, and the reduction of stigma. These efforts took advantage of the “Train the trainers” initiative, so that informed health professionals could work in collaboration with other partners of the health system, in order to communicate efficiently with dementia patients and family members.

To support people with dementia to stay socially connected and engaged, EENAA and the Municipal Larissa Elderly Care Nursing Home joined forces and planned year-round activities, that include both ambulatory, and non-ambulatory residents. September was dedicated to the historical annual Traditional and Native Breeds National Show. The weekly workshops pursued childhood memories and fair evolution. Residents were challenged to a virtual tour to the new location of the market, while ambulatory residents took the first steps on “Metis” path. They learned the myth of Goddess Metis, representing sly cleverness, as seen in Odysseus and the fox, and they practiced walking. On the opening day, 24 September, residents accompanied by Artemissia-Phoebe Nifli and Efstatia Raili took the Metis path to the open-air fair area, strolled through the allies, and were invited to explore all the goods on display. EENAA is thankful to all exhibitors and salesmen that allowed them to touch almost everything, and were willing to discuss and share their produce with the visitors.
In addition, during September, in a pilot effort, one of the municipal primary health care units joined EENAA’s efforts to promote mental health. Initially, the unit’s personnel, a general physician, a nurse, a visiting nurse, a social worker, a physiotherapist and the two administrative assistants met bi-weekly, in order to discuss everyday challenges. They evaluated the effects of behaviours, mediators, and outcomes through virtual scenarios, and re-designed peer communication. The primary health care unit is expected to provide health care services to 10,000 people, and the deriving benefits for patients with neurodegenerative disorders were presented to the public on 18 September. The progress of the team regarding patient monitoring and the provision of care is to be followed.

21 September: The Alzheimer Society of Finland celebrates thirty years

The 30th birthday of the Alzheimer Society of Finland (Muistiliitto) was celebrated at a Memory Gala on World Alzheimer’s Day.

Top Finnish artists and 250 guests gathered together at the Memory Gala in Helsinki. The world-known research scientist Mia Kivipelto was awarded the “golden decoration” of the Alzheimer Society of Finland. The Gala highlighted Memory Week, which traditionally takes place in Finland in September, around World’s Alzheimer Day (week 38).

Big celebrations and events were organised all over the country during the week. The theme of Memory Week 2018 was “Take Memory-Friendly Actions”. The actions were rewarded by local associations. The work of volunteers was celebrated at two events: in Rovaniemi and Helsinki. Many volunteers of different associations were rewarded as well.

Memories of these 30 years important work in Finland have been highlighted throughout the year. Pictures, together with recollections of milestones and accomplishments have been actively shared on social media.

The Alzheimer Society of Finland was established in 1988 to provide help and assistance for people with Alzheimer’s disease and their caregivers. The society is a non-profit organisation.

21 September: Malta announces initiatives to raise awareness on a national scale this World Alzheimer’s Day

To mark World Alzheimer’s Day, the Malta Dementia Society announced a number of initiatives, in collaboration with the local government, to raise awareness on a national scale, starting with the mailing of a booklet on dementia explaining the symptoms, services available and what to do if one notices the first symptoms. The booklet is being sent to each and every household in the Maltese Islands. There are also a number of other interesting initiatives ongoing in Malta:

- Work has started on two different localities in order to make them dementia-friendly communities.
- A TV slot on dementia will be aired in a number of local TV stations in order to increase awareness.
- Next year, a 13-series TV discussion programme will be aired each week on the national TV network.
- A street theatre representation dealing with what a typical family goes through following a diagnosis of dementia will be presented in five different localities across Malta followed by a discussion by the audience.
- Work is also ongoing on the launch of the Dementia Friendly Community. The Personality of the Year Award (an award presented to an individual or group of individuals) who in the last year have distinguished themselves in the local dementia scene.

21 September: 50 percent of older people have reduced cognitive abilities, says new study by Alzheimer Croatia

Alzheimer Croatia conducted a cognitive ability study during World Alzheimer’s Day in Zagreb, the capital of Croatia. The MiniCog test showed that 49% of the elderly had mid to severe cognitive impairments. The research was carried out with the support of the City of Zagreb Health Office, which is leading the development of Zagreb’s Dementia Friendly Community. All persons who are shown to have cognitive impairments were referred to a medical examination. This was one of the first actions of the City of Zagreb to introduce early diagnosis of dementia, and the very first in Croatia. The results of this research coincide with last year’s survey conducted in the County of Zagreb and are really worrying, says Alzheimer Croatia.

During World Alzheimer’s Month Alzheimer Croatia also ran a number of other activities. With their support, the leading Croatian Neurological Clinic - Referral Centre for neurodegenerative diseases - also marked World Alzheimer’s Day. In the presence of high level representatives of the Ministry of Health and the City of Zagreb, once again the need for National Dementia Action Plan was emphasised.

As per tradition, in the centre of the Croatian capital, meetings were held with citizens, during which activists from Alzheimer Croatia provided information and advice on dementia, as well as information brochures. These meetings were attended by the Mayor of the City of Zagreb, who pointed out that the City of Zagreb has very seriously understood the need to develop a Dementia Friendly Community and wishes to be a model for other cities in this respect.
In the City of Zagreb and in the City of Split, the second largest city in Croatia, several public lectures on dementia were held. The first Alzheimer Café was held in the City of Split, which will be held every month from now on.

World Alzheimer’s Day also brought great media attention. National television and radio stations broadcast news about it, and members of the Managing Board of the Alzheimer Croatia spoke about this priority public health problem in numerous other news programmes and interviews in leading daily newspapers.

Pictured: MiniCog testing in City of Zagreb during World Alzheimer’s Day

21 September: Former MEP Antigoni Papadopoulou supports Cyprus Alzheimer Association’s World Alzheimer’s Day activities

In order to raise awareness about Alzheimer’s disease (AD) on the occasion of the World Alzheimer’s Day (WAD), the Cyprus Alzheimer Association organised two presentations. In the district of Nicosia the Association organised a presentation with the theme “How to protect our memory” by Dr Savvas Papacostas, neurologist at the Cyprus Institute of Neurology and Genetics.

The event was held at a Gallery belonging to Antigoni Papadopoulou, former Member of the European Parliament. Ms Papadopoulou has been a great advocate for the Cyprus Alzheimer Association for many years.

The event was very successful and offered the public an opportunity to ask questions about the multidisciplinary nature of AD.

In the district of Limassol, the Cyprus Alzheimer Association cooperated with the Cyprus University of Technology and organised a presentation to inform the public about AD. The presenter was Dr Yiolanda Christou, neurologist at the Cyprus Institute of Neurology and Genetics. Following her presentation was the launch of children’s book “My Grandpa and Mr Alzheimer”. Author Epi Michi Zeggou, who travelled from Greece, presented the aims and the benefits of the book for the whole family.

An interesting application was presented by Dr Theologia Tsitsi of the Cyprus University of Technology: “Apps4carers” can be downloaded to mobile devices and laptops.

In the district of Larnaca a concert was organised at the Municipality Theatre, given by popular singer Marina Georgiou and dedicated to people living with dementia. The concert was held in cooperation with the Cyprus –Chinese Association.

Finally, the Association marked WAD by raising awareness through television and radio channels.

21 September: Bosnia and Herzegovina reports on its World Alzheimer’s Month celebrations

During Alzheimer month, we started a big community project called: “Marking a space of health institutions for people with cognitive impairment”.

People with cognitive impairment can have difficulties with recognition of colours, shapes, spatial awareness and orientation, as well as problems understanding written or pictorial information.

Health institutions in Bosnia are not adapted to facilitate independent movement, and Bosnian regulations do not recognise cognitive impairment as a disability.

Our goals are: to raise awareness about the problems encountered by people with cognitive impairment; to help people with cognitive impairment to achieve disability status; and to standardise signs for better marking of spaces in health facilities. We want to develop adapted signs for easier and better independent movement and make these a standard for all health facilities.

21 September: Finland’s Dementia Friends campaign launched, session held in Parliament on World Alzheimer’s Day

The Alzheimer Society of Finland (Muistikumit) has launched Muistikummit, during “Memory Week”. Muistikumit is a Finnish version of Dementia Friends. It simply means finding out more about memory-related diseases, how these diseases affect a person and how you can act appreciatively and with understanding when meeting someone with a memory-related disease. The information sessions are organised by volunteers of local associations across Finland. After a one-hour session everyone can turn their new knowledge into memory-friendly actions.

The world gained its northernmost Dementia Friends on 19 September, with a session being held in Utjoki, in Lapland. Altogether, 28 persons attended the session.

There was even a session of Muistikummit in the Finnish Parliament on World Alzheimer’s Day, 21 September. There are already over 1,000 Muistikummit in Finland!

“Every action counts, no matter how small. United, we can transform the way of thinking and acting”, says Muistikummit. Our aim is “to build a memory-friendly society step by step, action by action. Everyone with a memory-related disease feels part of, not apart from, that society. The aim of Finnish National Memory Programme 2012-2020 is to create a memory-friendly Finland.” To find out more please go to: https://www.muistikummit.fi
To introduce this topic, we organised a central event in the Abdullah Nakaš General Hospital in Sarajevo. There were lecturers from the Alzheimer association A&R, the centre for dementia, the Federal agency for health sector accreditation, the public health institute of Canton Sarajevo and from the General Hospital. We invited all stakeholders. The conclusion of the event was that the project, which is necessary, should be launched immediately and a contest will be launched to design the new signs for spaces in health institutions, which should be adopted as standard following some pilot projects in the General Hospital.

The next two events were held in Banja Luka and Mostar, with the aim of gathering opinions, advice and support from the biggest centres in the country.

**21 September: UK Ministers support World Alzheimer’s Day**

Matt Hancock, the UK’s Secretary of State of Health and Social Care and Caroline Dinenage, Minister of State for Care marked World Alzheimer’s Day with media statements of support.

Reflecting on the global impact of dementia and Alzheimer’s Disease International’s 2018 “Every 3 Seconds” theme, the Secretary of State said: “on World Alzheimer’s Day, it is worth reflecting on the scale of the challenge posed by dementia to health and social care systems around the world. As individuals and as a country, it is vital that we do something about it.”

Matt Hancock referenced a much-anticipated Green Paper on social care, committing the government will “support our dedicated carers, both paid and very often unpaid, who do so much”. The UK Alzheimer’s Society responded with appreciation for the government’s progress and commitment to tackle dementia nationally and globally and with a call for the government to use the Green Paper as an opportunity to put forward bold reforms to fix dementia care in the UK, to end the inequity of “vulnerable people forced to lose their savings and sell their homes to pay for what’s often poor care”.

Minister of State for Care Caroline Dinenage described her personal experience of dementia. Recognising that “designing adequate, affordable and sustainable care for people with dementia is a necessity for every government” she promised a commitment “to meeting this challenge by creating a stable and skilled health and care workforce, by finding a solution to funding dementia care, and through the provision of high quality, person-centred post-diagnostic support.”

Both ministers reaffirmed their strong support for the dementia-friendly approach, urging everyone, as they have done, to become Dementia Friends.

Read Matt Hancock’s words here: https://bit.ly/200BPT1
Read Caroline Dinenage’s words here: https://bit.ly/2NebRqW

**21 September: NVO Futura tells us how World Alzheimer’s Day was celebrated in Montenegro**

On the occasion of World Alzheimer’s Day, we had a campaign under the name “Remember me”, in cooperation with Podgorica Capital City. Deputy Mayor Dr Sladjana Vujacic, together with the Director of NVO Futura Alma Orahovac, signed a memorandum of cooperation between NVO Futura and Podgorica Capital City on Friday 21 September at 5pm in the Royal Park. It deals with a more effective measure of improvement of the social and health care for those affected by dementia.

After the signing of the memorandum, there was a chess tournament organised for pensioners. Also, all present had the opportunity to do mini medical tests, as well as to consult our doctors and professional associates. The company “Osmi red-D” provided gifts of Q10-EPA for those present, as well as free blood glucose level and blood pressure tests. Benu” Pharmacy in Podgorica handed out free Omega 3 capsules to older persons and those with dementia.

During the month of September, we also cooperated with Dr Ilija Stolic at the polyclinic “Hipokrat”, to provide fifteen free neurological examinations to patients in need.

This year, in cooperation with the Institute for the Elderly, in the city centre of Bijelo Polje in the north of Montenegro, an information stand desk was set up, to give out promotional and informative material, brochures. Professional associates were present, to tell citizens about dementia and its symptoms.

We also signed a Memorandum of Cooperation with the Faculty of Medicine. The Faculty has a scientific research center dealing with projects and research related to Alzheimer’s disease and we will be their partners and associates in some of these, in the near future.

**22 September: ALA tells us about Luxembourg’s 17th Memory Walk**

On 22 September, Luxembourg’s 17th Memory Walk took place on Place Clairefontaine in Luxembourg City. Memory Walks are organised by Alzheimer’s associations around the world, with the aim of informing and educating the general public about dementia. Since 2002, Association Luxembourg Alzheimer (ALA) has organised Luxembourg’s edition.

From 11am to 6pm, ALA welcomed visitors to Place Clairefontaine in the city centre, where they could learn about the services offered by ALA, about Alzheimer’s disease and all other forms of dementia.
In the Alzheimer’s Café, our advisory service gave them an idea of the work ALA does every day. In this relaxed atmosphere, visitors had the opportunity to meet and participate in many discussions. Besides the information stands, visitors, both young and old, were also able to enjoy many activities.

The theme of the 2018 Memory Walk was “self-determination despite dementia”. Self-determination is the basic expression of human freedom and makes active participation in everyday life possible. People who are diagnosed with dementia are often deprived of this participation. We tend to decide for them and not with them. For years, ALA has been striving to provide a platform for those affected. A platform that promotes their integration and social participation and invites us to take another look at how to live with dementia. By walking with us, participants showed their solidarity with people with Alzheimer’s and other dementias.

This year, the participants were invited to discover the Lëtzebuerg City Museum with its panoramic lift, the Corniche and the Bock.

**MEMBERS’ NEWS**

**1 September: Association Luxembourg Alzheimer opens Northern branch of its home care and support service**

On 1 September, Association Luxembourg Alzheimer (ALA) opened a new branch in the north of the country for its home care and support service, “ALA plus”. The new site, the third of its kind in Luxembourg, is in Erpeldange-sur-Sûre, with its predecessors being in Bonnevoie and Esch-sur-Alzette. Created in 2017, ALA plus allows ALA to provide comprehensive care by offering assistance, care, supervision and support.

Since 1987, ALA has offered specific care for people with dementia. It is to allow these people to live as long as possible at home, to maintain their quality of life and to ensure the continuity of an efficient care that ALA plus was created. With 30 years of experience in the field of dementia, ALA also offers information, advice and support to people with dementia and their loved ones.

The services offered by the ALA plus service:

- care, supervision and support in the context of health insurance
- benefits in the context of long-term care insurance
- help with domestic chores
- the support of caregivers
- individual supervision by a professional, competent and multidisciplinary team
- prevention measures to improve the quality of life

ALA plus help and home care service is available from 6.00 to 22.00, 7 days a week. Requests for support can be made by telephoning (+352) 26 007-420.

**11 September: Eila Okkonen steps down as Executive Director of Muistiliitto**

On 11 September, Eila Okkonen announced that she is stepping down from her position as Executive Director at Alzheimer Society of Finland (Muistiliitto) effective end of September. Ms Okkonen said the work has been rewarding and she believes that much has already been achieved in her almost seven years in this position at Muistiliitto (activities and funding have doubled) and she feels she has done her duty and would now like to focus on other things. Anna Tamminen will now act as deputy until the position is filled.

**13 September: Slovenian nursing home wins European award as best facility for elderly and dementia care**

On 13 September, the EAN-ECREAS (European Centre for Research and Education in Ageing Services) awarded the Dom Danice Vogrinec Maribor nursing home in Slovenia the title of best facility in Europe for elderly care, including its unit for persons with dementia.

The ceremony took place at the EAN conference in Prague, Czech Republic.

Alzheimer Slovenia is thrilled that a Slovenian facility has been recognised for its professional and dedicated work and is sure the staff will continue their hard work in the coming years.


**13 September: The Alzheimer’s Society launches a dementia-friendly media, arts and drama guide**

Too often, people affected by dementia tell us that the portrayal of the condition in newspapers, TV dramas, radio and comedy shows is repeatedly misinformed and negative, leaving them feeling angry, excluded and ashamed.

On 13 September, professionals from across the media and arts industries from the UK came together for the launch of the Alzheimer’s Society’s new dementia-friendly media, arts and drama guide. The launch included a panel discussion, exploring how dementia is portrayed in the industry and the impact that has.
At the launch, Oscar-winning screenwriter, author, actor and director Julian Fellowes said: "I know that the stereotypes, misconceptions and inaccuracies portrayed about dementia in popular culture are neither true nor reflective of this complex condition [...] The language usually associated with the portrayal of dementia in drama heightens people’s fear of it, which stops people getting a diagnosis and reinforces stigma. The media, from news to dramas and documentaries, arts and popular culture have a critical role in driving a cultural shift."

Developed following thorough consultation with people with dementia, as well as representatives across the media, arts and culture sectors, the Dementia-friendly media and broadcast guide includes information about dementia, the impact portrayal of dementia has on society, practical advice on how to improve practices, language to use and avoid, and tips on how to interview someone living with the condition.

The Alzheimer’s Society is now encouraging people from across the industry to download the guide and embed its practices in their work.

Jeremy Hughes, Chief Executive Officer at the Alzheimer’s Society, said: “The power of the media to bring about change has been demonstrated through mental health and disability rights campaigns [...] by addressing enduring issues in dementia representation in the media, arts and popular culture, we can tackle stigma, improving the lives and experiences of people affected by dementia.”


17 September: Romanian Alzheimer Society tells us about SUCCESS project

Due to growing life expectancy and unhealthy lifestyles, dementia is a fast-growing, chronic disease that affects the behaviour and communication abilities of people living with this neurological disorder. Caregivers are often challenged by this fact, which could lead to stress, helplessness, aggressive situations and caregiver burnout.

The SUCCESS project provides an innovative mobile training application to support formal and informal caregivers to appropriately interact with people with dementia. The application provides evidence-based communication and intervention strategies and guides the user to effectively respond to specific situations in dementia care.

SUCCESS takes into account verbal and non-verbal communication. To provide an interesting and innovative way of teaching and guidance, SUCCESS will support the user through conversations with an avatar allowing enjoyable training and role plays between the user and the fictional character.

The avatars demonstrate typical behaviours of people with dementia and also provide companionship for the carers. Realistic scenarios allow for practical orientation to better integrate the learnings into the everyday care routine. Gamification elements motivate users to increase their knowledge about interaction strategies and everyday activities with people with dementia.

In addition to communication support, SUCCESS also aims to create meaningful activities for people with dementia in order to maintain a sense of purpose at their individual level of ability. Emotional support is provided to help carers keep a balance between care responsibilities and personal needs.

SUCCESS aims to deliver a fully-integrated, mobile pilot application that will be evaluated in long-term field studies in Austria and Romania. SUCCESS hopes to relieve caregiver stress and self-stigma, as well as increasing the well-being and communication of people with dementia by improving relationships with caregivers.

18 September: Belgian Ligue Nationale Alzheimer awards biennial Santkin prize to Bernard Hanseeuw

On 18 September, the Ligue Nationale Alzheimer Liga (LINAL) organised an academic session to present the Santkin prize 2018. Every two years since 2005, LINAL, the member of Alzheimer Europe for Belgium, has selected a winner, whose research on Alzheimer’s is then funded to the tune of EUR 10,000.

The 2018 winner is Dr Bernard Hanseeuw, who carried out his research on “Using molecular PET imaging to diagnose Alzheimer’s disease before the first memory loss”. Dr Hanseeuw presented his research during the academic session of 18 September.

https://bit.ly/2Or1jcD

27 September: Denmark releases encouraging results of a first-of-its-kind follow-up survey on dementia-friendliness

"Lack of knowledge about dementia is the biggest obstacle on the road to a dementia friendly society." This was the conclusion of a survey done by the Danish Alzheimer’s association (Alzheimerforeningen) in 2016, which asked people with dementia and their relatives about the greatest challenges faced when living with dementia.

Fortunately, since 2016, the Danes’ knowledge of dementia has progressed significantly. Another survey from a representative sample of the Danish population conducted in
2016 and again in 2018 shows that the proportion of Danes who have some, great or extensive knowledge about dementia is up 20%, from 44% to 53% since 2016. In the same period, the proportion of Danes who know nothing at all about dementia has fallen by 40%, from 10% to 7%.

More Danes know how to help a person with dementia

The surveys in 2016 and 2018 also asked about how well prepared people feel to deal with dementia if a family member is diagnosed. And the results from the survey are positive. The proportion of Danes who feel confident they would know how to support a person with dementia has almost tripled, from 7% in 2016 to 18% in 2018. The progress is welcomed by Alzheimerforeningen Director, Nis Peter Nissen:

“More and more people are living with dementia, and many encounter attitudes and prejudices that most often are borne of ignorance. That’s why it’s great to witness this positive development, which has a huge impact on all people with dementia and their relatives - especially when it means that there are even more Danes who can give a helping hand to families affected by dementia.”

Mr Nissen attributes the great progress to the increasing focus that has been placed on dementia in recent years and points to three key factors: The launch of the National Action Plan for Dementia in 2017; The first ever “Dementia Week” on national television in 2017 - a collaboration between TV2 and Alzheimerforeningen; And finally, he most especially highlights the importance of the Danish Dementia Friends campaign, which he says has been instrumental in Danes becoming more dementia-friendly. The Dementia Friends campaign is now known by 15% of the Danish population, which is twice as many as in 2016, and by September 2018 there were 70,000 Dementia Friends in Denmark, which has approximately 87,000 people with Alzheimer’s disease or other dementias. However, there is still a good way to go, he concludes, referring to the study, which also shows that there is still ignorance about certain aspects of dementia. For example, three out of four Danes do not know that dementia is fatal, despite the fact that it is the fifth most frequent cause of death in the country. The survey report is available here (in Danish):

https://bit.ly/2y3l7Hz

27 September: The Alzheimer Society of Ireland calls on Government to invest EUR 12 million for community supports for people with dementia

The Alzheimer Society of Ireland (ASI) is asking members of the Irish public to make their voice heard and contact their local member of parliament (TD) to ask them to call on Government to invest over EUR 12 million towards community supports for people with dementia in the upcoming Budget 2019 announcement in October. Members of the public can email TDs via http://www.alzheimers.promozoo.ie/launch.php and it will take less than 30 seconds to send. The ASI is calling on the Government to build communities of care for the 55,000 people living with dementia in Ireland today.


POLICY WATCH

1 September: Scottish Government/Alzheimer Scotland publish Report into Specialist Dementia Units

The Scottish Government has published ‘Transforming Specialist Dementia Hospital Care’, a detailed review of the nature and challenges of specialist dementia care across Scotland which Alzheimer Scotland was commissioned to review.

The report examined all aspects of care within specialist dementia units within Scotland and sets out key findings under seven areas:

- Admission Units.
- Specialist Beds and Transitions.
- Specialist Bed Costs.
- Environments and Therapeutic Activity.
- Specialist AHP, Pharmacy and Psychology.
- Skills, Knowledge and Workforce.
- Experience of People with Dementia and their Families.

The report introduces a vision of what a good specialist dementia unit should look like, based on the evidence and work of many practitioners who informed the report, as well as the views of people with dementia and carers. It explores the nature of the teams, the quality of care and the size of specialist dementia units, as well as highlighting that in many areas, current units are not fit for purpose and must be rebuilt.

The report makes the case that individuals should be supported and funded to make a safe transition to a more suitable form of care provision and that in areas where a more suitable form of care provision does not exist, the local Integrated Joint Board should consider commissioning such a service. The Scottish Government has fully accepted the recommendations of the report and acknowledged a key finding, which states that such transitions must not result in the individual with dementia, their partner or family having to pay for any aspect of care under the new arrangements.

20 September: German Government commits to developing national dementia strategy

The German Government has given the go-ahead for Germany to develop a National Dementia Strategy. Federal Health Minister Jens Spahn of the CDU and Federal Family Minister Franziska Giffey of the SPD announced that they had given the go-ahead for the development of a national dementia strategy at the launch of the “Allianz for People with Dementia 2014-2018” report, which outlines some of the work on dementia, including around 450 projects, which has taken place across Germany over the past four years.

The ”Alliance for People with Dementia“ brings together federal, state and local umbrella organizations as well as more than 20 associations and institutions from the nursing and health sector, science and civil society, including the German Alzheimer’s Association (Deutsche Alzheimer Gesellschaft - DAlzG). Monika Kaus, Chairperson of the DAlzG commented “it is necessary to go on working together to support people with dementia and their families. For this work resources are needed.”

According to Mr Spahn and Ms Giffey, the next steps will now be to establish a branch office at the German Center for Gerontology, jointly funded by the Federal Family and Health Ministry. After this, work to develop the dementia strategy is scheduled to begin in the autumn of 2018 with the intention of receiving sign-off from the Federal Cabinet at the beginning of 2020.

https://bit.ly/2DMgM2O

SCIENCE WATCH

29 August: Biogen and Eisai report Phase Ib extension data of aducanumab

On 29 August, Biogen and Eisai announced data from their ongoing long-term extension Phase Ib study of aducanumab, an investigational treatment for mild cognitive impairment (MCI) due to Alzheimer’s disease (AD) and mild AD dementia. The Phase Ib study is a randomised, double-blind and placebo-controlled study evaluating the safety, tolerability, pharmacokinetics and pharmacodynamics of multiple doses of aducanumab in participants with prodromal or mild AD dementia. 196 participants received the experimental drug or the placebo, of which 143 entered the ongoing long-term extension Phase Ib study.

The companies reported that the generated data were similar to previous interim analyses and no changes were reported to the risk-benefit profile of aducanumab. The level of amyloid plaques showed a decrease in a dose and time-dependent matter. In addition, a clinical benefit was also observed using the Clinical Dementia Rating Sum of Boxes (CDR-SB) and the Mini-Mental State Examination (MMSE). Both companies expect to present detailed results at a future meeting.


29 August: Researchers report that a liver disease drug could improve mitochondrial dysfunction observed in AD

On 29 August, a team of scientists from the Sheffield Institute for Translational Neuroscience, University of Sheffield (UK), published an article in the Journal of Molecular Biology reporting that ursodeoxycholic acid (UDCA) could improve the mitochondrial dysfunction observed in Alzheimer’s disease (AD). UDCA is used for the treatment of primary biliary cirrhosis, a chronic liver disease.

In the published study, researchers used tissues collected from people with sporadic and familial AD. They firstly showed alterations in both mitochondrial function and morphology in the principal active cell of connective tissue named fibroblasts. Then, they reported that the treatment with UDCA could correct the mitochondrial membrane potential in fibroblasts from people with AD, through a specific pathway including the dynamin-related protein 1.

https://bit.ly/2QkFVCW

4 September: Scientists report on absolute 10-year risk of dementia by age, sex and APOE genotype in a Danish population study

On 4 September, a team of scientists from Denmark published an article on the absolute 10-year risk of dementia by age, sex and APOE genotype among white people of Danish descent in the journal cmaj. Previous evidence suggests ties between the probability of developing dementia as well as Alzheimer’s disease (AD) and factors such as age, sex and varieties of a genotype called “APOE”.

In order to shed further light into this area, the team analysed data from 104,537 people. The data was drawn from the Copenhagen General Population Study (2003 to 2014), the Copenhagen City Heart Study (1991 to 1994 and 2001 to 2003) and the Danish National Patient Registry (from which diagnoses of dementia were obtained). Of all included people, 2,160 developed dementia. The team included information from six different variations of the APOE gene and reported that the ten-year absolute risk of all dementia increased from $22$ to $32$ to $33$ to $42$ to $43$ to $44$ in both sexes across all age groups. They also reported that for AD, $22$ had a slightly higher 10-year absolute risk than $32$ and $33$ in both sexes. Furthermore, their evidence suggests that the absolute 10-year risk of AD for $44$ carriers is modified by age and sex:

- 60-69 years 7% in women, 6% in men
4 September: Scientists report on potential link between season and cognitive test performance as well as biomarkers for AD

On 4 September, an international team of researchers published an analysis on the link between season, cognition as well as neurobiological correlates (biomarkers) of Alzheimer’s disease (AD) in the journal PLOS medicine.

The team analysed data on neuropsychological test performance from 5 observational studies including 3,353 participants from the United States, Canada and France. Furthermore, they evaluated AD biomarkers retrieved from spinal fluid in a subset of participants and measured brain gene expression through autopsies in a subset of participants who died during the study period.

Interestingly, the researchers found fluctuations in older adults’ (with and without dementia) thinking and concentration performance. The results provided insights that these abilities may be better in the late summer as well as in early fall than in winter and spring.

In addition to this, their analyses also showed that the fluctuations were accompanied by the AD related proteins in both spinal fluid as well as in the expression of specific genes in the brain.

Considering limitations of the study, the scientists noted that each participant only provided one data point per yearly cycle, whereas it would be better to have several measures throughout the year in order to measure the link between season, cognition and AD biomarkers.

Regarding the implications of their findings, the team stated that, “there may be benefit to increased dementia diagnosis and care resources in the winter and early spring, when individuals’ thinking and concentration are at their worst”.

http://www.cmaj.ca/content/190/35/E1033

13 September: M3 Biotechnology begins testing its AD therapy NDX-1017

On 13 September, M3 Biotechnology, a Seattle-based clinical-stage company with a novel platform of disease-modifying therapies particularly relevant to neurodegenerative diseases, announced that it has started to test its novel therapy NDX-1017 in people with Alzheimer’s disease (AD) and mild cognitive impairment (MCI). The investigational drug, NDX-1017, is designed to halt or reverse the disease progression.

This Phase I randomised, placebo-controlled and double-blinded study is evaluating the safety, tolerability and pharmacokinetics of single and multiple ascending doses of NDX-1017 in people with mild AD and amnestic MCI. A total of 92 participants will be recruited in the United States and France. They will be aged between 18 and 85 years.


16 September: Scientists find no evidence of Aspirin prolonging disability-free survival

On 16 September, researchers from ASPREE Investigator Group published an article on the effect of Aspirin on disability-free survival over a period of 5 years in the New England Journal of Medicine.

For their investigation, the team recruited over 19,000 people without disability, heart or blood vessel diseases and dementia that were over the age of 65. The recruitment was conducted in both Australia and the United States. People were then randomly assigned to receive either 100 mg of aspirin per day or a placebo on a daily basis.

The trial was discontinued after the scientists determined that there would be no beneficial effect of aspirin regarding

5 September: Eli Lilly announces positive Phase III results for its Flortaucipir imaging agent

On 5 September, the pharmaceutical company Eli Lilly and its wholly owned subsidiary Avid Radiopharmaceuticals, announced that Flortaucipir F 18 met its two primary endpoints in a Phase III trial.

This Positron Emission Tomography (PET) investigational imaging agent has been reported to predict, post-mortem, brain Tau pathology and related Alzheimer’s disease (AD) neuropathologic changes.

The Phase III study enrolled a total of 156 people with dementia, mild cognitive impairment, or normal cognition who were approaching the end of their lives and who consented to donating their brains for autopsy. They underwent Flortaucipir PET imaging. The company has declared that 67 of these volunteers were evaluated post-mortem and expects to present more detailed results at the Clinical Trials on Alzheimer’s Disease (CTAD) meeting in Barcelona in October.


http://www.cmaj.ca/content/190/35/E1033


https://bit.ly/2PA3xDk
disability-free survival. The team reported a median of 4.7 years of follow-up and that the rate of major haemorrhage was significantly higher in the aspirin group than in the placebo group.

https://bit.ly/2NHQe6L

18 September: Researchers test method for improved Alzheimer's disease diagnosis

On 18 September, an international team of researchers from Sweden, South Korea, the Netherlands as well as the United States published findings on the evaluation of a novel method to differentiate between Alzheimer’s disease (AD) dementia and other neurodegenerative diseases in the journal JAMA.

The scientists set up a cross-sectional study including 719 participants with a variety of diagnosed neurological diseases, syndromes or impairments. The participants were recruited via academic memory disorder clinics from the four participating countries.

Each person received an intravenous injection of a special marker and then underwent brain scans using a positron emission tomography (PET). The new marker is also referred to as a tracer “[18F] flortaucipir” and has the ability to highlight tau aggregation in the brain under the scan. Tau is one of the two proteins linked to AD. It forms tangles within brain cells and causes them to die.

Reporting on the results, the team stated that the method had an estimated ability of 89.9% to correctly identify AD and a specificity (proportion of actual negatives that are correctly identified as such) of 90.6% versus other neurodegenerative diseases. Furthermore, the method outperformed established volumetric magnetic resonance imaging measures that are used in research practice.

Nevertheless, the scientists also reported some limitations of their study, calling for further research in more representative populations as well as the need for a consensus on the optimal methodology to determine tau positivity.

https://jamanetwork.com/journals/jama/article-abstract/2702872

19 September: Researchers report on causal link between inactive brain cells in an AD mouse model and neurodegeneration

On 19 September, researchers from the Mayo Clinic published a letter about a method that may be effective to preserve cognitive function in an Alzheimer’s disease (AD) mouse model in the journal “Nature”.

The scientists found out that a special mouse model - which develops tau-dependent neurodegenerative disease - accumulates brain cells that go into a state in which they stop the cell-cycle and do not divide anymore (senescent astrocytes and microglia).

Furthermore, the researchers then used that mouse model with genetic modifications so that these “senescent” cells could be eliminated. They then reported that once these cells were removed, the mice didn’t experience neurodegeneration and preserved their cognitive function.

While these are interesting results contributing to the scientific understanding of neurodegeneration and the causal link to senescent brain cells, future research is needed to show if this method can be translated to other mouse models.

https://go.nature.com/2DLE75p

24 September: Researchers publish the findings of the NILVAL Phase III trial

On 24 September, an international team coordinated by researchers from Trinity College Dublin (Ireland) published the results of the NILVAL trial investigating nilvadipine in mild to moderate Alzheimer’s disease (AD) in the journal PLOS Medicine. Nilvadipine is licensed to treat high blood pressure.

The Phase III trial was an 18-month, randomised, placebo-controlled and double-blind study testing the efficacy and safety of nilvadipine in 511 people with mild to moderate AD in nine European countries. Although nilvadipine was well tolerated, the findings showed no benefit on slowing the rate of cognitive decline in people with mild to moderate AD. The study failed to meet its primary outcome of cognition as measured by ADAS-cog 12 (Alzheimer’s Disease Assessment Scale Cognitive-12). In addition, nilvadipine did not show any clinically meaningful effects on the secondary outcomes measured by CRD-sb (Clinical Dementia Rating Scale sum of boxes) and DAD (Disability Assessment for Dementia).

https://bit.ly/2xZi67A

DEMENTIA IN SOCIETY

11 September: Dementia could be leading cause of death among men in England by 2020

Public Health England (PHE) has published a new report, Health Profile for England (2018), which details health and protection issues such as life expectancy, major causes of death and mortality trends. This data is used in shaping long-term planning in the NHS in England and Wales.

The report has projected that by 2020, the death rate (number of deaths per 100,000 population) for dementia and Alzheimer’s disease may overtake heart disease in men. Dementia and Alzheimer’s disease are already the leading
cause of death in women. In 2016, dementia accounted for 15.8% of deaths of women in England, compared to 8.6% for men.

Additionally, the report showed that for people aged over 80, dementia and Alzheimer’s disease are already the leading cause of death for both sexes, a fact already noted in 2015, in the annual report from the Office of National Statistics (ONS) on deaths in England and Wales. In 2013, the ONS’ report had already shown that dementia was the leading cause of female deaths.


12 September: Play about Alzheimer's disease to donate proceeds to Alzheimer Europe

A production of the play The Father, which explores the theme of Alzheimer’s disease, is to be staged in Brussels from 23 to 27 October.

Playwright Florian Zeller aims to provide a glimpse into the world of someone living with dementia via his protagonist André. André lives with his adult daughter Anne and is looking for people to tell him the truth in an ever-changing world, while trying to make sense of his environment despite the reigning chaos around him. According to Mr Zeller, "The Father is a puzzle with a missing piece and no one ever knows which piece it is". The play will last approximately 1h40 and there is no interval.

Tickets are EUR 15 each and a EUR 2 donation will be made to the Alzheimer Europe Foundation from each ticket sold. Alzheimer Europe is very grateful for this support and wishes the production every success. Tickets are being sold via: https://thelittleboxoffice.com/ecn

20 September: Alzheimer's opera “Sky on Swings” opens in Philadelphia


Commissioned by Opera Philadelphia for the first night of its season-opening O18 festival, the 78-minute work debuted on the eve of World Alzheimer's Day. It explores the cognitive decline of Danny and Martha. "There was a feeling that the orchestral music in the piece needed to be about disintegration or degeneration in some way," Mr Beecher said of his opera, the result of a third collaboration with librettist Hannah Moscovitch.

Ms Moscovitch's libretto explores the place of older people in a society with longer life spans and focuses on the cognitive decline of the two principal characters in their individual homes and at a nonspecific facility.

https://www.operaphila.org/festival/

LIVING WITH DEMENTIA

27 August: Chris Roberts and Jayne Goodrick talk about the importance of patient engagement

Chris Roberts is the Vice-Chair of the European Working Group of People with Dementia (EWGPWD). The group participated in a consultation for the PARADIGM project on 27-28 June in Brussels. In a subsequent interview, Mr Roberts and his wife, Jayne Goodrick spoke about their experiences of being involved in this consultation and about patient engagement in general.

Some of the interview is featured in a blog post on the PARADIGM website, and some will appear in Alzheimer Europe’s upcoming Dementia in Europe magazine (28th edition, October 2018).

The PARADIGM blog post, posted on 27 August, consists of a four-question Q&A, opening with:

How do you feel about the idea of patient engagement in the process of developing medicines? Do you think this is relevant for people with dementia?

Chris: Patient engagement and involvement is absolutely necessary, it can save money and time, give valuable insight and advice that you can only receive from someone living with the condition. I am living with my illness daily. I experience and feel things that can’t always be learnt by the professionals in my care or who sat around a committee table. Also do not forget that some people with dementia may have been a doctor, a researcher or a professor before they got dementia. There is the misconception that after one gets a diagnosis of dementia you suddenly become stupid. We just need extra support, understanding and reasonable adjustments to be made, we need to be asked what we require to participate.

Jayne: If this is relevant to other disease areas, why wouldn’t it be relevant in the dementia area? Rather than asking is this relevant to you? Let’s look at why it would not be relevant for you, and that then goes on to other relevant criteria. The stage of dementia for example, may have an influence on that, but the diagnosis itself would not say whether or not that person is going to be able to take part. It is about supporting the person in any way that may be needed, making sure that the person feels confident about participating in these high-level medical discussions. And those on a more local level.

To read the full PARADIGM blog post, see: https://bit.ly/2Wk7eG5
Tomaž Gržinič was diagnosed with Alzheimer’s dementia in 2016 and joined the Slovenian Working Group for People with Dementia in 2017. He is now the group’s President and in autumn 2017, was nominated by Spominčica - Alzheimer Slovenia to join the European Working Group of People with Dementia (EWGPWD).

He was recently interviewed about dementia and technology, by Spominčica magazine for its September 2018 edition and his supporter Alenka Virant has translated the text into English for us:

We could not imagine our daily routine without technology anymore. Some people define ICT tools as a necessary support for tasks, while for some it is too challenging and complex. ICT pros and cons vary among people. So, what role does ICT play for people with dementia?

Tomaž Gržinič talks about ICT tools in terms of better quality of life. In the last volume of Spominčica magazine, his point of view was on how technology convinced him to start monitoring his everyday activities and see where the limit is between private and technology.

How do you think the development of ICT tools and other medical equipment encourages autonomy for persons with dementia, and can it enhance their safety at home?

Tomaž: This technology is useful in every perspective, in particular for individuals with dementia living alone. Dementia is a disease in which chronic memory problems (e.g. you forget to close the door, fridge and windows) influence your every step. Devices, such as sensors and reminders, significantly reduce negative impacts of dementia. A sensor, for instance, could detect some movements or falls. In case you cannot move and you lay on the floor for over 15 minutes, the device itself can notify carers to intervene. If you forget to lock the door, the system reminds you before it becomes dangerous. These examples are just one aspect of the process of creating a “safe home”

What is your opinion about ICT tools – are they suitable for older people or are they too complex to use?

Tomaž: In my experience, I would say they are definitely useful, because professionals usually prepare and set all the preferences and specifications for ease of use. You do not have to worry about that. However, some adaptations and considerations need to be taken into account: one of them is that older people often have poor eyesight or hearing problems, but all devices and reminders can be tailored to individual needs, so this should be OK, on the whole.

Do you find modern technology (sensors, devices, reminders) easy to use? Are they useful in terms of maintaining autonomy in everyday tasks and household chores?

Tomaž: The general idea is definitely positive, especially when adaptation for each individual is possible, which is of huge importance, depending on the type of dementia and limitations you are facing. In my case, sensors are really important, for example giving me some sound alerts if I forget to close the freezer. I am still good at closing fridge door, though. The whole smart system supports you in the areas you need it most.

Do you think modern technology make you feel more safe, secure and less dependent on caregivers?

Tomaž: Yes, I am positive about that. Overall, I feel safer, because the system warns relatives, carers or significant others about critical medical problems or events such as falls, if you are injured or even unconscious. This was my personal experience. The technology I use has more advantages than disadvantages. Therefore, I would recommend it to others, too. It is, however, the choice of each individual, whether they would like to use such technology, and to what extent. Some people are reserved or skeptical about new technology at first, because they have a big fear of it controlling or having a negative impact on their lives. Personally, I still think a smart system is very supportive for persons with dementia and has, for me, no obvious downsides.

EDUCATION

1 September: University of Stirling offers one-day course on Post-diagnostic support for people with learning disability & dementia

This evidence based course is designed to increase the knowledge and confidence of staff supporting people with a learning disability and dementia. The course will be running on 7 November 2018 from 9.30am to 4.30pm.

https://bit.ly/ZQmDq3f

NEW PUBLICATIONS & RESOURCES

1 September: ARUK launches online tool to help educate young people about dementia

Alzheimer’s Research UK (ARUK) has developed an online tool to help children and teenagers understand dementia, how it affects someone and how this could impact on their lives. The tool was launched on 1 September.

https://kids.alzheimersresearchuk.org/
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>1 October</td>
<td>Interprofessional Conference of Social Cluster Association (Budapest, Hungary)</td>
<td>Jean</td>
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<tr>
<td>1-5 October</td>
<td>EPAD WP6 Meeting (Amsterdam, Netherlands)</td>
<td>Jean and Cindy</td>
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<tr>
<td>8 October</td>
<td>EPF-Medicines for Europe Annual Dialogue, European Patients Forum (EPF) – Medicines for Europe (MfE) (Brussels, Belgium)</td>
<td>Owen</td>
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<tr>
<td>8-9 October</td>
<td>ROADMAP General Assembly Meeting (Barcelona, Spain)</td>
<td>Chris</td>
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<tr>
<td>8-9 October</td>
<td>AMYPAD General Assembly Meeting (Berlin, Germany)</td>
<td>Cindy</td>
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<tr>
<td>9 October</td>
<td>Universal Access to Health event – EPF/MfE (Brussels, Belgium)</td>
<td>Owen</td>
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<tr>
<td>9-10 October</td>
<td>Transforming Health Systems to Change the Course of Alzheimer’s Disease (Lausanne, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>11 October</td>
<td>European Disabilities Forum, European Non-Governmental Organisations Network (Brussels, Belgium)</td>
<td>Owen</td>
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<td>11 October</td>
<td>Big Data for Better Outcomes – (Brussels, Belgium)</td>
<td>Owen</td>
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<td>21-22 October</td>
<td>Patient Advocacy Seminar – EPF (Brussels, Belgium)</td>
<td>Owen</td>
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<tr>
<td>22-23 October</td>
<td>IMI 10th Anniversary Scientific Symposium (Brussels, Belgium)</td>
<td>Cindy and Chris</td>
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<tr>
<td>24-27 October</td>
<td>Clinical Trials in Alzheimer’s Disease (CTAD) Conference (Barcelona, Spain)</td>
<td>Jean</td>
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<td>28 October</td>
<td>European Working Group of People with Dementia (Barcelona, Spain)</td>
<td>EWGPWD members, Dianne, Ana and Jean</td>
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<tr>
<td>29 October</td>
<td>AE Board (Barcelona, Spain)</td>
<td>AE Board, Jean and Dianne</td>
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<tr>
<td>29 October</td>
<td>AE Annual General Meeting (Barcelona, Spain)</td>
<td>AE Board, members and staff</td>
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<tr>
<td>29-31 October</td>
<td>28th Alzheimer Europe Conference “Making dementia a European priority”, AE Board, AE Annual General Meeting</td>
<td>AE Board, members and staff</td>
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### CONFERENCES 2018

<table>
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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>3-5 October</td>
<td>European Health Forum Gastein, <a href="https://www.ehfg.org/">https://www.ehfg.org/</a></td>
<td>Bad Hofgastein, Austria</td>
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<tr>
<td>3-6 October</td>
<td>Croatian Congress on Alzheimer’s disease (CROCAD), <a href="http://btravel.pro/en/crocad-18/">http://btravel.pro/en/crocad-18/</a></td>
<td>Novigrad, Croatia</td>
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<td>18-19 October</td>
<td>2nd MINC Symposium, <a href="http://mmni.de/minc-2018/">http://mmni.de/minc-2018/</a></td>
<td>Cologne, Germany</td>
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<td>18-20 October</td>
<td>10th Alzheimer Germany Congress, <a href="https://www.alzheimer-kongress.de/">https://www.alzheimer-kongress.de/</a></td>
<td>Weimar, Germany</td>
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<td>24-27 October</td>
<td>11th Clinical Trials on Alzheimer Conference (CTAD), <a href="http://www.ctad-alzheimer.com">www.ctad-alzheimer.com</a></td>
<td>Barcelona, Spain</td>
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<td>1-4 November</td>
<td>CNS Summit, <a href="http://cnssummit.org/">http://cnssummit.org/</a></td>
<td>Boca Raton, Florida, USA</td>
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<td>11-14 November</td>
<td>11th International Conference on Frontotemporal Dementias, <a href="https://www.dcconferences.com.au">https://www.dcconferences.com.au</a></td>
<td>Sydney, Australia</td>
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<td>4-7 April 2019</td>
<td>13th World Congress on Controversies in Neurology, <a href="http://www.comtecmad.com">http://www.comtecmad.com</a></td>
<td>Madrid, Spain</td>
</tr>
<tr>
<td>22-25 October 2019</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague, Netherlands</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.