WELCOME

It has been over a month since #29AEC. Thank you, all, for your positive feedback and for the blog posts some of you have written. We now have a dedicated page on our website for these. If you have written one, do send us the link, as we will be happy to include it. I would also encourage you to mark the dates for #30AEC, which will take place in Bucharest, Romania, on 20-22 October 2020.

November saw the launch of another European project in which we are involved. I was delighted to attend the kick-off meeting for MIRIADE (Multi-omics Interdisciplinary Research Integration to Address Dementia diagnosis). Alzheimer Europe will support the dissemination and communication activities and provide secondments to two early-stage researchers, during the course of the project. MIRIADE currently has two open positions. See page 25 for more information.

EPAD has announced the release of its first wave of data, including the baseline data from the first 500 research participants. This is a very exciting step for the project, which is one of the world’s leading dementia prevention studies. We are very proud to be involved in this work.

Despite some forward strides, dementia research is still hugely underfunded, as is demonstrated by a report published this month in The Lancet. This is especially apparent in non-biomedical research. There is also some positive funding news, however, with Bill Gates investing a further USD 10 million; this time in the Alzheimer’s Association “Part the Cloud” research funding programme.

On the policy front, we congratulate our colleagues in Switzerland, where a decision has been taken to transform the current National Dementia Strategy 2014-2019 into a new “National Dementia Platform”, as from January 2020. The platform aims to continue the work of the strategy.

Meanwhile, in France, a carers’ strategy has been announced, the outlines of which should be known by the beginning of 2020. It will be included in the government’s general reform on ageing and autonomy.

On the EU policy front, the European Parliament has confirmed the College of Commissioners and the Commission has just begun its new term. We are pleased to welcome three new MEPs to the European Alzheimer’s Alliance - Sara Cerdas, Cláudia Monteiro de Aguiar and Pierfrancesco Majorino. The total number of members is now 96. We appreciate their support and hope to see them at our lunch debate in Brussels, on 10 December.

Last but by no means least, I would like to extend our congratulations to Helen Rochford-Brennan, Chairperson of the EWGPWD, whose advocacy work has been recognised at the inaugural edition of Ireland’s Sunday Independent / Gala Retail Inspiration Awards.

Our December newsletter will be published on 6 January 2020. Until then, I wish you all an excellent festive season and a positive end to another eventful year!

Jean Georges
Executive Director
ALZHEIMER EUROPE

11 November: Enjoyed #29AEC? Mark the dates for #30AEC!

Our 29th Annual Conference #29AEC is over and we are delighted with its success. We have added a blog section to our website, and have added links to some conference blogs: https://www.alzheimer-europe.org/Conferences/Previous-conferences/2019-The-Hague/Conference-blogs

If you have written a blog post about the conference, feel free to send us the link. We may decide to include it.

If you attended and enjoyed #29AEC or were unable to join us in The Hague and were sorry to miss out, then mark the dates for the 30th Alzheimer Europe Conference! #30AEC will take place in Bucharest, Romania, on 20-22 October 2020.

One lucky delegate already has a guaranteed spot – Congratulations to Nicola Saccasan, who won her free place by filling in the poster evaluation form. Each year, we enter all poster evaluators into a random draw and the lucky winner gets a free registration for the following year’s conference, courtesy of the Alzheimer Europe Foundation.

More information about the conference in Bucharest will soon be available on our website. The call for abstracts will open in the early part of next year (typically in February) and the registrations soon after that (typically in March). Keep an eye out for updates in our newsletter, on our social media accounts and of course in the conference section of our website: https://www.alzheimer-europe.org/Conferences/Bucharest-2020

Alzheimer Europe networking

On 12 November (Amsterdam, Netherlands), Jean attended the launch meeting of the MIRIADE project.

On 12 November (Berlin, Germany), Dianne attended a conference organised by Robert Bosch Stiftung on dementia in hospitals.

On 12-13 November (Brussels, Belgium), Ana attended the EPF Congress Advancing meaningful patient involvement: A path to more effective health systems.

On 13 November (Luxembourg, Luxembourg), Dianne attended a conference on the end of life organised by the Luxembourg Ministry of Health and the Ministry of the Family, Integration and the Grand Region.

On 13-14 November (Lausanne, Switzerland), Jean participated in the Lausanne VI meeting “Preparing the Alzheimer’s Disease Consortium for a Timely, Accurate and Compassionate Diagnosis”.

On 15 November (Amsterdam, Netherlands), Jean attended the EPAD change management team meeting.

From 16 to 18 November (Barcelona, Spain), Gwladys attended the IBTM Forum for Young Professionals.

On 19 November (Brussels, Belgium), Angela attended a multi-stakeholder seminar organised by ISC Intelligence entitled ‘The Impact of the GDPR on Health Research’.

On 19-20 November (Barcelona, Spain), Gwladys attended the Incentive Business Meeting Management trade show.

On 13 and 14 November (Brussels, Belgium), Ana attended the workshop “The role of patient’s organizations in scientific and technological research” organised by the Spanish Parkinson Federation.

On 27-28 November (Barcelona, Spain), Jean attended a conference of the Joint Programme for Neurodegenerative Diseases Research (JPND).

On 27-28 November (Brussels, Belgium), Angela attended the “Joining the Dots” Conference of the European Institute for Innovation through Health Data (I~HD).
24 October: RADAR-AD project leader Dag Aarsland speaks at 29th Alzheimer Europe Conference

RADAR-AD’s project leader, Professor Dag Aarsland (King’s College London) gave a presentation at the 29th Alzheimer Europe Conference (#29AEC). His presentation took place on day two, 24 October 2019, which focused on diagnosis, post-diagnostic support, technology and e-health. In his presentation “What role for ‘wearables’ in the detection of people at risk of dementia and in monitoring disease progression?”, Prof. Aarsland explained that measures of functional impairment in Alzheimer’s disease (AD) depend on direct clinical observation or on caregiver recall. This, he stated, makes them more difficult to achieve and, in fact, less accurate. In this regard, when diagnosing AD, the presence of functional impairment is compulsory. However, research into daily activities has discovered that functional impairment develops during the pre-clinical stages of AD.

Measuring cognitive, behavioural and other clinically relevant domains, in people who have been diagnosed with AD in their daily environments, has been made possible through the use of remote measurement technologies. These technologies present an opportunity to obtain detailed data from different time sets, which essentially constitutes a valuable improvement of the current situation regarding assessment. Moreover, Prof. Aarsland elaborated that in RADAR-AD a combination of devices is used, including wearables and smartphone applications that present a promising novel approach in personalised medicine. He explained that this will be done “by offering the right treatments to the right patients for maximum effectiveness and minimum waste”.

During his presentation, Prof. Aarsland explained that everyday activities are key criteria for diagnosis, and that aspects which people worry about, such as changes in daily function, have a great impact on quality of life. Nevertheless, he asserted, sensitive outcome measures for functional decline are still missing. He also emphasised the fact that remote technologies offer great opportunities to fill this gap.


24 October: INDUC'T project launches Best Practice Guidance for Technology in Dementia at Alzheimer Europe Conference in The Hague

From September 2016 until September 2019, fifteen Early Stage Researchers (ESRs) at seven universities in Europe investigated different topics of technology use in dementia within the EU-Marie Skłodowska Curie-funded INDUC'T Innovative Training Network. The recommendations resulting from their projects were integrated in a Best Practice Guidance on Interaction with Technology in Dementia.

On 24 October, during the parallel session organised by INDUC'T at the 29th Alzheimer Europe Conference in The Hague, the web-based version of this Best Practice Guidance was officially launched by the research coordinator of INDUC'T, Prof. Rose-Marie Dröes. After an introduction by INDUC’T coordinator Prof. Martin Orrell, who explained the aim and methods of INDUC’T, 11 ESRs pitched some of the recommendations that emerged from their research projects. The dynamic web-based Best Practice Guidance already contains more than 40 recommendations in three different areas of technology (everyday life, meaningful activities, and health care) relevant for a variety of target groups, such as users, designers/developers, care professionals and providers, researchers, politicians and the media. Each target group can easily find specific recommendations relevant to them by means of theme and target group-oriented search engines.

Additional recommendations will be added in the coming months. Recommendations resulting from the newly-launched DISTINCT-ITN project (2019-2023), which will focus on technology to promote social health in people with dementia, will be included in this web-based Best Practice Guidance in the coming years.

Take a look at www.dementiainduct.eu/guidance/ and find out which recommendations are relevant to you! You can also download the full PDF of the Best Practice Guidance with all recommendations.

11 November: MIRIADE project holds official kick-off meeting

The MIRIADE Marie Curie ITN project was kicked-off on 11 November at a meeting in Amsterdam. MIRIADE aims to generate a novel generation of scientists
able to accelerate fluid biomarker development for dementias.

The extreme Dutch weather was optimal for the participants to interact and learn about the goals and strategies of MIRIADE. The very motivated consortium members got to know each other very well during a nice dinner (likewise with pouring rain outside) and a game in which they built a tower out of spaghetti, a rope and tape, on which a marshmallow was balanced.

In dedicated workshops, the participants elaborated the contents of the individual projects for the early stage researchers (ESRs) to be hired. The first two vacancies are already online!

Alzheimer Europe will support the dissemination and communication activities and provide secondments to two ESRs, during the course of the project.

15 November: AETIONOMY results presented to IMI leadership

AETIONOMY was started more than five years ago to explore the idea that conventional disease definition (that is, the expert clinical assessment of groups of symptoms leading to an eventual diagnosis) is an increasingly outdated concept in the current medical environment.

AETIONOMY sought to explore the factors that define or drive Alzheimer’s and Parkinsonian syndromes and their outcomes. To this end, there was a critical focus on integrating data from a range of external studies, as well as studies conceived and managed within the project, into a central database. This investigation has been performed by a broad group of scientists from clinical, research and data-science institutions and organisations across Europe.

The project has now ended and has been reported here and in other publications. The results were presented to IMI leadership in Brussels on 15 November.

The key outcomes of AETIONOMY offer the community interesting insights into the potential to differentiate subtypes of neurodegenerative disorders. The project has delivered several computational models to link molecular features to different clinical presentations or outcomes, such as the speed of disease progression.

The hope now is for ongoing research and clinical trials to utilise insights like these to understand options for differential treatment paths - indeed some members of the AETIONOMY consortium are already leading or participating in such initiatives.

It is too early to speak about treatment or diagnostic advances, but the team has demonstrated the power of data to identify valuable insights. Researchers will continue to build on the legacy of the project, as they leverage the AETIONOMY database and methods to further refine these findings.

www.aetionomy.eu

18 November: MinD project visits Netherlands and UK

Over the past month, the MinD project visited the Netherlands and the United Kingdom (UK).

From 21 October-4 November 2019, the project was hosted in Deventer, Netherlands and from 4-18 November in Nottingham, UK.

Now rapidly drawing to a close, this was the last secondment of the MinD project in the Netherlands, while there will be a further secondment in the UK in January 2020. In both secondments, colleagues focused on collating, publishing and sharing results.

In the Netherlands, Kristina Niedderer from Manchester Metropolitan University focused on completing a chapter reporting on the “Let’s meet up!” system and its development through involvement of groups of experts with lived experience in the UK and Spain for a forthcoming book on design, assistive technology and dementia edited by Gail Kenning and Rens Braenkert. In discussion with Ingeborg from Panton Design, she revised a toolkit to help designers to understand and envision people with dementia and their lives. The toolkit will be available on the project website when it is completed in February 2020: www.designingfordementia.eu.

She also revised a journal paper on the use of design to embed mindfulness in people’s lives to support people with dementia with wellbeing, self-empowerment and social engagement.

In the UK, Rosa and Yolanda from Intras, Spain, were hosted by Nottinghamshire Healthcare NHS Foundation, Institute of Mental Health. They worked on completing a journal paper on the data collection with people with dementia and carers in the first half of this project. They also started on a journal paper for reporting the results of the evaluation of the Good Life Kit “This is Me” part, which is a board game to engender social interaction and self-empowerment. During the second week, a former MinD colleague also joined the team for a day. Dr Isabelle Tournier, who now works at the Info-Zenter Demenz in Luxembourg, visited to give a presentation about the work of the centre. Her presentation (pictured) was met
with great interest by colleagues from the MinD project and from Nottinghamshire Healthcare Trust and Nottingham University.

**18 November: EPAD releases its first wave of data**

The European Prevention of Alzheimer’s Dementia (EPAD) project, a major Europe-wide initiative aiming to improve the understanding of the early stages of Alzheimer’s disease, has announced the release of its first wave of data including the baseline data from the first 500 research participants (V500.0). The project is one of the world’s leading dementia prevention studies involving 39 organisations across multiple sectors. It offers a unique platform for testing and developing preventative treatments for Alzheimer’s dementia. This represents the first formal public data release from the EPAD project for use by academic researchers and institutions worldwide, which consists of data from research participants over 50 years old who do not have a diagnosis of dementia. The domains of assessment are cognition, neuroimaging, fluid biomarkers, genetics, lifestyle, clinical and psychiatric assessment, neuropsychiatric symptoms, function and basic demography.

Data are provided via secure online tools in order to facilitate collaboration between people and teams with similar research aims. Academic researchers and institutions from all over the world are invited to begin the application process. To access the data, you will need to make an online request by following the link at www.ep-ad.org/erap where you will find a variety of resources to support your research.

In the chosen nomenclature (V500.0): V=version, ‘500’ is the number of sequentially recruited research participants in each dataset and ‘.0’ refers to the study visit the dataset includes (visit 0 refers to the baseline data). Each dataset will have a digital object identifier (DOI) to reference the source of the data in subsequent publication (V500.0:doi:10.34688/epadics_v500.0_19.05.10).

**20 November: Neuronet team meeting focuses on the key assets and collaborations of IMI neurodegeneration projects**

On 20 November (Madrid, Spain), Angela Bradshaw represented Alzheimer Europe at a Neuronet core team meeting with representatives from SYNAPSE Research Management Partners and Janssen Pharmaceutica NV. Previously, Neuronet had convened a meeting of its high-level, overarching Scientific Coordination Board (SCB), which is composed of 15 leaders of Innovative Medicines Initiative (IMI) projects in the area of neurodegeneration. As part of this SCB meeting, 9 of the IMI project leaders were interviewed by the Neuronet project leaders, Carlos Diaz (SYNAPSE Research Management Partners) and Lennert Steukers (Janssen Pharmaceutica NV). The primary aims of the team meeting were to follow up on the actions identified during the October SCB meeting, and to collate the information gathered during the project leader interviews. Discussions were focused on identifying the key assets, challenges experienced and best practice developed for each project. Collaborations and connections between different projects in the Neuronet project portfolio were also mapped, based on information provided by the project leaders. This work will be presented at the next Neuronet consortium and SCB meeting, to be held in early 2020.

Find out more about the project here: [www.imi-neuronet.org](http://www.imi-neuronet.org)

**25 November: The PRODEMOS project holds its General Assembly meeting in Cambridge**

On 25-26 November, the Prevention of Dementia using Mobile phone applications (PRODEMOS) project held its General Assembly meeting in Cambridge (UK).

The meeting commenced with Carol Brayne welcoming almost 30 delegates. Edo Richard introduced the meeting and gave an overview of the project. The aim of this project is to make an evidence-based dementia prevention strategy using mobile Health (mHealth), accessible to those at increased risk of dementia, who are usually not reached by preventive medicine. Older people at increased risk of dementia in China and a vulnerable population with low socio-economic status in UK will be randomised to join the PRODEMOS trial. Edo Richard reiterated that the PRODEMOS platform will be built upon the evidence-based HATICE internet platform developed in the FP-7 funded HATICE project. This platform helps people to improve their risk factors for cardiovascular disease and dementia, such as hypertension, high cholesterol, diabetes mellitus, unhealthy diet, smoking and physical inactivity using an interactive self-management strategy. Edo Richard also announced that the HATICE results have been published in the journal Lancet Digital Health in November 2019. Linda Barnes then presented the dissemination work and highlighted that the PRODEMOS consortium has already done impressive dissemination activities. After that, Nicola Coley gave an update on the systematic reviews conducted within WP2 (Strategies for dementia prevention) including the latest results. This was quickly followed up by an overview of the qualitative research and interviews conducted across UK, Netherlands and China. Main findings and most important...
implications for the platform were discussed. The next session was then dedicated to the mHealth platform with a demonstration of the platform, which is ready for the pilot study to be started in November 2019 in UK and January 2020 in China. First experiences and implications were shared. The day was brought to a close by Anders Wimo and Ron Handels who reported on the health economic aspects including the cost-effectiveness analysis.

The second day of the meeting was dedicated to the preparation of the trial. All necessary approvals for the pilot and the trial have been received. A very fruitful session took place on the trial practicalities including the recruitment strategies, procedures, measurement devices, data collection and trainings.

Jean Georges and Cindy Birck attended the general assembly meeting on behalf of Alzheimer Europe (AE). AE is partner in the project and is involved in the coordination and management, crossing cultural barriers and dissemination and communication work packages of this project. The projects in this newsletter with EU funding are: from the European Union’s Horizon 2020 research and innovation programme and EFPIA.

Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support; Sergei Stanichev (S&D); Ruža Tomašić (ECR). -EPP); Elissavet Vozemberg (Greens/EFA); Erik Marquardt (Greens/EFA); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Anne Sander (EPP). Finland: Monika Vana (Greens/EFA). -EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyراكki (EPP).

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

The projects in this newsletter with EU funding are: AETIONOMY - grant agreement 115568 EPAD - grant agreement 115736 Neuronet - grant agreement 821513

Currently, the total number of MEPs in the Alliance stands at 96, 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 (EAA):

Austria: Monika Vana (Greens/EFA). Belgium: Petra de Sutter (Greens/EFA); Frédérique Ries (ALDE); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). Bulgaria: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Sergei Stanichev (S&D). Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). Cyprus: Costas Mavrides (S&D). Czech Republic: Tomáš Zdechovský (EPP). Denmark: Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). Estonia: Urmas Paet (ALDE). Finland: Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). France: François-Xavier Bellamy (EPP); Dominique Bilde (ENF); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Eyren (EPP); Sylvie Guillame (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Anne Sander (EPP). Germany: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). Greece: Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyarakki (EPP); Elissavet Vozemberg-Vrionidi (EPP).
EUROPEAN ALZHEIMER’S ALLIANCE

6 November: Sara Cerdas MEP joins the European Alzheimer’s Alliance

Alzheimer Europe is delighted to announce that Sara Cerdas MEP (S&D, Portugal) has become the latest member of the European Alzheimer’s Alliance. Alzheimer Europe offers its apologies to Ms Cerdas, who indicated her support and intention to join the EAA in July 2019. Due to an internal error, this support was not acknowledged at the time and our records were not updated, which may have created the impression that Ms Cerdas was not supportive of our aims - we are of course happy to correct this and are grateful for her support to make dementia a European priority. We look forward to working with Ms Cerdas over the course of the coming parliamentary term, to prioritise dementia in European policy and research.

7 November: MEPs Cláudia Monteiro de Aguiar and Pierfrancesco Majorino join the EAA

Alzheimer Europe is delighted to announce that MEPs Cláudia Monteiro de Aguiar (EPP, Portugal) and Pierfrancesco Majorino (S&D, Italy) have become the latest member of the European Alzheimer’s Alliance. Alzheimer Europe is grateful for their support and looks forward to working with both Ms Monteiro de Aguiar and Mr Majorino over the course of the coming parliamentary term, to prioritise dementia in European policy and research.

EU DEVELOPMENTS

24 October: Council of the European Union adopts Conclusions on the Economy of Wellbeing

At their October session, the Council of the European Union adopted the Conclusions on the Economy of Wellbeing, tabled at the Initiative of the Finnish Presidency. The draft Council Conclusions were agreed by member state delegations in the 16 October meeting of the Committee of the Permanent Representatives (Part 1) with the exception of Bulgaria, which voiced a scrutiny reservation on the changes to paragraphs 24 and 4. The Council Conclusions on the Economy of Wellbeing aim to put people and their wellbeing at the centre of policymaking, pointing out the link between health and wellbeing and economic growth, productivity and long-term sustainability. The Conclusions specifically referenced data and data on health, highlighting the potential of digitalisation and AI to increase the cost-effectiveness, efficiency and quality of health and social services. The Conclusions also underlined the importance of improving peoples’ access to their own health and social data, and of raising awareness on health and social data protection. They re-iterated the necessity of respecting data protection rules and ethical principles, whilst capitalising on the benefits of health and social data re-use for advancing public health, research and innovation.

In their Conclusions, the Council invited Member States and the European Commission to anticipate the impacts of demographic changes caused by ageing and longevity, calling on them to promote healthy and active ageing across all policies. The Council also asked that Commission and Member States continue their development of rigorous data collection and statistical analysis methods to measure and monitor
wellbeing, so that these data could contribute to policy and decision-making at an EU level.

Of particular relevance to health data sharing, the Council asked the Member States and European Commission to ensure the benefits of digitalisation for people’s wellbeing, by accelerating work on innovative digital solutions, strengthening initiatives for cross-border exchange of health data and by deploying innovative digital technologies. Importantly, the Council asked that digital inclusion be promoted for all citizens, including those beyond the digital divide.


12 November: European Patients’ Forum Congress takes place in Brussels

From 12 to 14 November 2019, the EPF Congress took place in Brussels. This was the first European Congress on patient involvement driven by patients. The aim of the Congress was to instigate a narrative of real and lasting change in attitudes, knowledge and resources for participants. The Congress combined key note speeches, panel discussions and interactive parallel working sessions on the main topics of: patient involvement; inclusion, equity and diversity; culture change and leadership; and patients as teachers. The congress was attended by over 300 participants, including a high-level Advisory Board of 12 ambassadors, 69 speakers and a wide range of health stakeholders, ranging from patient representatives, regulatory and HTA experts healthcare professionals and experts, national organisations, representatives from industry, academia, and local governments. Chris Roberts, vice-chair of AE’s European Working Group of People with Dementia was an invited speaker in the panel “Ensuring equity, inclusivity and diversity of the patients’ voice”. From AE, Ana Diaz (Project Officer), Chris Roberts (EWGPWD) and his wife, Jayne Goodrick, attended the Congress.

12 November: Data Saves Lives Initiative is launched at EPF Congress

The Data Saves Lives initiative and website were launched on the opening day of the European Patients’ Forum (EPF) Congress, which is focused on patient involvement and is driven by representatives of the patient community and patient experts.

Data Saves Lives is a multi-stakeholder initiative that is led by the EPF and the European Institute for Innovation through Health Data (l*HD). The primary goal of this initiative is to raise wider patient and public awareness about the importance of health data, how it is used in practice and how this can deliver benefits for patients and citizens. Data Saves Lives will establish a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe, while empowering patients and healthcare professionals to realise the potential of new sources of data and digital technologies. It will also create resources adaptable for use at national and local level and show real-life examples of how data is used for the benefit of patients.

The Data Saves Lives team is now welcoming applications from interested parties to join and contribute to the initiative.

https://datasaveslives.eu/

20 November: European Parliament approves Internal Market Commissioner-designate

Members of the European Parliament’s Internal Market and Consumer Affairs committee (IMCO) have confirmed Thierry Breton, France’s nominee for the internal market portfolio.

The coordinators of the European People’s Party, the Socialists & Democrats, the European Conservatives and Reformists, and Renew Europe voted in favour of Mr Breton. His confirmation follows the committee’s hearings for French Sylvie Goulard in October, where they rejected France’s first choice for the post, citing legal and ethical concerns.

In her mandate letter to Mr Breton, President-elect Ursula sets out a revised vision of the mandate for the position. Of particular relevance:

- … enhancing Europe’s technological sovereignty. This means investing in the next frontier of technologies, such as blockchain, high-performance computing, algorithms, and data-sharing and data-usage tools. It also means jointly defining standards for 5G networks and new-generation technologies.
- … lead the work on a coordinated European approach on artificial intelligence and on the new Digital Services Act.
- … day-to-day functioning of the single market. I want you to focus on the implementation and enforcement of rules at the European, national, regional and local levels.

Mr Breton served as Minister of the Economy, Finance and Industry in France between 2005 and 2007, under President Jacques Chirac. Since 2008, he has served as Chairman and CEO of Atos. A vote on the full Commission by a plenary session of the European Parliament is scheduled for 27 November in Strasbourg.
20 November: European Council and Parliament agree 2020 budget

The European Council and Parliament have reached an agreement on the EU budget for 2020, with a considerable focus placed on growth and competitiveness and climate action.

The total budget is EUR 168.7 billion, representing an increase of 1.5% compared to the 2019 budget. The agreed figures are based on the premise that the UK will continue to participate fully in the financing and implementation of the EU budget for 2020. The budget for 2020 strengthens support for the EU’s priority areas and best-performing programmes, including Horizon 2020.

The Parliament and the Council now have 14 days to formally approve the agreement reached. The Council is expected to endorse it on 25 November. The vote in the European Parliament is scheduled for 27 November.

27 November: European Parliament approves European College of Commissioners

Following the conclusion of the hearings process, the European Parliament has approved the new College of Commissioners, who will lead the European Commission for the next five years. During the plenary session of the Parliament, 461 voted in favour, 157 against and 89 abstained. The College of Commissioners will be led by President Ursula von der Leyen. There are 27 portfolios, with portfolios with the greatest relevance to dementia policy being as follows:

- Margrethe Vestager – Executive Vice President – Europe Fit for Digital Age
- Valdis Dombrovskis – Executive Vice President – An Economy that Works for People
- Věra Jourová – Vice President for Values and Transparency
- Dubravka Šuica – Vice President for Democracy and Demography
- Thierry Breton – Commissioner for the Internal Market
- Mariya Gabriel – Commissioner for Research, Innovation, Education, Culture & Youth
- Johannes Hahn – Commissioner for Budget and Administration
- Stella Kyriakides – Commissioner for Health.

One significant change which was announced prior to the vote, was the renaming of the portfolio of Mariya Gabriel, from “Innovation and Youth” to “Research, Innovation, Education, Culture & Youth”. The new Commission will officially take office on 1 December 2019. The full list of Commissioners can be found:
https://ec.europa.eu/commission/interim/commissioners-designate

27 November: i~HD holds conference on “Ensuring better data for person-centred health and care”

On 27 and 28 November, the European Institute for Innovation through Health Data (i~HD) held a conference entitled “Joining the Dots: ensuring better data for person-centred health and care, optimised research and Learning Health Systems”. The meeting was held in Brussels, Belgium, and was attended by stakeholders from academia, industry, regulatory bodies, EU Institutions and patient organisations. The conference aimed to facilitate the exchange of use cases, methods, successes and challenges in 6 key areas: 1) quality and interoperability of high-value health datasets; 2) patient empowerment in access and use of health data; 3) promoting and sustaining federated health data ecosystems; 4) advancing solutions for multimorbidity; 5) legal and ethical challenges of health data; and 6) boosting digital transformation.

Dipak Kalra, President of i~HD, kicked off the conference by facilitating an opening session with presentations from six EU projects: C3-Cloud, Trillium II, Digital Health Europe, eHealth Action, EHR2EDC and EHDEN. All of these projects are built around eHealth and electronic health record (EHR) use, either in the context of standard healthcare or (in the case of EHR2EDC) clinical trials. Another commonality between these projects is the involvement of academic, industry and regulatory stakeholders. Following this opening session, conference attendees participated in parallel morning and
MEMBERS’ NEWS

22 October: Fundación Alzheimer España partners with public health service centres to deliver staff training

It is one of the core beliefs of Fundación Alzheimer España (FAE) that information and training are, by far, the best weapons in the strenuous battle against dementia. FAE believes that old conventional wisdom on AD needs to be phased out and that the public should be kept updated on the latest scientific developments, as well as, more importantly, on improved personal strategies. The association also says that public policies and resources must become aligned in a joint approach to treat the disease.

With this objective in mind, FAE tries its best to spread accurate and useful knowledge on dementia. They have recently successfully partnered with a number of public health service-related centres to roll out both patient and carer-oriented training sessions. These training sessions are now providing caregivers with a fair share of relief and useful knowledge, with the added benefit of greater focus within highly-specialised healthcare provision bodies on the issue of caring for people with dementia. All sessions were given by FAE’s own highly-trained staff. The use of non-pharmacological therapies and approaches was highlighted throughout.

During the month of September, two training sessions, of two consecutive days each, were held at FAE headquarters and at Fuencarral Healthcare Centre, a public service that covers the northernmost area of Madrid, where the local population has a high proportion of older people. On 4 October, another training session took place at 12 de Octubre Hospital, an important institution in public healthcare, in partnership with members of a dementia-pioneering team from the neurology department. Such has been the success and scope of these actions that the association is currently in the process of establishing a permanent, regular collaborative effort with these centres to keep “spreading the love”.

22 October: Mira Dajčić elected as new President of Alzheimer Croatia

On 22 October 2019, at the regular assembly meeting of Alzheimer Croatia, new leadership was voted in. Mira Dajčić (pictured) was elected as the new President, Tomislav Huić, Nataša Klepac and Ninoslav Mimica as Vice-Presidents, and Tajana Dajčić as Secretary.

Mrs Dajčić, founder and former Vice-President of the society, was previously a family caregiver. She is well known for her tireless running of a counselling centre and for educating formal and informal carers of people with dementia and fighting for their rights. In 2011, she received the Volunteer of the Year Award in Croatia, and in 2012 she received the prestigious City of Zagreb Award for the highest merits and achievements in areas of social health in the City of Zagreb. Tomislav Huić, was a family caregiver and has had a professional career as a journalist, marketing director, creative
director at advertising agencies, and senior lecturer of marketing communications. On behalf of Alzheimer Croatia, he has led corporate communications and projects, developed the Dementia Friends Croatia initiative and Alzheimer’s Educational Conferences, as well as other operational activities.

Nataša Klepac is a cognitive neurologist at the Clinic for Neurology of the Clinical Hospital Center Zagreb, and is a professor at the Zagreb School of Medicine. In her past work for Alzheimer Croatia, she has helped many people with dementia and their family carers. She has also run education programmes about dementia for physicians and nurses.

Ninoslav Mimica, President of Alzheimer Croatia for the past three terms, is a specialist in psychiatry, and professor at the Faculty of Medicine in Zagreb. In his many years working for Alzheimer Croatia, he has distinguished himself through the struggle to understand dementia as an important public health problem and is one of the main contributors to the proposal of the Croatian national Alzheimer’s strategy.

Tajana Dajić, current and re-elected Secretary, was a family caregiver, educated as an economist and is the only full-time employee of the society. She is the fundraising manager and project manager of European and national projects.

In her inaugural address, the new President, Mrs Dajić, thanked the members of the Board of Alzheimer Croatia for their contributions, to date. She stressed the need to continue to work hard so that people with dementia can live better and longer lives. Stronger demands need to be made for changes in public health policies, and especially for the adoption of a dementia strategy in Croatia. Finally, Mrs Dajić expressed the hope that Alzheimer Croatia will grow into a professional body and that it will build stronger bonds with Alzheimer Europe and Alzheimer’s Disease International.

25 October: Panhellenic Federation of Alzheimer’s Disease and Related Disorders reports on carers’ seminar in Heraklion

The 7th edition of a “Training Seminar for Family Carers and Professional Carers for people with Dementia” was successfully completed on 25-26 October 2019, in Heraklion, Crete. The seminar took place at the Chamber of Commerce and Industry and was co-organised by the Heraklion Association of Alzheimer’s Disease and Healthy Aging “Solidarity” and the Region of Crete. It was sponsored by Alzheimer Hellas, the Municipality of Heraklion, the 7th Crete Rector, the Medical School, the Heraklion Medical Association and Medical Society.

The scientific programme of the seminar included sessions on preserving the safety and dignity of the patient with dementia; management of patients’ neuropsychiatric symptoms; management of stress and depression in carers; technology and ageing; and rehabilitation. It also included other services for patients and family support, such as workshops with exercise presentation and techniques for relaxation of patients and carers.

The seminar was attended by more than 200 participants, among which were health professionals and students from the Nursing School, the School of Social Work and the School of Medicine. Many citizens of Heraklion also participated.

19 November: Fundación Alzheimer España explores the use of virtual reality-based tools to treat cognitive decline

Interns have always done a brilliant job of lending a helping hand at Fundación Alzheimer España (FAE) and new technologies applied to dementia treatment have traditionally been a great focus of attention for the association. To kill two birds with one stone, FAE recently asked its overseas interns to put together a therapeutic approach to dementia, which relies on virtual reality (VR)-based cognitive therapy. Aided by a few expert guidelines, the two students in question have been given the green light to proceed. The choice has been theirs in terms of conducting previous literature research, choosing the apps to go with the VR goggles, and the design and implementation of the programme.

Underlying this, there is a distinct, differential touch. Virtual Reality has, up to now, been widely used in all manner of therapies, from psychotherapy, through brain-training to neuro-rehabilitation. However, the focus of this project is the transformation of a simple, easy-to-use, non-therapeutic, everyday VR app (the kind one would use for leisure), which is not tailored to the individual user content-wise, into an adaptable, customisable intervention tool. This VR tool aims to contribute towards the improvement of general cognition, the promotion of socialisation, and mood-stabilisation through an enhanced sense of self-efficacy, usefulness and the simple fact that it is good fun.

This project has just taken its first steps. Soon, solid, evidence-based protocols will be composed and different measuring strategies will be used to get a general measure, in the long
run, of the effects this therapy has on people living with dementia. Initial trials are currently being rolled out and that association says that by the look of things, it seems like a promising, low-cost and highly-engaging new avenue.

20 November: Deutsche Alzheimer Gesellschaft hosts symposium exploring the importance of technology in dementia care

In November, Deutsche Alzheimer Gesellschaft (DAIzG) and the Dementia Competence Center in Schleswig-Holstein, invited people to a symposium on current developments, ethical and legal issues and perspectives in technology. 160 participants from all over Germany attended lectures on the advantages and disadvantages of the use of digital technology in the care of people with dementia.

Swen Staack, DAIzG Board member and Head of the Dementia Competence Centre in Schleswig-Holstein, emphasised that technology was an important factor in attracting nursing staff. Birgit Michels-Riess of the Bodelschwinghsche Stiftungen Bethel, also confirmed that the use in practice would only be possible "with the participation of the nursing staff". In addition, such applications are not self-perpetuating, she said: "A caregiver is needed for the technology".

Dr Katrin Grüber of the Institut Mensch, Ethik und Wissenschaft promoted the idea that ethical considerations should be seen as an aid to reflection. Also that ethical questions should be used as a tool for decision-making processes. She called for the needs of people with dementia and their relatives to be taken into account, from the very beginning, in development and research.

Various exhibitors at the symposium, demonstrated technology which is already available on the market or is about to be launched on the market. The participants were able to test the technology on offer, on site.

A main conclusion from this symposium was that living with, and care of, dementia can be made easier by using technical support, but that it must not be a substitute for human closeness and affection.

22 November: Finland holds annual Memory Conference

In Helsinki, on 13-14 November, the Alzheimer Society of Finland (Muistiliitto) organised its annual Memory Conference. The event gathered together researchers, people with memory-related diseases and their families, and the professionals working in local associations affiliated with the Alzheimer Society of Finland.

The themes of the lectures included early-onset memory-related diseases, experiences of caregivers, and the self-determination of people with memory-related diseases. A very heart-warming and personal life story was shared by Marja Häkkinen, who bravely talked about her life with frontotemporal degeneration. She got her diagnosis when she was 56 years old, but despite this, she decided to live fully and start new hobbies.

The conference itself was held in a local movie theatre in Helsinki. The audience also saw short videos highlighting volunteers with memory-related diseases.

Every year, the Alzheimer Society of Finland awards a volunteer in person or for a particular act they have done. The nominees are put forward by local associations. This year, the Volunteer of the Year Award went to Seija Helminen, who volunteers with a local association in Pirkanmaa. Many of her family members have memory-related diseases and she has been recognised for her many acts of kindness and commitment, such as leading peer support groups. She is also a member of local and national working groups for people with memory-related diseases and caregivers.

Pictured: Marja Häkkinen (photo by Jonna Lång)


Through daily contact with many carers of people with dementia, it was noticed that a frequent question was how to talk to the younger members of the family about dementia. In order to meet this need, an experiential workshop was created to inform the grandchildren of those with Alzheimer’s disease, and to raise awareness in children aged 6-12. To date, more than 500
children have participated in this experimental workshop, entitled "Who Am I, grandpa?", which won the 2nd Alzheimer’s Disease International (ADI) World Prize during the 29th World Congress in 2014.

Through experiential techniques, the children played an active role and shared their feelings and thoughts. The resulting material formed the basis of the present book. Many of the questions and answers of the children were used individually, enriching the narrative with their endless creativity and imagination. The children explain Alzheimer’s to other children in their own words, thoughts and images, which is what makes this an original book.

The story is about a group of children who discover that their grandfather has Alzheimer’s. Two siblings, Philip and Anna, along with their friends, Kostis and Danae, are the four protagonists. Together they try to find answers to the various strange behaviours their grandfather recently displayed. What has happened and why has he changed? How can Philip and Anna help their grandfather? Will their friends help them? Will the grandfather be able to change as soon as they find out what is behind his strange behaviour? What will be the role of technology and their digital friend, Alze, be? All four of the friends have a long way to go before they can answer all these questions.

“Who am I, grandpa?” is currently being released by Iwrite Publications in Greek and, soon, the English version will be released. It is hoped that this book will be a compass for children, parents and teachers, helping to guide them in increasing their knowledge and awareness of Alzheimer’s disease.

25 November: The Alzheimer Society of Ireland reflects on its participation at the 29th Alzheimer Europe Conference

Advocacy officer, Laura Reid (pictured, right), repeats a quote from the Opening Day speech of Dr Helen Rochford Brennan, Chair of the European Working Group and member of the Irish Dementia Working Group: “I urge you to think of the theme of the conference: ‘Making Valuable Connections’ as PPI (Person Public Involvement) is critical to success”. The passionate intentions of those in attendance was clearly conveyed by the prolonged round of applause which followed this speech.

As advocacy officer for The Alzheimer Society of Ireland, Laura’s main responsibility is the Dementia Carers Campaign Network (DCCN), which is a group of volunteer family carer advocates. One of these advocates, Helena Quaid, spoke on the topic of the ‘lived experience of carer resilience’. Research findings offering new possibilities and real hope on this significant topic was presented at the opening ceremony by inspirational speaker, Marjolein de Vugt who stressed the importance of overcoming implementation barriers which effectively mean that “only 3% of research for eHealth interventions to support caregivers makes it to practice”.

Laura recounts that several of her most meaningful moments were in listening to those advocates who are currently living with dementia. Colleagues Dr Laura O’Philbin and advocate Kevin Quaid presented on the importance of ‘Person Public Involvement’ in research. The Irish Dementia Working Group presented on the real-life topic that you can face challenges and still ‘look well’. Valuable new connections were made with international volunteer advocates such as Archie Noone, Chair of the Scottish Dementia Working Group and Muriel Reid who is a Scottish volunteer family carer advocate for NDCAN.

Ireland was robustly represented at the conference by researchers, clinicians and people living with dementia allowing many more opportunities to re-connect and network with Irish delegates.

25 November: Alzheimer’s Society Accelerator Programme links market products to people with dementia

The Alzheimer’s Society Accelerator Programme invests in the products and services that will have the biggest impact on the lives of people affected by dementia.

The programme is a 12-month partnership with investment of GBP 100,000 (EUR 117,000) and Accelerator partners work closely with an “innovation buddy” from the Innovation Team at Alzheimer’s Society.

The Society received almost 50 applications from a variety of start-ups, established organisations with new products, community groups and individuals from across the UK. Six of these were shortlisted and ultimately two were chosen for investment:

How Do I? - a mobile video support tool for people affected by dementia and their families.
Jelly Drops - hydrating sweets to overcome the challenges faced for people with dementia experiencing dehydration.

Through the first six months it has become clear that the value of the programme is the ability to link continuing product development to people affected by dementia, facilitating further testing with potential users. Additionally, association with the Alzheimer’s Society brand, and promotion through events including the Alzheimer’s Society Annual Conference, have been crucial in building an audience for both products.

Continuous improvement is a key aspect of the Accelerator Programme. Development for the next round includes a change to the investment structure for new ideas, with a portion of the investment to be delivered as in-kind business support, with a focus on ensuring the teams delivering the products and services of the future are able to rely on bespoke support to ensure they can cope with the challenges of bringing a new product to market. This brings the Accelerator Programme in line with other similar schemes across the private sector.

Work is also underway to ensure the Accelerator Programme is as sustainable as possible. The intention is to negotiate an even stronger return on investments made, to ensure the Society is well positioned to keep boosting the best ideas to market in the future.

25 November: Alzheimer’s Society (UK) launches new personalised support service for people affected by dementia

Following successful pilot tests, a pioneering new service by Alzheimer’s Society, called Dementia Connect, has launched in the Wales and West Midlands region, with the aim of rolling out in stages across the whole of England, Wales and Northern Ireland, by springtime 2022.

Dementia Connect, Alzheimer’s Society's new personalised support service, means people with dementia are only one click or call away from additional support. The service is free, easy to access, and puts people in contact with trained Dementia Advisers. The objective of the new service is to make life easier by connecting people with dementia to the support they need.
Alzheimer’s Society reports that its Dementia Advisers can support people directly by phone or face to face, and connect people affected by dementia to a range of local services and online support. People affected by dementia have told Alzheimer’s Society that what they need most is information, advice and one point of contact to guide them.

Dementia Connect provides: advice with legal and financial documents; emotional support when things get tough; connections with local support groups; help in how to understand and live with dementia; in addition to coping techniques. This service works hand in hand with the clinical and social care that people receive, and helps them to take back control of their lives and live independently for longer.

Jeremy Hughes, Chief Executive at Alzheimer’s Society, noted that getting the right support can make a life-changing difference to those with dementia. He advised that many people with dementia and their families just don’t know what support is available or struggle to access it and that what they want is someone experienced in dementia who can guide them through it and help along the way. Mr Hughes is of the opinion that no-one should face dementia alone and that, with the right supports in place, such as Dementia Connect, no one would have to.

For more information on Dementia Connect visit: www.alzheimers.org.uk/dementiaconnect

**POLICY WATCH**

**23 October: France launches national strategy for informal carers**

On 23 October, a new national strategy for informal carers was unveiled. France Alzheimer attended the launch and has said that, while this is a step forward, it will remain vigilant on specific points. Here is France Alzheimer’s report on this new carers’ strategy:

There are between 8 and 11 million informal carers in France today and this number keeps increasing, mainly due to the ageing of the population.

Prime Minister Edouard Philippe, Minister of Health Agnès Buzyn and Secretary of State for Disabled People Sophie Cluzel, presented an experimental national plan to support informal carers in their daily commitment. This strategy will be tested for the next 2 years and focuses on 6 priorities, with a EUR 400 million budget.

France Alzheimer attended the presentation, which took place near Paris, and Martine Bou, President of one of the local branches of the Association, took the floor to describe her life as carer of her own mother diagnosed with Alzheimer’s disease. With this plan, the French government wants to overcome the isolation of millions of carers and support them by providing new social rights and facilitating administrative procedures. The main objectives are to enable carers to balance their working and family lives, to increase and diversify respite solutions, to help them take care of their own health and to support younger informal carers.

These priorities will be implemented through 17 concrete measures. France Alzheimer highlights, in particular, doubling the capacity of respite centres by 2022, the identification of carers’ roles in the medical file of people living with dementia (starting in 2020), the implementation of a national telephone helpline, and the promotion of the national education staff’s awareness regarding issues met by younger carers.

Another positive development is paid leave for carers who continue working while taking care of a relative, for a maximum period of 3 months during their entire career. This leave, which does not have to be taken in one shot, will soon be paid at a rate of between EUR 43 and EUR 52 a day (depending on the household’s composition), will apply to employees, independents, civil servants and unemployed people. Benoit Durand, CEO of France Alzheimer, said: “This new plan is to be welcomed but we must remain vigilant on several points, such as the paid leave. Indeed, this measure must benefit all carers. Today, access to this right is too restrictive and too limited, according to the national compensation system”.

He also mentions the period of leave: “3 months is a start but it will have to be extended for carers of people living with dementia. Moreover, we are concerned about another point. Will this new mechanism apply to all the carers of a same person? To all siblings for example?”

Also concerned by the increasing residual charges at the expense of French families, France Alzheimer advocates for the deployment of innovative interventions such as “baluchonnage”, a Canadian initiative to respond to the respite needs of carers.

The outlines of this new strategy should be known by the beginning of next year and then included in the general reform on ageing and autonomy the French government is currently working on.

**24 October: Confederation and cantons launch National Platform on Dementia in Switzerland**

On 24 October 2019, the Swiss Government announced that it will transform the National Dementia Strategy 2014-2019 into a new “National Dementia Platform”. The aim of the National Dementia Strategy was to improve the
quality of life of people with dementia and their families. It expires at the end of 2019 and offered the various players an important, pioneering framework for collaboration in their dementia-related activities. A total of 18 projects were launched, such as quality standards for diagnostics, awareness-raising measures for the public, medical-ethical guidelines for the care and treatment of people with dementia. Many cantons have now developed their own dementia strategies.

In order to achieve a sustainable impact of the projects launched, a platform is to be created, from January 2020. The platform aims to continue the work started with the strategy and to facilitate the professional exchange between national actors, cantonal authorities and municipalities, the joint development of measures and their implementation in practice. The various activities in the field of dementia will thus be coordinated on a national level and implemented regionally.

Three main objectives will focus on:
- development and optimisation of services and offers, and promoting low-threshold access to high-quality services for people with dementia and their families
- expansion of dementia-specific competencies for professionals
- and raising awareness among the public.

Innovation is a key aspect of the new platform. On the one hand, innovative projects will be funded and made public. On the other hand, there are new ideas about how to implement the findings in practice. The plan is to re-evaluate the platform after 4-5 years, and then to hand it over to a third party.

13-14 November: Dementia experts meet in Lausanne to discuss Alzheimer’s diagnosis

The 2019 Lausanne Workshop is the 6th in a series, launched in 2014 as a response to the international call to action to stop dementia by 2025. Over the past five years, the Workshop has become a highly-curated platform for global Alzheimer’s stakeholders to identify challenges, set solution paths, measure progress and hold each other accountable to act.

Lausanne VI was organised under the auspices of the Organisation for Economic Co-Operation and Development (OECD) and supported by The Global CEO Initiative on Alzheimer’s Disease (CEOi) and Alzheimer’s Disease International (ADI). The theme of the workshop was: “Preparing the Alzheimer’s Disease Ecosystem for a Timely, Accurate and Compassionate Diagnosis”.

Some announcements coming out of the meeting:
- An initial working session will be held during the 50th WEF Annual Meeting, taking place on 21-24 January 2020, in Davos. The aim will be to find successful ways to stimulate finance; to improve preclinical research and drug development; to attract greater investment; and to develop biomarkers to support precision medicine.
- A new AD Biomarker & Diagnostic Repository has been launched by ResearchersAgainstAlzheimer’s. It seeks to raise awareness and visibility regarding recent innovation; to enable the development of a clear pathway for these innovations to get to market; and to provide a solid foundation for a broader global blueprint of Alzheimer’s research and innovation: https://www.usagainstalzheimers.org/biomarkers
- In collaboration with CEOi, the Duke-Margolis Center for Health Policy showcased an upcoming White Paper on Advancing Access Issues in AD, examining payment for future early-stage AD therapies.

Alzheimer Europe was represented at Lausanne VI by its Director, Jean Georges.

Pictured: The Keynote speech at LausanneVI was given by Jim Daly, Minister for Mental Health and Older People, Ireland.

19 November: Representatives from NIH, academia, industry and European Commission discuss impact of GDPR on health research

On 19 November (Brussels, Belgium) ISC Intelligence hosted a meeting on the impact of the general data protection regulation (GDPR) on health research. The meeting was held at the Mission of Switzerland to the EU, and was co-organised by ISC and the US National Institutes of Health (NIH), Medical University, Graz, the Multi-Regional Clinical Trials Center of Harvard University and Brigham and Women’s Hospital, Ropes and Gray LLP, University College Dublin, and Legal Pathways Netherlands. Attendees of the meeting included representatives from each of these organisations, as well as stakeholders from academia, industry and the European Commission.

Kurt Zatloukal of Graz Medical University kicked off the meeting with a keynote presentation on the impact of the GDPR on EU health research programmes. Highlighting the importance of including patients as partners in research, he identified some key opportunities and challenges brought by the GDPR, which forms the basis of a trusted environment for accessing patient data whilst also creating barriers due to heterogeneous implementation across EU member states.
The next keynote was given by Robert Eiss from the NIH, who spoke on the topic of ‘Implications of the GDPR for EU-US Cooperation in Biomedical Science’. ‘Alzheimer’s disease prevention and therapy’ was identified as one of four transformative opportunities for EU-US collaboration. However, he highlighted some obstacles posed by the GDPR for transatlantic clinical research: varying standards of anonymisation between EEA member states, infeasible legal bases for data transfers, and issues with the consent requirements for secondary use of data. These issues have caused substantial delays in data transfers from EU partners of the NIH; for example, the International Genomics of Alzheimer’s project now has to run separate analyses on DNA sequencing data from US and EU sites, which limits the scope of analysis.

After the two keynote presentations, four panel sessions were held. The first focused on the appropriate GDPR safeguards for research, the second focused on the reuse of personal data for research, the third focused on transnational transfers of data for research and the final panel focused on challenges for international academic and industry collaborations and Horizon Europe. Speakers on these panels included representatives from the Innovative Medicines Initiative (IMI), DG Justice and Research & Innovation from the EU Commission, Privacy lawyers and Data Protection Officers, and academic project leaders. Common issues that were raised during the lively Q & A sessions included difficulties in identifying the appropriate legal basis for data collection and sharing, heterogeneous application of GDPR clauses due to member state derogations, and problems with international data transfers, for example in multi-site clinical trials.

Following on from the meeting, the Science journal published an article which summarised some of the key issues that were discussed. ISC Intelligence will hold a follow-up seminar in May 2020.


22 November: Analysis of global dementia research investment finds lack of investment in non-biomedical research

On 22 November 2019, an analysis of global dementia research investment was published in The Lancet journal, by James Pickett, Head of Research at Alzheimer’s Society (UK) and Carol Brayne, Professor of Public Health Medicine at the University of Cambridge. Their article “The scale and profile of global dementia research funding” shows that the level of funding varies considerably between countries and that, while a good start has been made in the area of funding, it is imperative that it continue to rise. There is particular emphasis on the lack of investment in non-biomedical research, such as innovation for health and social care. Funding in this area falls far short of the real need, the article concludes.

Read the analysis in The Lancet, here: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)32599-1/ppt

The Alzheimer’s Society have also written an accompanying blog post, “Dementia research investment needs to reflect the enormous cost of dementia care”, calling for the UK Government to match the level of dementia research funding to parity with other diseases and their burden. This would mean tripling current investment. They also call for GBP 100 million (EUR 117 million) of research funding to be earmarked specifically for health and social care research.

Read the blog post, here: https://www.alzheimers.org.uk/for-researchers/election-manifesto-dementia-research-investment

22 November: Italy publishes dementia-friendly community recommendations emerging from 2nd EU Joint Action on dementia

In 2016, the Dementia Friendly Community (DFC) of Abbiategrasso in Italy, was founded as a pilot project, by Federazione Alzheimer Italia, the Italian Ministry of Health and the National Institute of Health. Together, they chose this DFC to take part in Work Package 7 (WP7) of the 2nd EU Joint Action on dementia (“Act on Dementia”), along with Greece, Bulgaria and the United Kingdom. Abbiategrasso DFC was chosen as a test project, both for the implementation and for the adaptation of best practices.

The main objective of the Joint Action’s WP7 programme was to create a framework for dementia-friendly communities and translate the experiences that emerged from each pilot site into concrete implementations. The work of the project was presented during the 29th Alzheimer Europe Conference, in The Hague.
Students from a local high school in Abbiategrasso created a video, organised a flash-mob in the main town square and distributed a dementia questionnaire to people attending the weekly market. The information gathered from these initiatives was used to measure the impact of the DFC, with the objective of determining what further action is needed to ensure that dementia-inclusive initiatives are meaningful and have real impact on the lives of people with dementia.

The findings from this project and other similar projects, and from the Joint Action final report itself, have been incorporated into a "Recommendation for the development of the Dementia Friendly Community", drafted by the monitoring group for the implementation of Italy’s National Dementia Plan.

The group, coordinated by the Ministry of Health is composed not only of other general departments directly involved (Health Planning and Information Systems) but also of representatives of all the Italian Regions, of the National Institute of Health, of the National Alzheimer associations and of scientific societies. Starting from February 2015, the implementation of the National Dementia Plan is monitored through the Monitoring Table, coordinated by the Ministry, which aims to check the transposition of the National Dementia Plan at the regional level.

Two previous documents, produced by this monitoring group, have already been approved by the State-Regions Conference: National Guidelines on Assistive Therapeutic Diagnostic Paths (PDTA) and National Guidelines on the use of Information Systems.

Federazione Alzheimer Italia says that in the coming weeks, the document on dementia-friendly communities will be examined and, it hopes, approved quickly thereafter, so as to inspire other communities in Italy to join, thanks to good practices and tested national and international models.

25 November: Dementia care costs in the UK to nearly treble in the next two decades

The cost of social care for people with dementia in the UK will nearly treble over the next two decades, finds a new report, commissioned by Alzheimer’s Society from the London School of Economics and Political Science. It will rise from today’s cost of GBP 15.7 billion (EUR 18.34 billion) to GBP 45.4 billion (EUR 53.03 billion) in 2040. The report predicts that, as the population ages, a higher proportion of people with dementia will have higher care needs and will require social care for longer, driving up the average amount spent on care.

The report also shows the cost of care that falls on people with dementia and their families. People affected by dementia pay GBP 9 billion (EUR 10.51 billion) a year in social care costs – 57% of the total social care cost, with the rest covered by the state. Many people are forced to sell their homes to pay for care. Families are also providing GBP 13.9 billion (EUR 16.23 billion) a year in unpaid care for people with dementia.

The report found the total cost of dementia to the UK economy, including costs of health care, social care and unpaid care, is GBP 34.7 billion (EUR 40.53 billion), which will rise to GBP 94.1 billion (EUR 109.9 billion) by 2040, when the number of people with dementia in the UK will have increased from around 850,000 to 1.6 million.

With families already struggling to cope, these report findings highlight the urgent need for action. As the UK heads towards a Christmas general election, Alzheimer’s Society is calling for all political parties to commit to radically reform dementia care, for the cost of social care to be shared across society, funded like other public services in the UK, such as the NHS and education.


More information on Alzheimer’s Society’s Fix Dementia Care campaign: https://www.alzheimers.org.uk/get-involved/our-campaigns/fix-dementia-care

SCIENCE WATCH

2 November: China approves Shanghai Green Valley Pharmaceuticals’ Oligomannate for mild to moderate Alzheimer’s disease

On 2 November, Shanghai Green Valley Pharmaceuticals announced that it has received approval from China’s National Medical Products Administration (NMPA) for Oligomannate as a new oral treatment for mild to moderate Alzheimer’s disease (AD).
The new drug called Oligomannate or GV-971 is derived from marine brown algae, a seaweed, and works by restoring balance to the gut microbiota. It is the first new drug to receive regulatory approval globally in the world for Alzheimer’s disease since 2003 based on its demonstration to help improve cognitive function in people with mild to moderate AD.

Results of a 36-week multicentre, randomised and double-blind Phase III clinical trial showed that Oligomannate led to a statistically significant improvement in cognitive function in people with mild to moderate AD compared to placebo as early as week four and continued at each follow-up assessment visit. According to the company, Oligomannate and placebo groups showed a statistically significant difference of 2.54 in the Alzheimer’s Disease Assessment Scale–Cognitive Subscale 12 (ADAS-Cog-12), a standard cognitive measure commonly used in clinical trials for AD. The study was conducted in 34 hospitals in China and involved 818 participants.

Oligomannate was found to be safe and well tolerated. Adverse effects were comparable between the drug and the placebo. Although full data on the drug have not yet been published, the drug is expected to be available in China by the end of 2019. The company will have to submit additional research on the drug’s pharmacological mechanism, long-term safety and effectiveness. Early next year, the company plans to initiate a global Phase III study (GREEN MEMORY) in the US, Europe and Asia.

On 4 November, Joseph F. Arboleda-Velasquez and colleagues published a paper showing that a rare gene mutation may protect against the onset of symptoms in Alzheimer’s disease (AD). Findings were published in the journal Nature Medicine.

It is a single case report of a women in Colombia who carried the E280A mutation in the gene called PSEN1, which is known to cause early-onset AD. The woman was at high risk for early-onset AD and predisposed to develop AD in her forties but remained unimpaired until her seventies, three decades after the expected age of clinical onset.

In the published study, researchers analysed genetic data from a Colombian family with more than 6,000 living members. They identified about 1,200 individuals in the family who had the E280A mutation and developed mild cognitive impairment (MCI) at about 44 years old and dementia at 49 years old. They found that one women who carried the E280A mutation didn’t develop MCI until she was in her seventies. Like her relatives, she carried the E280A mutation and had large amounts of brain amyloid-beta deposits in her forties. However, she had limited tau tangles and minor neurodegeneration. Researchers suggested that she may have been protected because she had a rare mutation in the APOE gene, a gene associated with AD. Analysis showed that she was the only one who carried two copies of the APOE3 gene variant, named Christchurch.

As the findings from this study relate to a single individual, further research is needed to understand the role of APOE in the pathogenesis, treatment and prevention of AD.

4 November: Bill Gates contributes USD 10 million award to the Alzheimer’s Association “Part the Cloud” programme

On 4 November, the Alzheimer’s Association announced the contribution of USD 10 million (EUR 9.08 million) by Bill Gates to its ‘Part the Cloud’ research funding programme. Along with the USD 30 million (EUR 27.25 million) already raised by the Alzheimer’s Association, this brings the total Part the Cloud clinical research investment to USD 60 million (EUR 54.51 million).

Part the Cloud was founded in 2012 by Michaela “Mikey” Hoag, whose parents both died of Alzheimer’s disease. Part the Cloud specifically funds early-phase clinical research, aiming to accelerate translation of laboratory findings into possible disease therapies. The USD 10 million Gates award will specifically fund clinical trials of novel therapeutic approaches that target mitochondria, vascular pathologies, protein clearance-related mechanisms and neuro-inflammation.

More information about the funding programme can be found here:
https://alz.org/research/for_researchers/grants/types-of-grants/partnership_funding_programs/part-the-cloud-gates-2020-partnership

4 November: T3D Therapeutics raises USD 15 million in funding to initiate its Phase II study in people with mild to moderate AD

On 4 November, T3D Therapeutics, a clinical stage drug development company developing new drugs for the treatment of neurodegenerative diseases including Alzheimer’s disease (AD) and Huntington’s disease, announced it has secured the funding to initiate its Phase II PIONEER study of T3D-959 for the treatment of AD. This investigational drug is designed to improve glucose and lipid metabolism dysfunctions present in AD.

The funding includes USD 15 million (EUR 13.63 million) from an investor and USD 9 million (EUR 8.18 million) received from a grant by the National Institute on Aging, part of the National Institutes of Health. The company is now fully funded to begin
its Phase II PIONEER study. It is a double-blind, placebo-controlled and parallel-group trial evaluating the safety and efficacy of different doses of T3D-959 in people with mild to moderate AD. Starting in early 2020, the trial is expected to enrol up to 250 participants.

https://prn.to/2OTMo97

7 November: EIP Pharma announces results from Phase II REVERSE-SD trial of neflamapimod in early AD

On 7 November, EIP Pharma Inc., a company developing therapeutic drugs to benefit patients with neurodegenerative diseases including Alzheimer’s disease (AD), dementia with Lewy Bodies (DLB) and Huntington’s disease, announced results from the Phase II REVERSE-SD study that examined neflamapimod in early AD. Neflamapimod is an oral brain-penetrant molecule that inhibits the protein kinase p38 alpha, a kinase suggested to lead to the dysfunction of synapses that causes cognitive function deficits related to several neurodegenerative diseases.

REVERSE-SD was designed as a randomised, double-blind and placebo-controlled study, enrolling 161 participants with early AD from 38 centres across US and Europe. Over a period of 24 weeks, participants received capsules of neflamapimod (40 mg) or a placebo control twice daily with food. The company reported that the study failed to meet its primary objective of demonstrating improvement in episodic memory and delayed recall at week 24. The improvement was determined using the Hopkins Verbal Learning Test (HVLT) and the Wechsler Memory Scale (WMS). However, the study met its secondary objectives of target engagement and proof-of-mechanism demonstrating a statistically significant decrease in phospho-tau and tau protein levels, two known markers of neurodegeneration, in the cerebrospinal fluid compared to the placebo. Neflamapimod was found to be well tolerated with two discontinuations due to adverse events of nausea and myeloma. Data will be presented at the upcoming CTAD conference (San Diego, 4–7 December 2019).

Separately, EIP Pharma announced that neflamapimod has been granted fast track designation by the U.S. Food and Drug Administration (FDA) for the treatment of DLB. The company is currently recruiting participants for the Phase II AscenD-LB study. This double-blind and placebo-controlled trial evaluating neflamapimod in mild-to-moderate DLB is aiming to recruit 80 participants across 20 sites in the US and Netherlands. Data are expected in the second half of 2020.


9 November: Population-based study investigates connection between activity and social integration with risk of dementia related to cardiometabolic diseases

On 9 November, an international team of researchers from Sweden and China published an article on leisure activities as well as social integration and their potential influence on the risk of dementia associated to comorbid cardiometabolic diseases in the journal Alzheimer’s & Dementia. The researchers drew on data from the SNAC-K project, which is an ongoing study as part of the Swedish National Study on Aging and Care.

The researchers investigated data from 2,648 study participants out of which 1910 had no cardiometabolic disease, 576 had one, 145 two and 17 presented with three cardiometabolic diseases at the initial assessment. Looking at the correlations, the team found that people with cardiometabolic diseases (such as diabetes and stroke), especially when they had more than one, were also more likely to develop dementia. However, their findings also showed that leisure activities and social integration might mitigate this potential risk of developing dementia that seems to be associated with cardiometabolic diseases.


12 November: Prospective cohort study shows that large rises and falls in blood pressure are associated with higher long-term risk of dementia

On 12 November, Yuan Ma and colleagues published a study in the PLoS Medicine journal, showing that large variations in blood pressure over a period of years are associated with a higher long-term risk of developing dementia.

High blood pressure, also known as hypertension, is known to be a major risk factor for developing dementia in later life. However, studying the relationship between hypertension and dementia is complicated by the interlinked roles of aging and vascular comorbidities such as stroke. To investigate the association between dementia and long-term blood pressure variation, researchers turned to the Rotterdam study, a prospective cohort study that was initiated in 1989. The research team studied 5,273 participants who were dementia-free in 1989, 1,059 of whom developed dementia during the median follow-up period of 14.6 years.

After adjusting for factors such as age, sex, genotype and history of cardiovascular disease, participants were divided into 5 quintiles according to variation in systolic blood pressure (SBP) measured over a period of 2-4 years. Those who were in the highest quintile for SBP variation had the highest risk of developing dementia, which was most pronounced for the highest lag period in measurement of SBP variation (Hazard Ratio of 3.13 for a lag period ≥15 yrs, 95% CI 2.05-4.77). A higher risk of dementia was observed with both
rises and falls in blood pressure, suggesting that variation per se, rather than direction of blood pressure change, influences dementia risk. Further studies are now required to establish whether the observed association is causal and to assess the effect of reducing blood pressure variability on dementia.

14 November: Researchers mapping the brain interactome identify a high concentration of AD risk variants in microglia

On 14 November, Alexi Nott, Inge Holtman, Nicole Coufal and colleagues reported in the Science journal that genetic risk variants for Alzheimer’s disease (AD) are concentrated in the enhancer regions of microglia, immune cells that reside in the brain.

Genome-wide association studies (GWAS) have discovered hundreds of genetic mutations associated with the risk of neurological and psychiatric disorders such as AD, multiple sclerosis and autism. However, the vast majority of these genetic risk variants are located in areas of the human genome that do not encode proteins – also known as ‘non-coding’ areas of the genome. This makes it tricky to understand their function in disease development, as non-coding risk variants may affect the expression of genes that are not in their immediate genetic vicinity. To address this issue, researchers set out to create an atlas of interactions between gene promoters and enhancers, specialised regions of the non-coding genome that dictate the level, localisation and extent of gene expression.

First, the research team isolated the nuclei of microglia, neurons, oligodendrocytes and astrocytes from 6 individuals undergoing surgery for epilepsy treatment. Using advanced next-generation sequencing techniques, they profiled the gene promoters and enhancers that were ‘active’ in each of the different brain cell types. Next, they wanted to map the heritability of genetic risk variants for different neurological and psychological disorders, using GWAS datasets from thousands of individuals. Unlike many of the other disorders analysed, the most heritable AD risk variants were located in the enhancer regions of microglial genes, pointing to the importance of this cell type in the pathogenesis of AD. During gene transcription, epigenetic chromatin ‘loops’ are formed between gene promoters and regulatory regions such as enhancers. Using PLAC-seq (which profiles chromatin ‘loops’) in conjunction with computational fine mapping techniques, researchers were able to identify 41 genes that were strongly associated with AD risk. Of these, 25 were specifically identified in microglia. Interestingly, many of the microglia AD risk genes identified by PLAC-seq were highly connected with risk variants identified in GWAS studies: one of these, BIN1, was directly linked to a risk variant that has the second highest AD risk score after APOE. Although the sequencing studies were performed in young, healthy individuals, these results reinforce previous studies suggesting that microglia and neuroinflammation play an important role in the development of AD.

21 November: Researchers link risk of late-onset AD with genetic variation in the MUC6 locus

On 21 November, Yuriko Katsumata and colleagues published a paper in the Journal of Neuropathology and Experimental Neurology identifying a novel link between the MUC6 genetic locus and late-onset Alzheimer’s disease (LOAD). Although twin studies indicate that approximately 79% of LOAD risk is due to genetic factors, common genetic risk factors such as APOE4 can only account for 20-50% of LOAD diagnoses. The ‘missing heritability’ suggests that many genetic risk factors have yet to be identified. This may in part be due to limitations with the technical approach used to identify genetic risk factors: genome-wide association studies (GWAS) use stringent statistical cut-offs that exclude risk genes with modest effects, and may also ignore genomic regions containing repeated DNA sequences.

Katsumata and colleagues therefore turned to the Alzheimer’s Disease Sequencing Project whole-exome sequencing dataset (ADSP-WES). Whole-exome sequencing (WES) more accurately genotypes rare variants and genetic insertion/deletions, overcoming some of the issues encountered with GWAS studies. First, the researchers analysed WES data from 5,412 participants with AD and 4,889 healthy individuals. Mucin 6 (MUC6), a gene which includes a region with repeated sequences, had the strongest association with LOAD status in this dataset. Next, they showed that Tau pathology in the brains of 173 autopsied individuals with LOAD was positively associated with the number of MUC6 sequence repeats identified by WES. Further studies are now required to establish whether this genetic association with LOAD is causal and, if so, what the underlying biological mechanism might be. Link to article: https://academic.oup.com/jnen/advance-article/doi/10.1093/jnen/nlz116/5631811

DEMENTIA IN SOCIETY

9 October: No universal “best time” for people living with dementia to move to a care home, study finds

Researchers at the NIHR Health & Social Care Workforce Research Unit at King’s College London, United Kingdom, have completed a study called the “Optimal Time Study”, investigating when might be the best time for a person with dementia to move to a care home. The study, which drew on the experiences of people living with dementia and family
carers as well as social workers and care home managers, found that there is no such thing as a universal “best time”.

“We would emphasise the value of conversation – really talking to people with the right experience – in managing potential distress and exploring options as early as possible,” said Dr Kritika Samsi, who led the team at NIHR Health & Social Care Workforce Research Unit (HSCWRU). She continued: “It was clear from this study that determining the ‘right time’ for any move was highly individual, contextual and not dependent on the ‘stage’ of someone’s dementia.”

Her colleague Dr Laura Cole who interviewed many of the people affected by dementia in this study added: “Moving to a care home was a highly emotional time for many families. And some continued to ruminate on their decision long after it had happened. It is important to bear in mind that there is no perfect time – but the aim is that everyone’s point of view is taken into account.”

NIHR press release about the study: https://www.sscr.nihr.ac.uk/people-living-with-dementia-moving-to-care-homes/

NIHR full summary findings, published on 9 October 2019: https://www.sscr.nihr.ac.uk/wp-content/uploads/RF88.pdf

31 October: Sensory device to improve wellbeing for people with advanced dementia captures media attention in Wales

At the end of October 2019, the “HUG” - a sensory device designed to bring pleasure and comfort to people living with advanced dementia - caught the attention of the media in Wales (United Kingdom).

The device is a wearable, soft and has long arms, which “hug” the wearer. There is a heartbeat inside, music and sounds can be played, and the playlist can be personalised. The wearable technology is being tested in a Cardiff care-home setting and so far, the results have been very positive.

The “HUG” was created by the LAUGH (Ludic Artefacts Using Gesture and Haptics) research project, based at the Centre for Applied Research in Inclusive Arts & Design (CARIAD) at Cardiff Metropolitan University (Wales) was nominated as an “Outstanding Dementia Care Product” last year.

The LAUGH project, which aims to support people with late stage dementia with devices to amuse, comfort and engage with them, is delighted with the positive media attention they are receiving for their work and plans to make the “HUG” available for more people with dementia, soon.

Find out more about the LAUGH project and the HUG, here: https://www.laughproject.info/

11 November: Online campaign aims to raise awareness of the problem of pain under-diagnosis and under-treatment in dementia

“Shee pain more clearly” is a campaign aiming to ensure that people affected by dementia, and healthcare professionals working with them are familiar with the problem of pain being under-diagnosed and under-treated in people with dementia. It also aims to familiarise healthcare professionals and policy makers with a number of solutions to the problems faced in this area.

The campaign, spearheaded by Dr Thomas Hadjistavropoulos at the University of Regina, Canada, is being carried out on social media using the hashtag #seepainmoreclearly as well as via a website, a web-based survey and an online video.

Find out more and take the survey: www.seepainmoreclearly.org


12-13 November: Conference in Berlin explores important issues related to dementia in the acute hospital care setting

On 12-13 November, the Robert Bosch Stiftung organised a conference on the topic of dementia in hospitals. The first day of the conference was opened by Dr Bernadette Klapper from the Robert Bosch Stiftung and Prof. Konrad Beyreuther from the Ruprecht-Karls-Universität Heidelberg. This was a scientific day which addressed a range of important issues such as the autonomy of people with dementia in health/existential border situations, epidemiological perspectives, architectural design, “elder speak”, training, advance care planning, mobility, the use of restraint and the registration and screening processes. This was followed by a practice-orientated day which explored issues such as the experience of people with dementia and their carers in hospital, the impact of spaces and processes on care, good practices in relation to the care of people with dementia and delirium, new care concepts and the establishment of dementia-sensitive hospitals. The conference was well attended and there were lively debates between the
speakers and the member of the audience. Dianne Gove from Alzheimer Europe attended this meeting.

13 November: Luxembourg holds conference about wishes and decisions at the end of life... and before

On 13 November, a conference was held in Luxembourg, which was organised by the Ministry of Health and the Ministry of the Family, Integration and the Big Region and entitled “Ma volonté en fin de vie... et avant” (my wishes at the end of life…. And before). There were two key speeches. The first was about palliative care and euthanasia in which Dr Dominique Lossignol explored various related concepts such as compassion, suffering and the need to avoid making assumptions about people with dementia (i.e. what they may or may not wish, about quality of life, about capacity to decide and about awareness). In the second speech, Dr Philippe Lebercq looked at three laws in Luxembourg of relevance to the end of life. There were lively debates after each of the speeches. Dianne Gove attended this conference.

19 November: “Visual Storytelling Grant” awarded to Danish photographer Sofie Mathiassen by The Bob & Diane Fund

On 19 November 2019, The Bob & Diane Fund announced it was awarding USD 5,000 (EUR 4,518) to Danish photographer Sofie Mathiassen for her project, “But Greatest is Love”. The Bob & Diane Fund, launched in June 2016, is an American grant-making organisation dedicated to promoting awareness of Alzheimer’s and dementia-related diseases. It is the passion project of Gina Martin, whose mother, Diane, died from Alzheimer’s dementia. Diane’s husband of 50 years, Bob, who was her primary carer, died three months later.

The “Visual Storytelling Grant”, now in its fourth year, aims to bring awareness, interest, and support for funding research efforts, by awarding a photographer whose work tells the stories of people living with dementia, with dignity and respect. Sofie Mathiassen’s work, “But Greatest is Love” will be presented in the Washington Post and featured on www.bobanddianefund.org

20 November: Helen Rochford-Brennan recognised for her advocacy work, at Irish awards ceremony

Alzheimer Europe was delighted to learn that Helen Rochford-Brennan’s advocacy work has been recognised at the inaugural edition of Ireland’s Sunday Independent / Gala Retail Inspiration Awards. The award ceremony took place in Dublin’s Marker Hotel, on 20 November 2019.

Following a nationwide search to uncover Ireland’s most inspirational people, Gala Retail and the Sunday Independent revealed the 18 finalists, 3 in each of 6 categories. Helen was recognised in the “Inspiration in the Community” category. We would like to warmly congratulate Helen, who is the Chairperson of our European Working Group of People with Dementia (EWGPWD).

22 November: Former EWGPWD member Agnes Houston gives TEDx talk

On 22 November, former member of the European Working Group of People with Dementia (EWGPWD), Agnes Houston MBE (Scotland) gave a TEDx talk at Queen Margaret University, Edinburgh. The talk, “Flourishing through Connections”, focused on her lived experience of becoming a dementia activist and campaigner, the networks and organisations she works with and is supported by within her local and virtual communities.

Agnes Houston was diagnosed with early onset dementia of the Alzheimer type in 2006, at the age of 57 and was a member of the EWGPWD from 2012 to 2016, serving as Vice-Chairperson. She is also the former Chairperson of the Scottish Dementia Working Group and is a current board member of Dementia Alliance International.

Find out more about Agnes Houston and about her TEDx talk here: http://bit.ly/2DcuJE5
LIVING WITH DEMENTIA

15 October: Idalina Aguiar, member of the EWGPWD, talks about Dementia Friends on Portuguese television

I recently had the opportunity to talk openly about dementia and to share my knowledge and experience. I was invited to talk on a TV show called Madeira Viva about my participation in the “Amigos na Demencia” (Dementia Friends) campaign. I support and encourage this campaign, organised by Alzheimer Portugal, because one of its primary goals is to reduce the stigma attached to Alzheimer’s disease (AD). I was also asked to the opening of an exhibition, organised by the municipality of Machico, which informs the public on the realities of AD. This exhibition moved location through the various parishes of Machico, spreading the message of acceptance of those with AD.

As a person with dementia, I want ordinary people to take the time to learn a little more about this complex disease and understand how it affects people like me. I want people to know that dementia is caused by a brain disorder and is a disease, not just a normal part of ageing. Most importantly, I wanted to send out a message that a person is more than what they might appear and is definitely more than their dementia. I was happy to be invited to be a part of these projects and to do what I can to change the way society thinks, acts and talks about dementia. Everyone can and must do their part to improve the daily lives of those people around them who have dementia. I personally know and have felt the effects of stigma and lack of knowledge. It leads many people with dementia, like me, to isolation and social exclusion. I want to do my part to create a society that is friendlier to people with dementia.

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

https://www.facebook.com/nelida.aguiar/videos/10219348722885377/?t=9

NEW PUBLICATIONS AND RESOURCES

1 November: Interel publishes evidence briefing on association between dementia and insomnia

Interel has published an evidence briefing examining the relationship between insomnia and Alzheimer’s disease. The paper notes that up to 45% of people with Alzheimer’s disease will experience impaired sleep, highlighting the negative impact this can have both on the quality of life of the person with dementia, as well as for the informal caregiver.

The briefing also outlines some of the emerging research which has explored the association between sleep disturbances and the development of Alzheimer’s disease in the early stages.

An event entitled “Tackling insomnia in Alzheimer’s disease” will be held under the auspices of Tomislav Sokol MEP (EPP, Croatia), on 3 December 2019 in the European Parliament in Brussels, Belgium, at which the briefing will be discussed. Registration can be completed here: https://form.jotforme.com/92652630829362

11 November: Swedish book on living with dementia now available in English

The Swedish Dementia Centre – Svenskt Demenscentrum – has published “A book for you - Living with dementia” in English. The book is aimed at people recently diagnosed with dementia. It provides advice on how to make everyday life work as smoothly as possible, covering topics such as talking about the disease, useful gadgets and technology, and driving. It also includes a number of testimonials from people living with dementia. You can find out more about the Swedish Dementia Centre and order the book, here: http://demenscentrum.se/English1/

25 November: Alzheimer's Society supports VisitEngland and VisitScotland to launch Dementia-Friendly Tourism Guide

Alzheimer’s Society supported VisitEngland and VisitScotland to launch a new guide to help tourism businesses become more dementia-friendly.

The Dementia-Friendly Tourism Guide, launched in partnership with Alzheimer’s Society, supports tourism businesses in accommodating visitors living with dementia through top tips, case studies and signposts to resources.

The guide lists the benefits that businesses will experience alongside the huge impact that these can have on the lives of people living with dementia. Improvements do not need to
involve significant investment and the guide highlights the small steps businesses can take, organised around the themes of Information, People and Place.

Visitors with dementia face a number of challenges including having the confidence to travel, communicating in noisy environments and becoming disorientated when navigating new places or long routes.

By becoming dementia-friendly, a business will be able to help people with dementia live better lives. Employers will also experience many benefits, such as increased revenue and competitive advantage, improved customer service and enhanced reputation. It will also improve seasonal spread as tourists with dementia prefer to travel in quieter periods and will future-proof businesses by tapping into a growth market.

Sally Copley, Director of Policy and Campaigns at Alzheimer’s Society, said:

“Everyone deserves a short break or holiday to relax and recharge. We are delighted to be uniting with VisitEngland and VisitScotland and raising awareness of what’s possible when the right support and adjustments are put in place, so people with dementia can still get out and enjoy life while creating memories with loved ones.

“Until we find a cure, it’s vital that we do everything we can to make sure everyone with dementia can continue to lead full and meaningful lives. VisitEngland and VisitScotland join more than three million Dementia Friends and hundreds of communities and other organisations in making this a reality.”

To find out more and to apply: http://bit.ly/2Cww73U
To find out more about the DISTINCT project: www.dementiadistinct.com

13 November: MIRIADE project is hiring an Early Stage Researcher in Amsterdam

The MIRIADE (Multi-omics Interdisciplinary Research Integration to Address DEmentia diagnosis) project is seeking to recruit an Early Stage Researcher (ESR) to develop novel immunoassays to improve the diagnosis of dementia with Lewy Bodies, at the Amsterdam UMC. The successful applicant, who must be fluent in Dutch and have studied or worked outside the Netherlands in the past three years, would work full-time (36 hours per week), starting from July 2020.

The closing date for applications is 15 December 2019.

The four-year MIRIADE project (2019-2023), under the Marie Sklodowska-Curie Actions Programme, aims to train a new generation of scientists that become experts in effective development of novel biomarkers for dementia. Alzheimer Europe is an associated partner in this project. To find out more and to apply:

https://euraxess.ec.europa.eu/jobs/460168

To read more about the MIRIADE project:

11 November: DISTINCT Photo-activity project seeks Dutch-speaking Early Stage Researcher

A three-year vacancy is open for a full-time Early Stage Researcher in the Marie Curie DISTINCT Photo-activity project for people with moderate to severe dementia. The position is within the Department of Psychiatry of Amsterdam UMC. Candidates interested in the subject, who are in the first four years of their research career and can speak Dutch are invited to apply until 16 December 2019.
### AE CALENDAR

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<th>AE representative</th>
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<tr>
<td>4-7 December</td>
<td>Clinical Trials on Alzheimer’s disease (CTAD) (San Diego, USA)</td>
<td>Jean</td>
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<tr>
<td>9-10 December</td>
<td>Alzheimer Europe Board Meeting (Brussels, Belgium)</td>
<td>AE Board and staff</td>
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<tr>
<td>10 December</td>
<td>European Parliament lunch debate “Improving the diagnosis of dementia – Findings from European research collaborations (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<td>10 December</td>
<td>Company round table meeting (Brussels, Belgium)</td>
<td>AE Board, sponsors and staff</td>
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<tr>
<td>10-11 December</td>
<td>Alzheimer’s Association Academy (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<td>10-11 December</td>
<td>Governmental Expert Group on Dementia (Brussels, Belgium)</td>
<td>Jean, Owen</td>
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<tr>
<td>10-12 December</td>
<td>Meeting of the European Working Group of People with Dementia (Brussels, Belgium)</td>
<td>Dianne, Ana</td>
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<td>12 December</td>
<td>GSK Health Advisory Board (Brussels, Belgium)</td>
<td>Jean</td>
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<td>17 December</td>
<td>Active Assisted Living (AAL) ‘Ethics and Data Privacy Certification’ workshop (Brussels, Belgium)</td>
<td>Angela</td>
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<tr>
<td>18 December</td>
<td>EPAD change management meeting (Brussels, Belgium)</td>
<td>Jean</td>
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### CONFERENCES

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<tr>
<th>Date</th>
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<tr>
<td>26-29 March</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://cony.com/">http://cony.com/</a></td>
<td>London, UK</td>
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<tr>
<td>2-5 April</td>
<td>International Conference on Alzheimer’s and Parkinson’s Diseases and related neurological disorders (AD/PD), <a href="https://aat-adpd.kenes.com/">https://aat-adpd.kenes.com/</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>11-12 June</td>
<td>Care in the Age of Outrage, <a href="http://dementiaconference.com">dementiaconference.com</a></td>
<td>Sydney, Australia</td>
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<tr>
<td>26-30 July</td>
<td>Alzheimer’s Association International Conference (AAIC), <a href="https://www.alz.org/">https://www.alz.org/</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>20-22 October</td>
<td>30th Alzheimer Europe Conference “Building bridges”</td>
<td>Bucharest, Romania</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.