**WELCOME**

Firstly, huge congratulations to our members for their hard work this September, also known as World Alzheimer’s Month, particularly around World Alzheimer’s Day (21 September). Find out more in our special “World Alzheimer’s Day” section.

For our part, we marked this important day with the launch of the European Alzheimer’s Alliance (EAA) for the 2019-2024 parliamentary term. You can find out more about this in the EAA section.

We also launched a new searchable web database of intercultural dementia care initiatives, this month. This follows on from our 2018 report “The development of intercultural care and support for people with dementia from minority ethnic groups”.

On the project front, I would like to congratulate PARADIGM on the publication of its article “Evaluating the return on patient engagement initiatives in medicines research and development: A literature review”. Congratulations, as well, to Project Officer Ana Diaz for her involvement. The PARADIGM project also held its first ever General Assembly this month.

On the research front, unfortunately, more clinical trials have been discontinued at Phase III. Eisai and Biogen stopped two trials of elenbecstat and ACADIA halted its HARMONY trial.

There have been a number of important European initiatives launched this month, to which we have lent our support: The EU4Health recommendations on the European Council conclusions on the “Economy of Wellbeing”; A “job specification” setting out the qualities that the Health Commissioner should possess. The statement was published to coincide with the announcement of Commissioners-designate, by European Commission President-elect Ursula von der Leyen; Finally, a statement on Rail Passenger Rights launched by the European Disability Forum. Also at the European level, the Patients’ and Consumers’ Working Party of the European Medicines Agency has re-elected Kaisa Immonen (European Patients’ Forum) as its co-chair. Congratulations to Ms Immonen. I look forward to our continued collaboration.

WHO Europe held a landmark workshop on national level public health responses to dementia, which I was honoured to attend. Helen Rochford Brennan, Chair of the European Working Group of People with Dementia, opened the meeting, emphasizing the need for a human-rights-based approach. WHO Europe also held its 69th Regional Committee, in Copenhagen, this month.

Finally, we are putting the finishing touches to our conference #29AEC. Registrations close on 13 October – see you there!

Jean Georges  
Executive Director
20 August: Carol Hargreaves, member of the EWGPWD, receives community award

Alzheimer Europe was delighted to learn that a member of its European Working Group of People with Dementia (EWGPWD), Carol Hargreaves was recently honoured with a Govanhill Community Award, in the Good Neighbour category. We would like to warmly congratulate Carol!

The award ceremony took place in Govanhill, Glasgow, Scotland (UK) on 20 August 2019.

Carol said “I was so proud in receiving this. I think it does prove we can live as normal a life as possible. I have always said getting involved with the working group has made me a better person.”

20 September: Alzheimer Europe launches searchable web database of intercultural dementia care initiatives

Alzheimer Europe has decided to develop concise summaries of the most pertinent areas of its 2018 report, targeted at policy makers and at high-level health and social care professionals.

Alzheimer Europe would like to thank all the members of the expert working group, for their work on the 2018 report, and their ongoing work on the searchable database and upcoming policy summaries. The members (pictured – except for Jean Georges and Debi Lahav) are:

Jean Georges (LU), Daphna Golan-Shemesh (ISR), Dianne Gove, Chair (LU), Michal Herz (ISR), Siiri Jaakson (FIN), Ripaljeet Kaur (UK), Debi Lahav (ISR), T. Rune Nielsen (DK), Sahdia Parveen (UK), Charlotta Plejert (SWE), Mohammed Akhlak Rauf (UK) and Carolien Smits (NL).

We are also grateful to the EWGPWD for its important input to the report and database.

The repository of intercultural care initiatives can be found at: www.alzheimer-europe.org/Ethics/Database-of-initiatives-for-intercultural-care-and-support

We would be pleased to hear from readers about any other initiatives and relevant materials they may be aware of, in Europe. Please send any information or feedback to: dianne.gove@alzheimer-europe.org

Acknowledgements

The 2018 report “The development of intercultural care and support for people with dementia from minority ethnic groups” received funding, under an operating grant from the European Union’s Health Programme (2014-2020), and from the Robert Bosch Stiftung. The ongoing work of the expert working group, on the searchable database and on the policy summaries, is receiving funding from the Robert Bosch Stiftung.

30 September: Make sure you register for #29AEC before 13 October!

Delegates can register for the 29th Alzheimer Europe Conference in The Hague until 13 October. The conference,
“Making valuable connections” will take place from 23-25 October 2019.

The full registration fee includes:

- Admission to all sessions
- Delegate bag and final programme including the abstract book
- Opening ceremony
- Scheduled coffee breaks and lunches on 24 and 25 October.

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

See you in The Hague! If you cannot attend, you can also follow the event on Twitter, using the hashtag #29AEC.

For more information about registrations: https://www.alzheimer-europe.org/Conferences/The-Hague-2019/Conference-registrations


#29AEC - MEET THE SPEAKERS

Geoff Huggins, United Kingdom (UK)

Geoff Huggins is the Director of the NES Digital Service which is part of NHS Scotland and has responsibility for developing Scotland’s National Digital Platform. From 2014 to 2018 he was Director for Health and Social Care Integration and prior to that was Head of Mental Health at the Scottish Government. He led the production and delivery of Scotland’s three dementia strategies. He has been the lead for the Second EU Joint Action on Dementia and currently chairs the European Expert Group. Mr Huggins is one of the speakers in Plenary 1, on 24 October.

Elina Suzuki, OECD

Elina Suzuki is an Advisor to the Director of Employment, Labour and Social Affairs at the Organisation for Economic Co-operation and Development (OECD) in Paris. Her work focuses primarily on dementia, ageing, long-term care, and the use of new digital tools for health. She co-authored the recent OECD report “Care Needed: Improving the Lives of People with Dementia”, which presents the most up-to-date and comprehensive cross-country assessment of the state of dementia care in OECD countries. Ms Suzuki is one of the speakers in Plenary 3, on 25 October.

Debby Gerritsen, Netherlands

Debby Gerritsen is a geropsychologist and professor of wellbeing among frail elderly people and people with chronic illnesses in long-term care at the Department of Primary and Community care of the Radboud university medical center in Nijmegen (Netherlands). She is Chair of the Special Interest Forum on challenging behaviour of the International Psychogeriatric Association (IPA) and a member of INTERDEM. She is also Vice-chair of the UKON network, a collaboration between Dutch healthcare organisations and the Radboudumc in science, education and implementation. Prof. Gerritsen is one of the speakers in Plenary 4, on 25 October.

Tiia Ngandu, Finland

Dr Tiia Ngandu is an associate professor currently working at the Finnish Institute for Health and Welfare (THL) in Helsinki, Finland. She works as a research manager and leader of the Dementia Prevention group. Her major research interests are in the area of dementia epidemiology, particularly risk factors and prevention of Alzheimer’s disease and cognitive impairment. She is the coordinator of the ongoing Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), and she is also...
involved in several other dementia prevention projects, including the recently launched World Wide FINGERS network. Dr Ngandu is one of the speakers in Plenary 4, on 25 October.

**Meike Vernooij, Netherlands**

Meike Vernooij is a professor of Population Imaging and a neuroradiologist at Erasmus MC in Rotterdam, Netherlands. She is an expert in applying medical imaging techniques in a population-based setting to study normal development as well as disease pathophysiology. Her particular expertise and focus is on studying the use of MRI in the investigation of age-related brain changes, specifically those which may be used as preclinical markers for cerebrovascular and neurodegenerative diseases. Her work has been recognised with the European Prize for Neuroradiology (Lucien Appel Prize 2014), the Stroke Innovation Award by the Journal Stroke, and the Lourens Penning Prize of the Dutch Society of Radiology. Prof. Vernooij is one of the speakers in Plenary 4, on 25 October.

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**Alzheimer Europe networking**

On 4 to 7 September (Helsinki Finland), Gwladys went on a site inspection for the 31st Alzheimer Europe Conference #31AEC. On 6 September (Barcelona, Spain), Angela and Jean participated in the VirtualBrainProject Consortium Meeting. From 9 to 10 September (Valetta, Malta), Helen Rochford-Brennan and Jean attended the WHO Dementia Meeting for the European and Eastern Mediterranean Regions. On 17 September (Brussels, Belgium), Angela participated in the inaugural Health Data Community meeting of the Data Saves Lives initiative. On 17 September (online) Dianne and Ana attended the AD Detection Prevention Steering Committee meeting. On 18 September (Brussels, Belgium), Ana and Dianne attended the PARADIGM General Assembly. On 18-19 September (Brussels, Belgium), Ana, Dianne, Angela and Hilary Doxford and Peter Paniccia attended the PARADIGM Patient Engagement Open Forum. On 18-19 September (Brussels, Belgium), Ana, Dianne and Angela attended the Patient Engagement Open Forum, organised by PARADIGM, PFMD and EUPATI. From 24 to 25 September (Amsterdam, Netherlands), Jean attended the meeting of the Patients’ and Consumers’ Working Party (PCWP) of the European Medicines Agency.

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**EU PROJECTS**

**1 September: The EPAD project is prolonged for six months until June 2020**

The European Prevention of Alzheimer’s Dementia (EPAD) project, originally scheduled to end in December 2019, has been extended. The Innovative Medicines Initiative has approved the request for a 6-month no-cost extension to the project, setting the end date in June 2020. This extension will allow the delivery of the start of the first EPAD Proof of Concept (PoC) appendix within the official lifetime of the project as well as the implementation of a sustainability model that allows EPAD to continue its activities after June 2020.

The project started in January 2015 with the goal of streamlining the testing and development of preventative treatments for Alzheimer’s disease. To this end, EPAD has been developing a platform on which new compounds can be tested in an efficient way, delivering more effective, targeted interventions that can slow or stop dementia.

By combining knowledge and expertise from 39 organisations across multiple sectors, EPAD has been able to accomplish a lot over the last 4.5 years. Examples of these accomplishments are the EPAD Register, the EPAD Longitudinal Cohort Study currently recruiting in 23 European sites and with more than 1800 research participants screened, and the establishment of the PoC framework. Good progress has been made on the PoC pipeline and the contract negotiations with the upcoming Intervention Owners. The team is looking forward to the inclusion of the first participant in the first PoC appendix in Q2 2020.

In addition, over the past few months, the EPAD sustainability work package has made significant progress in making sure that EPAD can continue running during the post IMI period, renamed as EPAD2.0, as of July 2020.
4 September: The AD Detect and Prevent project introduces itself

On 4 September 2019, the “AD Detect and Prevent” project has sent out a press release, titled “AD Detect and Prevent is an innovative EU-funded project developing a robust digital tool for the early detection of Alzheimer’s disease”. The project, which launched in November 2018, used the release to introduce itself to the research community and wider dementia community. Here is the main thrust of the release:

“AD Detect and Prevent” project, which is led by the Danish digital therapeutics company Brain+, is pursuing the ambitious aim of developing a digital tool to improve the detection of Alzheimer’s disease (AD) prior to the possible onset of dementia and combining this with lifestyle programmes for reducing lifestyle risk related to Alzheimer’s dementia. To achieve this, the project brings together a diverse group of partners with strong expertise in brain health, dementia, clinical neuroscience, neuroimaging and patient advocacy. The partners are Brain+, University of Oxford, Aarhus University, University of Nottingham, Alzheimer Europe and the European Brain Council. The project kicked-off in November 2018, is progressing fast and will continue over the next two years.

To date, dementia remains an incurable condition that affects around 9 million people in Europe1, many of whom have a diagnosis of Alzheimer’s dementia. Research has shown that the pathology associated with Alzheimer’s disease is present in the brain decades before symptom onset and its detection indicates a higher risk of developing the condition. Recent promising work in the field of AD prevention suggests that controlling some lifestyle factors (e.g. diabetes, hypertension and social isolation) may play an important role in reducing the risk of developing dementia and that “more than a third of dementia cases might, theoretically, be preventable”. Researchers from the University of Oxford have recently developed a novel method that has the potential to identify individuals who are more likely to develop Alzheimer’s disease but have not yet experienced overt cognitive symptoms. Also, Brain+, a digital therapeutics company located in Copenhagen has developed a digital platform for adaptive cognitive training and rehabilitation, and behavioural programmes for brain health. The objective of the AD Detect and Prevent project is to develop an integrated and seamless solution for people at increased risk of developing Alzheimer’s dementia. The solution will combine, gamify and further develop the novel detection method designed by the University of Oxford with the digital therapeutics platform developed by Brain+.

This integrated tool aims to first detect subtle cognitive signs associated with Alzheimer’s disease (before the possible emergence of clear symptoms) and to subsequently provide personalized intervention programmes that address risk factors connected to Alzheimer’s dementia. The University of Oxford, the University of Nottingham and Aarhus University will collaborate and carry out rigorous research studies to investigate the potential of this innovative tool.

The research studies that aim to test this tool are scheduled to start during the second half of 2019. Brain+ and the University of Oxford have been developing and testing various prototypes of the AD Detect tool in order to gain insight into the type of format that provides the best user experience whilst remaining a robust tool for the detection of the early signs of Alzheimer’s disease. The team at Aarhus University will validate the AD Detect tool with biomarkers detected by Positron Emission Tomography (PET) brain scan. Finally, researchers in Computer Science at the University of Nottingham will study the longitudinal use of the AD Prevent tool whilst researchers from NIHR MindTech MedTech Cooperative at the Institute of Mental Health, also at the University of Nottingham, will run Public and Patient Involvement (PPI) workshops with people with Alzheimer’s disease and their carers to explore the user dimension of the AD Detect and Prevent tool. Alzheimer Europe is also involved in the PPI work.

The AD Detect and Prevent tool is designed to be user-friendly and easily accessible, and will be delivered on various types of devices such as tablets, smartphones and computers. This digital solution will be initially launched in Denmark and the United Kingdom in 2020 but the consortium hopes to expand the tool to other European countries.

For further information about the consortium, and for contact details including social media accounts, see the full press release, here: http://bit.ly/ADDetectPrevent

6 September: The VirtualBrainCloud project holds its second General Assembly meeting

On 6 September, the VirtualBrainCloud project held its second General Assembly meeting in Barcelona, Spain, followed by a Technical Meeting on ‘Integration and Interfaces’. Jean Georges (Executive Director) and Angela Bradshaw (Project Officer) attended the meeting.

The VirtualBrainCloud (TVB_Cloud) project is aiming to create a decision support system for clinical practice, giving clinicians access to high-quality, multidisciplinary data on neurodegenerative disease via a cloud-based, personalised brain simulation platform. To achieve this aim, TVB_Cloud will
collect, collate and integrate multiple sources of clinical data, including EEG scans, MRI and PET images, genetic screening information and biomarker data. TVB_Cloud will also create an adapted cloud-based infrastructure for the integrated data sources, hosted on high-performance computing (HPC) clusters.

The TVB_Cloud General Assembly meeting focused primarily on the computational aspects of the project, although legal and ethical issues (e.g. data protection and patient confidentiality) were also briefly discussed. Project partners presented the work they have been doing to render data Findable, Accessible, Interoperable and Reuseable (FAIR), also highlighting data management and warehousing strategies that are being explored. Martin Hofmann-Apitius from the Fraunhofer Institute presented work from WP4, in which longitudinal models of Alzheimer’s and Parkinson’s disease are being generated based on existing clinical datasets. WP4 is also creating longitudinal “biotypes” for disease progression, hoping to improve patient stratification by integrating several biological and behavioural parameters. The General Assembly meeting concluded with data presentations from partners involved in WP8, showing the different computer pipelines that will be integrated into the personalised simulation platform of TVB_Cloud.

The Technical Meeting mainly focused on Cloud architecture: teams from Fraunhofer and Forschungszentrum Jülich discussed data ontologies, integration of the Cloud with HPC clusters and repository integration. The meeting drew to a close with lively discussions on the best computational approaches to use, aided by the arrival of two coffee machines and Spanish pastries.

6 September: PARADIGM publishes an article in the Journal of Health Expectations

The PARADIGM project is proud to present its new paper “Evaluating the return on patient engagement initiatives in medicines research and development: A literature review”, published in the Journal of Health Expectations on 6 September.

The article was led by Lidewij Eva Vat from the Athena Institute at the Vrije Universiteit Amsterdam. Alzheimer Europe Project Officer, Ana Diaz was involved in the paper. Alzheimer Europe offers its congratulations to the PARADIGM team on this publication.

PARADIGM is a public-private partnership and is co-led by the European Patients’ Forum and the European Federation of Pharmaceutical Industries and Associations (EFPIA).


17 September: AMYPAD DPMS has reached the 50% recruitment mark

The AMYPAD consortium is pleased to announce a major milestone. The Diagnostic and Patient Management Study (DPMS) has reached the 50% recruitment mark with more than 450 subjects enrolled since the study was initiated last April 2018.

The AMYPAD DPMS protocol has been approved in all seven participating countries (Switzerland, Netherlands, France, UK, Spain, Germany and Sweden). Out of a total of 900 expected participants, with an initial work-up of either subjective cognitive decline, mild cognitive impairment or suspected Alzheimer’s disease dementia, 471 research participants have already been recruited. The analysis of the PET images acquired in this study has also commenced, with the aim of determining the usefulness of β-amyloid imaging regarding diagnostic confidence, decision trees, change in diagnosis, and patient management plans.

17 September: Alzheimer’s Disease Detect and Prevent project Steering Committee organised in Copenhagen

On 17 September the Steering Committee of the Alzheimer’s Disease Detect and Prevent (ADDP) project met in Copenhagen to discuss about the progress of the project and the future work on the research studies planned to validate the ADDP solution. Steering Committee members had also the opportunity to learn about the Patient and Public Involvement (PPI) work which has been carried out so far by Alzheimer Europe and the University of Nottingham.

Alzheimer Europe presented the consultation that was carried out earlier this year with members of the European Working Group of People with Dementia and their supporters and, in particular, how the feedback provided by them could be in incorporated in the project. Dianne and Ana attended, online, the part of the meeting on PPI.

https://www.addp.eu/

18-19 September: 1st PARADIGM General Assembly and 2nd Patient Engagement Open Forum (PEOF) held in Brussels

The 1st PARADIGM General Assembly was held on 18 September in Brussels. During the meeting, project partners were informed about the progress of the project and also had the opportunity to discuss its upcoming mid-term review.

During the afternoon of 18 and on 19 September, the PEOF took place. The event was co-organised by PARADIGM, EUPATI and the Patient Focused Medicines Development (PFMD) initiative, and brought together a range of stakeholders interested in and committed to making meaningful and systematic patient engagement a reality.
Over the two days, 260 people from 140 different organisations actively participated in the different sessions and workshops and over 400 joined the live streaming sessions. This included people from pharmaceutical companies, academia, regulators and HTA agencies, patient organisations, patient advocates, and patients living with many different conditions and their carers, among many others. It was a very lively event with a combination of plenary sessions and workshops, where participants had the chance to discuss relevant topics on patient engagement, such as tools and recommendations for effective patient engagement, methods for monitoring and evaluating the impact and outcomes in patient engagement activities, and fair market compensation for patient input.

From Alzheimer Europe, Ana Diaz, Dianne Gove, Angela Bradshaw and Hilary Doxford and her husband Peter Paniccia attended the PEOF.

If you are interested in finding out more about this event, please visit the following links:

PEOF agenda: https://patientengagementopenforum.org/
Related blogs: https://imi-paradigm.eu/blog/
Streamed sessions: https://twitter.com/PEOForum

19-20 September: Mind project secondment takes place in Germany, with a focus on the MinD International Conference

This secondment, which was hosted by Alexianer St Hedwig Hospital in Berlin and Technische Universität Dresden, was focused on the MinD international conference 2019. Under the motto “Designing with and for People with Dementia: Wellbeing, Empowerment and Happiness”, the conference represented a unique opportunity to share state-of-the-art work in this field as well as to shape future trends by contributing to the transformation and innovation in products, services, housing, etc., putting people living with dementia at the very core of the design processes.

On the first day of the conference, after a warm welcome on the part of the organizers of this event, Kristina Niedderer framed the event into the objectives of the MIND Project: “Bringing together professionals from design and healthcare sector (…) to explore the potential of design to help and support people living with dementia, carers and professionals embedding mindfulness through design”.

Chris Roberts, Vice-chair of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD), was the first keynote speaker. He drew the audience’s full attention by offering the point of view of those affected, from his own experience. He described the difficult path following the diagnosis as “the most disempowering thing” and the overcoming of a number of important barriers, to achieve acceptance: “I’m still me. We don’t change overnight (…) but it is changing. We need to change our lives”.

Helma Van Rijn was the second keynote speaker, who gave an engaging presentation about “how to understand and design for the needs of users when they are difficult to reach”. For Helma, designing is all about bringing meaning to society. The key is not in what we design but for whom we do it, presenting a model that starts with “exploring” (listening to people through meaningful encounters), followed by “envisioning” (getting insights) and ending with “enabling” (designing new concepts).

On the second day, “Mindfulness and its relevance to cognitive decline and dementia” was the third and last keynote presentation, by Natalie Marchant. A wide number of positive outcomes of mindfulness-based interventions for dementia were elucidated by the speaker, drawing on scientific studies and evidence in the field. Particularly, interventions that reduce stress levels connected to dementia are key.

Parallel sessions and workshops taking place on the first day encompassed sessions about Co-Design, Wellbeing and Play, Design of Public Spaces and Care Centres Architecture: A wide realm of innovative works were presented such as how to convert disorder wandering into a guided activity, the AIR model of co-design, IoT design for dementia, interventions for positive moments, sound play for wellbeing, playful objects for dementia, designing dementia friendly public spaces, smart materials, care centres and architecture, etc. Ethics and Awareness and Storytelling.

The conference ended with a Panel Session that discussed core issues and questions put forward by the delegates of the conference, and which had emerged from the presentations and lessons learned during these two exciting days.
20 September: Neuronet launches its first newsletter issue and a social media campaign – Why we do what we do

On 20 September, the three-year Coordination and Support Action “Neuronet” announced the launch of its first newsletter issue and the start of a Twitter campaign to explain why they do what they do.

This and the future newsletter issues will introduce you to our fantastic early-career researchers and investigators, project achievements as well as our activities.

You can read the online version of the newsletter here: http://bit.ly/Neuronet-newsletter-1

Neuronet sets out to boost collaboration across the Innovative Medicines Initiative (IMI) projects of the Neurodegenerative Disorders (ND) portfolio, assisting in identifying gaps, multiplying its impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide.

Neuronet’s communication team and its community of communication representatives from the IMI projects on neurodegeneration are pleased to announce that they will celebrate the great people behind their projects.

Each day, one of the researchers respectively participants from the Innovative Medicines Initiative projects will speak up. They will link to some of the great findings, interesting activities and tools, none of which would have been possible without public-private collaboration. Follow them on Twitter so that you can keep up to date with the series and keep an eye on #WeAreNeuronet

https://twitter.com/IMI2_NEURONET
https://www.imi-neuronet.org/communication-campaign/

EU project acknowledgement

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

The projects in this newsletter with EU funding are:

**AD Detect and Prevent** – grant agreement 820636
**AMYPAD** – grant agreement 115952
**EPAD** - grant agreement 115736
**Neuronet** – grant agreement 821513
**PARADIGM** – grant agreement 777450
**VirtualBrainCloud** – grant agreement 826421

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 91, 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), **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); Mia Petra 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 Evren (EPP); Sylvie Guillaume (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 Kouoglou (GUE/NGL); Dimitrios Papadimonioul (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg (ECR), **Hungary:** Tamás Deutsch (EPP); Ádám Kósá (EPP), **Ireland:** Matt Carthy (GUE/NGL); Ciara Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ‘Ming’ Flanagan (GUE/NGL); Billy Kelleher (ALDE); Séan Kelly (EPP); Mairead McGuinness (EPP); Grace O’Sullivan (Greens/EFA), **Italy:** Isabella Adinolfi (EFDD); Brando Bенifi (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D), **Lithuania:** Vilija Blinkytevute (S&D), **Luxembourg:** Charles Goerens (ALDE); Christophe Hansen (EPP), **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D), **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP), **Poland:** Elżbieta Łukacijewska (EPP); Jan Olbrycht (EPP), **Portugal:** José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL), **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP), **Slovakia:** Ivan Stefanec (EPP), **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tonja Fajon (S&D); Klemen Grošelj (ALDE); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP), **Spain:** Izaskun Bilbao Barandica (ALDE); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA), **Sweden:** Åyte Guteland (S&D); Peter Lundgren (EFD), **United Kingdom:** Martina Anderson (GUE/NGL); Theresa Griffin (S&D); Jude Kirton-Darling (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Julie Ward (S&D).
EUROPEAN ALZHEIMER’S ALLIANCE


World Alzheimer’s Day, 21 September, is dedicated to raising awareness of Alzheimer’s and other types of dementia, as well as challenging the stigma that surrounds dementia. This year, Alzheimer Europe marked this important day with the launch of the European Alzheimer’s Alliance (EAA) for the 2019-2024 parliamentary term.

The EAA, which has been active in the European Parliament since 2007, is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) to support Alzheimer Europe and its members in making dementia a public health priority in Europe.

The work to engage with new and re-elected MEPs for the 2019-2024 term was largely done during our #DementiaPledge2019 campaign. The campaign, which was a collaborative effort between Alzheimer Europe and its member organisations, invited candidates at the May 2019 elections to pledge their support for our common cause - to make dementia a priority; to support dementia-inclusive initiatives at the national level; and to join the EAA, if elected. But the work does not end there. We continue to reach out to other MEPs, inviting them to join our European Parliament lunch debates, hosted by members of the EAA. These debates cover a wide variety of dementia-related topics. We also use these events, among other communication channels available to us, to ensure current and prospective EAA members understand the importance of dementia across a range of policy areas, as well as what they can do as parliamentarians to ensure it remains a priority. Following the campaign and the elections, the new EAA begins its terms with 91 members, hailing from 27 EU countries.

We are delighted that Sirpa Pietikäinen, MEP (Finland) has agreed to be the Chairperson of the EAA for the new term. To ensure that we have a balance of representation across the political spectrum, Alzheimer Europe has also written to EAA members from the EPP, S&D, Reform Europe, the EFA/Greens and GUE/NGL inviting them to become Vice-chairs of the group. Once confirmed, the names of the Vice-chairs will be made available on the Alzheimer Europe website.

Over the coming months, the European Commission will set out its legislative agenda and policy priorities for the next five years. Once details have been announced, Alzheimer Europe will identify the implications for dementia policy, working with members of the EAA to ensure that these policies reflect the priorities of people with dementia, their families and carers.

For more information about the European Alzheimer’s Alliance, including the names of the 91 MEPs: https://www.alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer's-Alliance/Members

EU DEVELOPMENTS

10 September: Alzheimer Europe signs up to Health Commissioner “job specification”

Alzheimer Europe, along with 43 other civil society organisations, has signed up to a “job specification” setting out their view of the qualities and characteristics which the next Health Commissioner must possess. The statement was published to coincide with the announcement of Commissioners-designate, by European Commission President-elect, Ursula von der Leyen.

The statement highlights the expectation among civil society organisations, that the future Health Commissioner will take strategic leadership of putting people and their health at the centre of EU policy-making. It further notes that whilst the EU has a mandate to protect human health in all EU policies, the relative status of health in the EU’s political agenda had diminished in recent years, compared with growth, migration and security, resulting in missed opportunities to decrease health inequalities.

Specifically, the job specification explains that the future Health Commissioner is expected to prioritise the public interest over those of economic and financial actors and put forward an explicit approach to deal with the commercial, economic, social and environmental determinants of health.

Once the structure of the next Commission is unveiled, the commissioners-designate will need to be vetted by the
European Parliament during hearings which will take place at the end of September and beginning of October.

The full text of the job specification can be found here:

10 September: Ursula von der Leyen unveils Commissioners-designate

Ursula von der Leyen, President-elect of the European Commission, has announced choices for the next College of Commissioners. Following approval of the nominees of each county by the European Council, Ms von der Leyen met with each individual before allocating their proposed remit within the future Commission. The Commissioners-designate will now face hearings by the European Parliament committees who have competence over each remit, at the end of September and beginning of October. The full College of Commissioners will then face a confirmatory vote in a plenary session of the European Parliament in the latter half of October. However, it is important to note that the following positions and individuals may change over the course of the coming weeks as the process continues.

The list of Commissioners, their countries and designated positions are as follows:

- Executive Vice President, Valdis Dombrovskis (Latvia): An “Economy that Works for People” and Commissioner for financial services.
- Executive Vice President, Frans Timmermans (Netherlands): A “European Green Deal” and climate action policy.
- Executive Vice President, Margrethe Vestager (Denmark): A "Europe fit for the digital age" and Commissioner for competition.

The five other Vice-Presidents are:

- Josep Borrell (Spain): High Representative-designate for foreign policy and "A Stronger Europe in the World"
- Věra Jourová (Czech Republic): Values and Transparency.
- Margaritis Schinas (Greece): Protecting Our European Way of Life.
- Maroš Šefčovič (Slovakia): Interinstitutional Relations and Foresight.
- Dubravka Šuica (Croatia): Democracy and Demography.

Other commissioners-designate:

- Johannes Hahn (Austria): Budget and Administration.
- Didier Reynders (Belgium): Justice (including the topic of the rule of law).
- Mariya Gabriel (Bulgaria): Innovation and Youth.
- Stella Kyriakides (Cyprus): Health.
- Kadri Simson (Estonia): Energy.
- Jutta Urpilainen (Finland): International Partnerships.
- Sylvie Goulard (France): Industrial policy, Digital Single Market.
- László Trócsányi (Hungary): Neighbourhood and Enlargement.
- Phil Hogan (Ireland): Trade.
- Paolo Gentiloni (Italy): Economy.
- Virginijus Sinkevičius (Lithuania): Environment and Oceans.
- Nicolas Schmit (Luxembourg): Jobs.
- Helena Dalli (Malta): Equality.
- Janusz Wojciechowski (Poland): Agriculture.
- Elisa Ferreira (Portugal): Cohesion and Reforms.
- Rovana Plumb (Romania): Transport.
- Janez Lenarčič (Slovenia): Crisis Management.
- Ylva Johansson (Sweden): Home Affairs.

The full list of Commissioners-designate, their biographies and copies of the mission letters they received from Ursula von der Leyen, can be found here:
https://ec.europa.eu/commission/interim/commissioners-designate_en

10 September: Alzheimer Europe supports EU4Health recommendations on the European Council conclusions

Civil society organisations represented in the EU4Health campaign have welcomed the conclusions of the European Council on the “Economy of Wellbeing” which will be adopted as part of the current EU Finnish Presidency. EU4Health is hopeful that the conclusions will help to contribute to, and guide the implementation of, the European Pillar of Social Rights in line with the new EU Strategic Agenda 2019-2024. EU4Health believes that a central pillar of the “Economy of Wellbeing” should be the maintenance of strong action on health and the reduction of inequalities in health both within and between EU Member States.

In the letter to the Finnish Presidency, the civil society organisations propose some revisions to the wording of the draft conclusions. Specifically, the recommendations address the definition of the economy of wellbeing, placing greater emphasis on prevention and promotion of mental health, to
complement the curative approach to health and disease. Additionally, the letter recommends that equity and rights-based principles must have greater significance in the balance between social cohesion and economic progress.

The letter, along with draft wording proposed by the civil society organisations, can be found here: http://bit.ly/2oRsOKM

The civil society organisations which signed up to the statement include:

- Alzheimer Europe
- Eurohealthnet
- European Heart Network
- European Public Health Association
- European Public Health Alliance
- European Respiratory Society
- EURORDIS Rare Diseases Group
- Global Health Advocates

16 September: Alzheimer Europe signs up to EDF statement on Rail Passenger Rights

Alzheimer Europe has signed a joint statement calling on the Council of the European Union to improve the rights of rail passengers. To date, 10 Members of the European Parliament and over 200 organisations who are active in the fields of disability, rights of older people, environment and passenger rights have signed the joint letter to EU leaders calling on them to reduce pre-notification periods for assistance during train travel in the upcoming revision of the EU Rail Passengers’ Regulation (1371/2006).

The letter notes that train travel is increasing important as a more environmentally sustainable means of transport, whilst highlighting that millions of persons with reduced mobility cannot access it freely, as obtaining the assistance needed to board the train is restricted and subject to lengthy pre-notification periods.

It is further highlighted that the revision of the Regulation has the potential to take a step in the right direction by making assistance available at all times. The European Parliament has proposed reducing the notification period from 48 hours to 2 hours, however, some EU Member States are blocking this change.

The letter calling on those Members States to support the proposal of the European Parliament, as well as a list of signatories, can be found here:

http://edf-feph.org/train-travel-future-dont-exclude-us

17 September: Data Saves Lives initiative holds inaugural Health Data Community meeting

On 17 September, the Data Saves Lives Initiative held its first Health Data Community Meeting in Brussels. Alzheimer Europe project officer Angela Bradshaw attended the meeting.

Data Saves Lives is co-funded by the European Federation of Pharmaceutical Industries and Associations (EFPIA) and EIT Health; it aims to enable patients and members of the public to participate in conversations around health data use and sharing. To facilitate this, Data Saves Lives is developing a web platform to provide understandable information on key topics around health data and data sharing. The Health Data Community (HDC) is composed of stakeholders from patient representative groups, regulatory agencies, NGOs, academia and industry.

During the inaugural HDC meeting, the ~60 attendees were asked for their input on a pilot version of the Data Saves Lives web portal. Attendees then worked in groups to identify ‘big questions’ that could be addressed through the Data Saves Lives initiative: key issues that emerged from this session included ‘how to increase public trust in health data sharing’ and ‘how to actively engage patients and citizens in data sharing’. Finally, participants worked on co-creating Guiding Principles for responsible health data research. Together, participants identified transparency, accountability, reciprocity, integrity and inclusivity as key Guiding Principles.

24 September: Patients’ and Consumers’ Working Party of the European Medicines Agency elects new co-chair

The European Medicines Agency (EMA)’s Patients’ and Consumers’ Working Party (PCWP) has re-elected Kaisa Immonen of the European Patients’ Forum (EPF) as co-chair. Ms Immonen will co-chair the PCWP meetings together with Juan Garcia Burgos, Head of Public Engagement at EMA, for the next three years. The vote took place during the PCWP meeting on 24 September 2019.

Kaisa Immonen has extensive experience in European Union health policy and serves currently as Director of Policy at the EPF. Accepting the re-election for her second mandate, Ms Immonen said “The PCWP plays a vital role in supporting the Agency in its efforts, as well as acting as a watchdog to ensure that patient engagement is taken as a strategic priority. It will need careful planning and facilitation to ensure the PCWP continues to fulfil its role as a platform for exchange and discussion in the next three years, but also goes beyond it to
keep advancing patients’ and consumers’ meaningful engagement in the work of EMA.”

The PCWP is a pillar of the EMA’s ever-increasing engagement with civil society. It provides recommendations to EMA and its scientific committees on all matters of interest to patients and consumers in relation to medicines.

Jean Georges, Executive Director of Alzheimer Europe attended the PCWP meeting. He expresses his, and Alzheimer Europe’s congratulations to Ms Immonen on her re-election.

The 2019-2022 work plan that will guide the work of both parties has also been endorsed by EMA’s scientific committees during their meetings in September 2019 and is now available.


t-new-co-chairs-0

WORLD ALZHEIMER’S DAY

5 September: CEAFA launches World Alzheimer’s Day campaign and urges government to approve National Alzheimer’s Plan

On 5 September, during a presentation of its 2019 World Alzheimer’s Day campaign #EVOLUCIÓN at the headquarters of Spain’s social services, Imserso, the Confederación Española de Alzheimer (CEAFA) urged the Spanish Government to approve the country’s National Alzheimer’s Plan.

Some of the main points of the campaign are:

- The importance of empowering people with dementia to be able to live with dignity;
- Combatting isolation for carers and reinforcing carers’ rights;
- Providing appropriate care for different types of dementia, respecting individual circumstances, and paying attention to the, thus far, unmet needs of people with young onset dementia.

For more information about the #EVOLUCIÓN campaign, see: https://www.youtube.com/watch?time_continue=2&v=DdScBdStlt4

21 September: Alzheimer Uniti organises a visit to the Botanical Gardens in Rome

A brilliantly sunny September day in Rome guaranteed the success of World Alzheimer’s Day this year, with its many celebratory events. As in the past years, Alzheimer Uniti Roma, together with both younger and older volunteers, organised a table in one of the historic piazzas in the centre of Rome, giving out brochures and information…and T-shirts and violets!

Earlier that day, the president of the association, together with a psychologist, led a group of people with dementia, together with their caregivers, on a visit to the Botanical Gardens, a place of peace and greenery in the heart of Trastevere. This contact with nature, with extraordinary trees, flowering shrubs and sweet-smelling plants was very stimulating for the group, both physically and socially, and was a wonderful opportunity to reminisce.

Later, in the piazza, there were throngs of Romans going to and fro, including some actors (such as the famous Inspector Montalbano actor, Luca Zingaretti) who attracted a small crowd. Tourists stopped to talk and interact with the volunteers.

The day ended with the usual concert of the Carabinieri, creating a wonderful atmosphere of solidarity, giving hope for a better future in a dementia-friendly community.

21 September: France Alzheimer focuses its message on inclusiveness for World Alzheimer’s Day

This year, for World Alzheimer’s Day, France Alzheimer and related diseases focused its message on inclusiveness and the necessity for all citizens to take into consideration people living with dementia and their caregivers. The association’s main objective was to raise awareness among society and to remove the stigma around the disease and its consequences.

France Alzheimer launched a national campaign, the effects of which will last long after the 2019 World Alzheimer’s Day. Their campaign has three main aims:
• to raise awareness and to train the major local actors (police, fire departments, etc.), with the help of its nationwide network of volunteers;
• to broadcast a unifying symbol of recognition to show their strong support for people living with dementia;
• to invite the mayor of every city in France to sign their pledge “Alzheimer Caring City” and to commit to engage in an inclusive approach.

For World Alzheimer’s Day, France Alzheimer also built a Village Alzheimer in the centre of Paris, which was open for free to the public from 20 September to 22 September. This Village enabled the association to welcome and inform the general public. They provided specific and relevant information about the disease, care services, research programmes and so on. Finally, their web-radio broadcasted all day long, alongside conferences and workshops presented by experts in the field of Alzheimer’s disease and dementia.

21 September: Turkey holds a press conference marking World Alzheimer’s Day

The Turkish Alzheimer Association organised a press conference, inviting the members of the press, people with dementia and their caregivers on 21 September, World Alzheimer’s Day. The event was organised at the Istanbul Day Care Center and kindergarten students visited after the conference. Everyone had a pleasant time together.

The President of the Turkish Alzheimer Association, Professor Haşmet Hanağışı said, in his opening speech:

“The number of patients with dementia doubles every 20 years. The number is around 50 million today, it is projected to reach 150 million by 2050. Good care for Alzheimer patients has a positive impact on the course of the disease.”

At this point, he emphasised the importance of Alzheimer’s daycare centres which provide great convenience for both people with dementia and their relatives. People living with dementia can socialise in Alzheimer’s daycare centres and activities such as dance, exercise, music and manual skills, which are guided under the supervision of experts, both contribute positively to the course of the disease and provide motivation to the centre users and their relatives. He added that these centres create a social environment that connects people with dementia to life, enables them to lead a quality life, gives life energy through activities and allows them to have a pleasant time. Prof. Hanağışı said that it is also very effective for the people who care for them, especially relatives, who can spare some time for themselves while their family members are in professional hands in a place where they will have a pleasant time, even for a short time. He pointed out that the relatives also very often participate in daytime activities and make friends with other relatives, while the person with dementia, who is constantly in contact with the smiling faces of the staff, has less anxiety.

21 September: Half of older people in Croatia have cognitive decline reports Alzheimer Croatia, following World Alzheimer’s Day survey

Marking World Alzheimer’s Day in the Croatian capital of Zagreb, in collaboration with the leadership of Dementia Friendly Zagreb, Alzheimer Croatia conducted a survey of cognitive abilities that found that half of people over 60 express cognitive impairment, and a quarter express severe problems with memory and orientation. The neurologist and psychiatrists who conducted the research recommended them for further medical examinations. This data is consistent with the results of previous surveys carried out continuously by Alzheimer Croatia for the third year in a row.

Events during World Alzheimer’s Day were just part of a rich programme to mark World Alzheimer’s Month in Croatia. A series of public and professional lectures on dementia and a round table on the stigma about dementia were held in the City of Zagreb. A regional conference on Alzheimer’s disease was held in Eastern Croatia, during which an agreement was signed with the City of Lipik to make it a dementia-friendly community, and in other cities, Memory Walks and Alzheimer Cafes were held. Occasional events were also held at a number of regional hospitals and retirement homes across Croatia.

As every year, the media strongly supported the activities carried out by Alzheimer Croatia and its affiliates, during World Alzheimer’s Month, which allowed many citizens to
become better informed about dementia and support the Friends of Dementia - Croatia initiative.


Within the framework of the INDA (Interprofessional Dementia Approach Program) project, an awareness-raising campaign was organised on World Alzheimer’s Day, 21 September, in the Fejér County capital, Székesfehérvár. The motto of the event was "Give your years a chance!" It was hosted by the Catholic Charity Service, the Diocese of Székesfehérvár and the Mayor’s Office of the City of Székesfehérvár.

In Hungary, nearly 250,000 people live with dementia. Add to this number their relatives, and the affected population is more than one million. The Catholic Charity Service and the Social Cluster Association have been helping people living with dementia and their families for 30 years, by implementing models of person-centred care.

During the day an “open diagnostic truck” operated by the Hungarian Health Protection Early Diagnostic Program, one of the partners of the Social Cluster Association, waited for those who are interested in the dementia diagnostic.

The event was opened by Antal Spányi County Bishop, Mayor András Cser-Palkovics, Anikó Horváth from the Ministry of Family Affairs, and Ágnes Egervári.

A conference was held in the City Hall of Székesfehérvár, to strengthen interdisciplinary collaboration among health and social protection experts, about the "Social Impact of Dementia and Possibilities of Prevention". Thematic and interactive tents were set (movement, music, consulting about eating and essential life skills) as well as stage performances by famous performers took place in front of the Town Hall. Róbert Koltai – a famous actor in Hungary - was present as an ambassador of dementia care. The closing of the programme was the local Alzheimer Cafe walking tour in the downtown area, and a Senior Dance Performance flash mob.

During the event, the Social Cluster Association announced the DIÓ programme. This is a one-year-long interactive programme, to support relatives in six Hungarian settlements. The aim of this programme is to answer the most important questions of family caregivers who are taking care their loved ones.

These World Alzheimer’s Day events were supported by the City of Székesfehérvár and the Diocese of Székesfehérvár. This collaboration is unique in Hungary, and it could be the basis for a new type of dementia-friendly community.

21 September: Alzheimer udruženja AiR celebrates World Alzheimer’s Month in Bosnia and Herzegovina

In Bosnia and Herzegovina, during World Alzheimer’s Month (September), Alzheimer udruženja AiR reported the following activities:

Dementia-friendly society – a meeting with the Minister of Internal Affairs for the Canton of Sarajevo

At police headquarters in Sarajevo, Alzheimer udruženja AiR had a meeting with the Minister. A significant problem of the Bosnian society is: not recognising “the face of dementia”; of not accepting the fact a person has dementia. Every day, in our society we have examples of missing people. Police systems and police officers aren’t prepared for the situations involving people with dementia, or are even the cause of a problem. Generally, then, the police react in an inappropriate way. We agreed that it is necessary educate police officers and adjust the system for better managing in crisis situations. The next steps will be: making the educational programme for police officers, including dementia issues in the police curriculum and developing new standards linked to dementia issues. In association with this issue in Bosnian society, one web portal did an interview: “The ways we can recognise a disoriented person with dementia and what we can do to find the missing person!”

Project “Let’s increase the percentage of diagnoses”

In the Bosnian society, we have less than 3% diagnosed people from the total number of those affected. Because of that, the Center for Dementia Sarajevo ran the project “Dementia through the Primary Health Care System – let’s increase the percentage of diagnoses in Bosnian society”. As the first step, on World Alzheimer Day, the Center for Dementia published a handbook “Dementia from the angle of Primary Health
Protection” by Dr Osman Kučuk, which will be used as educational material, and then as guidelines for GPs and nurses. The important thing is that the handbook brings “the protocol of medical research” to the timely diagnosis, which can help GPs to determine the necessary path to diagnose. The funds for the first two educational meetings (Sarajevo, Tuzla) are in place.

23 September: Global Dementia Friends Network: challenging stigma on a global scale to mark World Alzheimer’s Month

The over 60 Dementia Friends programmes in 50 countries, part of the Global Dementia Friends Network hosted by Alzheimer’s Society, challenge stigma, raise awareness and encourage more inclusive societies for people affected by dementia.

To mark this year’s World Alzheimer’s Month theme of ‘stigma’, members of the Global Dementia Friends Network used their Dementia Friends programme (or national equivalent) as part of their national strategy to challenge misconceptions and change how communities think, talk and act on dementia.

In Europe, activity included: Samen dementievriendelijk (Dementia Friends Netherlands) launching a partnership with railway and bus companies NS and Connexxion, to make transport dementia friendly; Germany’s Demenz Partner creating 50 thousand Dementia Friends; and, Alzheimer’s Society reaching a milestone of 3 million Dementia Friends in England, Wales and Northern Ireland. The Finnish Dementia Friends programme Muistikummit developed a route to create Dementia Friends online and the Portuguese programme Amigos na Demencia started delivering Dementia Friends face to face information sessions.

In other regions of the world, the Global Dementia Friends Network grew stronger with the national Alzheimer associations of Guatemala, Bonaire, Egypt and Panama joining and the programmes in El Salvador, Cuba and Bangalore launching their programme on World Alzheimer’s Day.

Members of the network also united to show via a short film the benefits of Dementia Friends programmes to address stigma and fear and make a positive change:

“People who participate in Dementia Friends information sessions are more knowledgeable and more tolerant towards the topic, less intimidated and more empathetic.”

“With acquiring more knowledge, the prejudices and discomfort about dealing with people with dementia decreases.”

On World Alzheimer’s Month the Global Dementia Friends Network showed a united global effort to talk about dementia. Become a Dementia Friend in one of the countries participating and join the global dementia friendly movement of 18 million Dementia Friends. For more information or to become a member of the biggest social action movement on dementia visit: www.alzheimers.org.uk/GDFN

23 September: Finland highlights memory-friendly actions during “Memory Week”

This year’s “Memory Week” took place in Finland, during September. The week was full of events organised by local associations across the country. The theme of the week was based around memory-friendly actions. The associations were able to reward actions locally.

On social media, the Alzheimer Society of Finland (Muistiliitto) encouraged everyone to do memory-friendly actions during the week and help to build a memory-friendly Finland. Every action counts, no matter how small.

The Alzheimer Society of Finland also promoted “Muistikummit”, the Finnish version of Dementia Friends, during the week. Muistikummit find out more about memory-related diseases, how these diseases affect a person and how you can act appreciatively and understandingly when meeting someone with a memory-related disease. After that, they can do memory-friendly actions in their everyday lives.

You are able to become a Muistikummit through a one-hour session, offered by local associations or webinars. During the Memory Week, a web-based version of the session was released. It allows people to become Muistikummit anywhere, anytime.

During the week 1,000 new people became Muistikummit. Around 300 of them used the webpage. Muistikummit was launched in Finland last year during Memory Week. Now there are already 8,700 Muistikummit. The Memory Week takes place traditionally in September, during the week of World’s Alzheimer Day.
25 September: NVO Futura marks World Alzheimer’s Month with events across Montenegro, including the country’s first ever Memory Walk

This September, for World Alzheimer’s Month, NVO Futura, an Association based in Podgorica, Montenegro and working on behalf of those with Alzheimer’s and related diseases, organised a number of activities both in the capital city of Podgorica and also in the north and south of the country.

21 September: In Kotor, in the south of Montenegro, working together with the local council and also with the local home for the elderly, a gathering was organised. An information stand was set up and local passers-by were given the opportunity to be informed about Alzheimer’s disease and dementia. Information flyers were distributed, surveys were carried out with the public and also people could take part in tests for recognition of early signs of dementia.

22 September: In the morning, in collaboration with the City of Podgorica and many other organisations and volunteers, the first Memory Walk of Montenegro (pictured) was organised to show support for people with dementia and their families. Many people participated in this walk including young volunteers, NGOs and members of a pensioner’s association. Also, medical staff from the public health institution, “Primary Health Care Centre, Podgorica” participated by measuring blood sugar and blood pressure. Along the route, there was an information centre, flyers were distributed, mini-tests were organised and surveys were taken. Local media and television broadcast the event live. Overall the first Memory Walk was a huge success.

23 September: In the North of Montenegro, in Bijelo Polje, again in partnership with a local home for the elderly, a presentation was organised to inform people about dementia.

25 September: In Niksic, located in the centre of Montenegro, a presentation about dementia was organised in a day care centre for the elderly, with collaboration from partners in the local centre for social work. During the month of September, NVO Futura was also part of mobility week and played chess, table tennis and promoted a healthy lifestyle. NVO Futura’s main campaign this year was “Let’s Talk about Dementia”. The message is that dementia can affect all of us, so we need to talk about dementia and learn to recognise the symptoms on time.

25 September: Panhellenic Association and its members celebrate World Alzheimer’s Month with events throughout Greece

A month full of events that were open to the public were organised by the Alzheimer’s Associations – members of the Panhellenic Association of Alzheimer’s Disease and Related Disorders in order to celebrate the World Alzheimer’s Day 2019. During September, which proved to be a month of awareness for Alzheimer’s disease, some of the events that took place throughout Greece were:

In Athens: The Athens Alzheimer Association organised a series of events to raise public awareness and fight stigma surrounding Alzheimer’s disease. This year’s main event was a conference hosted at Onassis Stegi Auditorium themed “Living well with dementia”, which had a huge public impact. More than 700 people, Ministers and Parliament members participated in the event. Dr Paraskevi Sakka, Chair of the National Dementia Observatory, in her introductory speech (pictured, below), presented the progress of the implementation of the Greek Dementia Action Plan and emphasised the importance of living well with dementia in dementia friendly communities, where there is access to early diagnosis, personalised treatment and quality care for every person living with dementia.

Prof. Nikolaos Skarmeas, in his speech “Research developments in the dementia field”, referred to the latest news and developments regarding dementia and Alzheimer’s disease. The highlight of the event was when a person with dementia, Mrs Dena Kliosi, spoke to the public about her life after diagnosis and how she has been living everyday life since then. At the end of the presentation, the audience shared experiences, asked questions and got answers from the experts on how to live well with dementia. They were also introduced to the range of services available for people with
dementia and their carers in Greece and many became members of the Athens Alzheimer Association.

In Thessaloniki: Alzheimer Hellas organised a series of events in order to raise awareness. There was an all-day information stand in the city centre; participation in two festivals, where specialised personnel gave reliable information to the citizens about the disease; speeches all over the city and in other cities of Northern Greece; a theatre play; as well as the launch of a new children’s book on Alzheimer’s, entitled “Who am I grandpa?”; and a book with cognitive exercises. Alzheimer Hellas also participated in the International Exhibition of Thessaloniki where a new cognitive assessment test for the early diagnosis of neurocognitive disorders R4Alz was presented to the public. A Facebook campaign called “Let’s talk about Dementia” was launched and Alzheimer Hellas participated in TV and radio shows informing and educating the public on matters concerning dementia. This year’s main event was held in the city of Giannitsa, where more than 500 people attended the speeches of well-acclaimed Professors of Neurology, including the speech of Prof. Magda Tsolaki (pictured, below), President of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders. The audience had the chance to share their questions with the health professionals. The audience also stated their interest in participating in a series of free memory tests that Alzheimer Hellas will run in their city for a period of 5 months.

In Crete: In Heraklion, a seminar for healthcare professionals and caregivers, an art exhibition and free memory tests were held by Alzheimer’s Disease and Related Disorders Association of Heraklion Prefecture - ALLILENGII.

In Chania, a seminar for healthcare professionals and caregivers and a voluntary blood donation were held by the Chania Alzheimer Institute.

Information seminars in Serres (by the SOFPSI association), Patra (by the Frontizo association) and Chalkida (by the Alzheimer’s Disease and Related Disorders Association of Chalkida), informational stand in other cities (Xanthi Alzheimer’ Association) and free memory tests by the Alzheimer Associations (Apostoli).

26 September: Two members of European Working Group of People with Dementia involved in Slovenian World Alzheimer’s Month events

Spominčica - Alzheimer Slovenija started World Alzheimer’s Month with the support of two members of the European Working Group of People with Dementia (EWGPWD), Tomaž Gržinič (Slovenia), and Miha Kastelic (Czech Republic) (pictured) who came to visit his relatives in Ljubljana. On 3 September, the association held the opening of its 150th “Dementia friendly spot” (DPT), at the National Institute for Public Health (NIJZ). Mr Gržinič and Mr Kastelic addressed the audience, 50 employees of NIJZ from the Institute’s offices across Slovenia.

Tomaž, with his always positive attitude, said:

“It is very important to realise you have problems with memory and address these problems, go to the doctor, and have a chance to organise your life. To me, it means a lot to have the support of Spominčica. I’ve realised I should not be alone, so I’ve joined sports and social activities. Being with people helps me. Such public-awareness-raising campaigns help all persons living with dementia, so their community accepts them. It is much easier when you don’t need to explain about the disease and they accept you as you are. I can even joke about my problems sometimes.”

Miha said he is very impressed to see how the community in Slovenia is becoming dementia-friendly, with initiatives such as these Dementia friendly spots. He also stressed the importance for persons with dementia and their families to have understanding, support and acceptance among people they live with, and also in society.

The DPT opening was followed by a social event, where everyday problems of families living with dementia were discussed.

The following week, on 9 September, the NIJZ, the Slovenian Academy of Sciences and Arts, and Spominčica organised a meeting of experts on "The Status and Challenges of Alzheimer’s disease in Slovenia”. Speakers were: the main
Slovenian medical experts on dementia; representatives of the Ministry of Health; and representatives of the Ministry of Labour, Family, Social Affairs and Equal Opportunities. Spominčica presented the challenges caregivers are facing, and addressed the gaps in the healthcare and social care system. The meeting also included a round-table with Slovenian MEPs Romana Tomc, Klemen Grošelj and Milan Brglez, who are all members of the European Alzheimer’s Alliance.

A press conference was held on World Alzheimer’s Day, at the Medical Chamber of Slovenia, involving Miha Kastelic (EWGPWD), Polona Rus Prelog (University psychiatric clinic Ljubljana), Štefanija Žlobec (Spominčica), Dr Zdenka Čebašek Travnik (Medical Chamber), Prof. Zvezdan Pirtošek (Medical faculty) and Dr Milica Gregorič Kramberger (University medical center Ljubljana).

They discussed the importance of timely diagnosis, post-diagnostic support for patients and families, the importance of continuing education about dementia, and the need to adopt the Long-term care Act. Miha informed the audience that he is a 46-year-old economist and father of three underage children. He expressed his satisfaction that he received a timely diagnosis. He said that this meant that he was able to start taking dementia drugs early on, which slow the progression of the disease. Dr Kramberger presented the positive results of the phase II clinical study Adamant. The press conference was followed by the opening of the 160th Dementia friendly spot at the Medical Chamber of Slovenia. All major Slovenian press and TV outlets reported about the event.

28 September: Czech Alzheimer Society aims to spread awareness about dementia and risk-reduction during “Memory Week”

Five years ago, Alzheimer’s Disease International (ADI) released material entitled “Dementia: Can we reduce the risk?” This September, the Czech Alzheimer Society decided to translate this material into the Czech language and release it to the public, along with a creative graphic visual. It was published and launched during Memory Week, which was organised by the Czech Alzheimer Society from 16 to 28 September.

Posters and postcards were distributed during the most important events: a national conference “Prague Days of Gerontology; the Mobile Counselling Centers” (memory counselling in different pharmacies - 14 dates, 6 cities); and the “Memory Days” with Český rozhlas, which involves free memory testing in the building of the main Czech public radio station. Lucie Hajkova, the project coordinator stated that: “The main objective during the events is to get closer to the public and to highlight memory problems, the importance of on-time diagnosis and post-diagnostic support, both for people with dementia and for those who care for them.”

Thanks to media support from the Czech radio station, the Czech Alzheimer Society hopes that the topic will be discussed and promoted in the regions, where people can get further and specific support in their community, with the help and assistance of the Czech Alzheimer Society.

MEMBERS’ NEWS

2 September: Alzheimer’s Society deliver open letter to UK Prime Minister calling on dementia care reform

On 2 September, Alzheimer’s Society went to Downing Street, the UK Prime Minister’s residence, to hand in a letter calling on the new Prime Minister Boris Johnson to make dementia care an urgent priority for the Government. The letter was signed by 112,752 Alzheimer’s Society supporters, showing just how important the issue of dementia care is to the public.

On the day, they were joined by former EastEnders (British television programme) actress Dame Barbara Windsor, who is living with dementia, her husband Scott Mitchell, and two Alzheimer’s Society campaigners, Nimisha and Namrata, whose father is living with dementia. It was great to see ambassadors and campaigners united together to demand that the Prime Minister takes action on dementia care.
After the letter hand in, Alzheimer’s Society CEO Jeremy Hughes, and Director of Policy, Campaigns and Partnerships, Sally Copley, joined Dame Barbara and Scott for a meeting with Boris Johnson. This was a great opportunity to speak to the Prime Minister directly about the issues with cost, quality and access in the care system faced by people with dementia every day, and to show him just how many people across the country are supporting the campaign. Overall, the day was a great success, with both national and regional media coverage of the letter hand in, demonstrating the public appetite for the issue of dementia care and the need for care reform. Alzheimer’s Society are pleased to see this attention on an issue which has been repeatedly passed over by successive Governments, and will be working to harness this momentum into the next stage of the Fix Dementia Care campaign.

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

19 September: Alzheimer’s Society reaches 3 million Dementia Friends milestone

On 19 September, Alzheimer’s Society (UK) announced that the Dementia Friends initiative had created 3 million Dementia Friends across England, Wales and Northern Ireland. Since 2013, Alzheimer’s Society’s Dementia Friends initiative has been tackling the stigma that surrounds the condition. A Dementia Friend learns about how dementia affects a person and uses that understanding to make a real difference for people affected by dementia.

Whether it’s telling family and friends about the initiative, having a cup of tea with a neighbour, or fundraising to provide vital support, Dementia Friends actions are changing perceptions about dementia across the UK.

And it’s not stopping there. With more people continuing to join the programme and taking action, everyone has a part to play in creating a dementia-friendly society.

Creating a dementia-friendly generation

Five-year-old Jennifer saw her Grandad, Ken, face the challenges and changes of his vascular dementia. But for Jennifer, her “Grandad was always just Grandad”. After Ken passed away, Jennifer’s Mum, Dena, became a Dementia Friend and then Jennifer joined up too. Together, Dena and Jennifer talked about the kinds of things people can do to help people with dementia. Jennifer’s action as a Dementia Friend is to “always be kind and I will be really kind if anyone has dementia”. Since becoming Dementia Friends, Jennifer’s family have also gone on to take part and fundraise through Memory Walks and Cupcake Days. Find out more about Dementia Friends here: www.dementiafriends.org.uk

19 September: Fundación Alzheimer España presents MiMe & SuMe - an innovative digital aid for people with dementia and their caregivers

MiMe and SuMe are short for Mi Memori and Su Memoria – “my memory” and “their memory”. Hidden behind such fancy names lie two interrelated ground-breaking technical resources which, each relying on a phone-like mobile device, have been created to bridge the gap between the encumbrances of memory deficits and a meaningful, independent and joyful life. The sort of life our elder loved ones, restricted as they may be by neurocognitive issues, rightfully deserve to enjoy to the fullest of extents.

With this objective, and also keeping in mind that those who care for people with dementia are an ever-growing, often-ignored group with particular needs that could also be met through this development, MiMe and Sume were designed and recently launched. This innovative project is a joint effort by experts in design thinking, UX, and technology, from the technology-oriented company Ibermática, alongside health care professionals and members of FAE (Fundación Alzheimer España /Spanish Alzheimer’s Association). Heads were put together with the aim of developing the best app of its kind, one with strong added value in that it can lend a helping hand to both Alzheimer-affected individuals and to their care providers and relatives.

Although still in the trial stages, some heart-warming and encouraging results have already been yielded. These results were recently presented at IMSERSO (the Spanish Institute for the Elderly and Social Services) on 19 September, to the delight of an audience comprised of IT and clinical
professionals, people with cognitive impairment and caregivers.

In a nutshell, this resource is based on two mobile, portable devices each one with a pre-installed app (MiMe for affected people and SuMe for their carers). This format allows for ease of use, while the apps override the devices’ original Operating System, so that no interference can occur. Some of the most relevant features of MiMe and SuMe are: real-time locating system, monitoring of medication intake, day-to-day reminder system, and the possibility to call for assistance in stressful situations and an emergency button. This app allows an individual affected by dementia or any neurocognitive disorder to remain as independent as possible for as long as possible, while simultaneously easing the burden on the caregiver. This result is the driving force behind the endeavour.

**23 September: Kathy Ryan voted as new Chair of the Irish Dementia Working Group**

Inspirational dementia advocate, Kathy Ryan, has been voted in as the new Chair of the Irish Dementia Working Group (IDWG), as the group held their first national meeting at the Ashling Hotel in Dublin, on 23 September, to mark World Alzheimer’s Month 2019.

This meeting aimed to encourage other people living with dementia to have their voice heard and to work towards upholding the human rights of people with this condition.

The IDWG is a national advocacy group which is supported by The Alzheimer Society of Ireland. The IDWG gives voice to the lived experience of dementia and has over 25 active members all of whom have a diagnosis of some form of dementia. Members range in age from 40 to 79 and are from all corners of the country.

Kathy Ryan was voted in as the new Chair of the IDWG, with a two-year term of office, by her fellow advocates and members of the group, with Limerick native, Kevin Quaid, voted in as new Vice-Chair of the group. A new steering committee has also been voted in today with the new members including Jacinta Dixon, Sean Mackel and Marguerite Keating as IDWG Steering Group members.

The full IDWG Steering Committee now consists of Kathy Ryan (Chair); Kevin Quaid (Vice-Chair); Dr Helen Rochford-Brennan (Chair of European Working Group of People with Dementia); Jacinta Dixon, Sean Mackel and Marguerite Keating as IDWG Steering Group members. Ronan Smith is the outgoing Chair of the IDWG.

**24 September: Türkiye Alzheimer Dernegi (Alzheimer Turkey) reports on its involvement in AD-AUTONOMY project**

“AD-AUTONOMY: Development of a Training Program for Enhancing the Autonomy of Persons with Alzheimer’s”, is an Erasmus+ KA2 project. This collaborative venture between organisations from Spain, UK, Greece, Slovenia and Turkey, has finally reached the completion stage. This project is unique in the sense that it is based on direct involvement of the end users, who are persons with dementia, their families and professionals. Another interesting aspect of the project is that it addresses families and professionals as “supports”, not only as caregivers.

The main objective of AD-AUTONOMY is to improve the quality of life of persons with dementia, their families and professionals. This is done using an innovative training programme that raises awareness of the need to maintain a person’s autonomy and independence. It introduces technology to assist and motivate a person with dementia, empowering them to make decisions and to live as independently as possible.

During the two years spent on the development of the training programme, training methodology, definition and dimensions of autonomy, assistive technologies that improve autonomy were thoroughly researched and the construction of the training package and the ePlatform were studied. It was concluded that AD-Autonomy has 9 dimensions, such as Safety and Security, Food and Housekeeping, Orientation and Navigation.

In the past few months, this material was presented to the stakeholders in a Pilot Training programme, in which the participants took part in both face-to-face and online training. The feedback received from participants was extremely positive.

**25 September: Dementia-inclusive garden wins People’s Choice Award at Ireland’s Bloom Festival**

“Dementia: Understand Together” is the national public awareness campaign in Ireland and The Alzheimer Society of Ireland is a key partner. The campaign’s “Memories are Made of This” 1950s-themed show garden, which was about facilitating the therapeutic benefits of reminiscence, was a dementia-inclusive garden at this year’s Bloom Festival, Ireland biggest garden show.

The garden, named after the song made famous by 1950s crooner Dean Martin, and the creation of award-winning
designer Robert Moore, took people back in time to when gardens not only provided food for the soul, but food for the table too. It featured a manicured formal space with box hedges and tea roses emblematic of the era, as well as a practical fruit and vegetable patch that provided much of what was on the menu in people’s homes at the time.

Many of the treasures from the 1950s featured in the garden, were inspired by the personal reflections of members of the Alzheimer Society of Ireland’s Bloomfield Social Club in Dublin, who engaged with the team in a series of workshops to inform the design and content elements of the garden.

Not only did the “Dementia: Understand Together” garden win the Silver Gilt medal, but on the final day of Bloom, it was announced as the winner of the People’s Choice Award, which was voted for by visitors to the show over the five days.

For more information on the Dementia: Understand Together campaign visit: www.understandtogether.ie

25 September: Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (DALzG) launches new app “Alzheimer & YOU – den Alltag aktiv gestalten”

The DALzG has launched a new app “Alzheimer & YOU – den Alltag aktiv gestalten” (create your daily routine). The app offers tips to help organise an active daily life for people with dementia. It was developed specially for relatives in search of suggestions for daily activities to do together with people with dementia. In the app, users find a variety of activities, divided into useful categories such as leisure time, home and garden, diet, wellbeing or safety.

Users can individualise the tips and fill in a name. Every tip is designed with a short text and an illustration. It is also possible for users to recommend their own tips. All new tips will be edited and published.

In addition to the tips, users will find some basic information about DalzG and its work: contact details, events, publications and projects. For those who like to play games, the app offers a short quiz.

The idea for the app came from two former pupils who won a contest “Alzheimer & YOU – zeig deinen Erfindergeist” (show your inventive talent) in 2016.

The app is free and is available in the App Store and Google Play Store. The financing of the app came from BARMER Health Insurance.

You can scan the QR code to find the app.

POLICY WATCH

9 September: WHO Europe convenes workshop on public health response to dementia at national level

For the first time, WHO/Europe has convened a workshop dedicated to promoting and supporting dementia policy and planning at the national level. The event, aimed at galvanising action on the public health response to dementia, was held on 9 and 10 September 2019, in Malta, and was hosted by the World Health Organization (WHO) and the Government of Malta.

National experts from 11 countries across the WHO European and Eastern Mediterranean regions (Bulgaria, Croatia, Czech Republic, Jordan, Malta, Morocco, North Macedonia, Qatar, Slovenia, Tunisia and Turkey) were in attendance. Alongside these official government representatives, Charles Scerri, the Chairperson of the Malta Dementia Society, Ninoslav Mimica, President of Alzheimer Croatia, and Štefanija Lukic Zlobek, President of Spominčica - Alzheimer Slovenija, also represented their countries at the meeting.

The workshop provided a platform for country delegates, and representatives of the WHO and international nongovernmental organisations active in the field of dementia (Alzheimer Europe, Alzheimer’s Disease International), to share their experiences, learn about successful initiatives taken across the two regions, and plan new national efforts for scaled-up action.

Helen Rochford-Brennan (Ireland) (pictured, overleaf, left), Chairperson of the European Working of People with Dementia (EWGPWD) opened the meeting, talking about the impact a diagnosis of dementia has on the person diagnosed. She emphasised, also, the need for a human-rights-based approach to the public health response to dementia. Jean Georges, Executive Director of Alzheimer Europe was also in attendance. He presented an overview of some of the organisation’s activities, such as its 2018 Yearbook on national dementia strategies, and the “European Dementia Monitor
“Such exchanges are vital to build understanding, provide inspiration and accelerate efforts towards making dementia a public health priority, which is one of the core objectives and action areas of WHO’s Global Action Plan on the Public Health Response to Dementia 2017–2025”, wrote the WHO in its meeting report. Only 16 out of 53 Member States in the European Region currently have a dementia plan or policy.

Further information, presentations, resolutions and summaries of the four days can be found on the WHO website here: http://www.euro.who.int/en/about-us/governance/regional-committee-for-europe/69th-session

23 September: United Nations General Assembly makes declaration on universal health coverage

On 23 September, the UN General Assembly held a high-level meeting entitled “Universal Health Coverage: Moving Together to Build a Healthier World”. During the meeting of heads of state, ministers, health leaders, policy-makers and others, a Political Declaration was adopted, specifically addressing universal health coverage (UHC). The opening paragraph of the Declaration states:

“We, Heads of State and Government and representatives of States and Governments, assembled at the United Nations on 23 September 2019 with a dedicated focus for the first time on universal health coverage, reaffirm that health is a precondition for and an outcome and indicator of all three dimensions of sustainable development and the implementation of the 2030 Agenda for Sustainable Development, and strongly recommit to achieve universal health coverage by 2030, with a view to scaling up the global effort to build a healthier world for all.”

In adopting the declaration, Member States have committed to investing in policies which would prevent financial hardship from out-of-pocket healthcare payments. It also aims to implement high-impact health interventions to combat diseases and protect women’s and children’s health.

More details on the high level conference can be found here: https://www.uhc2030.org/un-hlm-2019/

On 24 September, the World Health Organization (WHO) and 11 other multilateral organisations, launched their Global Action Plan for health and wellbeing for all. The plan will
ensure the 12 partners provide more streamlined support to countries to help deliver universal health coverage and achieve the health-related Sustainable Development Goals (SDGs) targets. The WHO plan can be found here:

https://www.who.int/sdg/global-action-plan

23 September: Alzheimer’s Society launches Dementia Guide to the UK’s National Health Service Long Term Plan

The UK’s National Health Service (NHS) Long Term Plan is a genuine opportunity for the sustainable transformation and integration of the health and social care services that are essential to people affected by dementia. As the UK’s largest charity representing the needs of people living with and affected by dementia, it was a privilege and commitment for Alzheimer’s Society to support the development of the Long Term Plan, and see the Dementia Guide to the NHS Long Term Plan launch at NHS Health and Care Innovation Expo this year. The Dementia Guide is designed to support the implementation planning; dementia policy development and strategy review; engagement with people living with or affected by dementia such as Alzheimer’s Society’s delivery of the Dementia Experience Toolkit for the Department for Health and Social Care (DHSC); investment in Research & Development; and Innovation and Technology. The NHS Long Term Plan sets out an ambition for Alzheimer’s Society’s Dementia Connect service to be rolled out nationally as a single point of access to a range of support and Alzheimer’s Society welcomes this ambition as they are committed to reaching every person affected by dementia.

Alzheimer’s Society wants to see the Long Term Plan work to improve the lives and wellbeing of the people they represent and recognises the absolute need for a Social Care funding commitment to enable the realisation of this. Therefore, Alzheimer’s Society continues to call for a solution to the crisis in social care in their Fix Dementia Care campaign. Read in full the Dementia Guide to the NHS Long Term Plan:


26 September: Two Slovenian Ministers become Dementia Friends

On 26 September, Spominčica - Alzheimer Slovenija reported that the Global Dementia Friends network had two new important members.

Firstly, the Minister of Public Affairs, Rudi Medved (pictured, left) became a “Prijatelj Spominčice” as Dementia Friends are called in Slovenia. Minister Medved is aware of the everyday problems people with dementia are facing, in relation to public administration among others. The Ministry of Public Affairs invited Spominčica to give a lecture about dementia, to the Heads of Administrative units at the XI days of Administrative units. They learned about recognition of the first signs of dementia, and about proper communication with people with dementia.

Secondly, the Minister of Labour, Family, Social Affairs and Equal Opportunities, Ksenija Klampfer (pictured, left) visited Spominčica’s offices, to meet with the team, caregivers and persons with dementia. Spominčica exchanged opinions and experiences with Minister Klampfer, in a very relaxed atmosphere. As a sign of support for the work being done, she also became a “Prijateljica Spominčice”.

13 August: A systematic review looks at relationship between air pollution and dementia

On 13 August, an international team of researchers published an article on a systematic review on the relationship between air pollution and dementia in the Journal of Alzheimer’s disease. The team found 13 published research articles that met their inclusion criteria. This brought together findings from the USA, Canada, Taiwan, Sweden and the United Kingdom. They then focused on the reports of the pollutants: particulate matter ≤2.5 μ (PM2.5), nitrogen dioxide (NO2), nitrous oxides (NOx), carbon monoxide (CO), and ozone. In addition, they looked at reports of models that aimed to see whether there could be an association between exposure to air pollution and a greater risk of developing dementia.

In their publication, the researchers explain that they found a great variation in how the different studies approached their research questions, underlining that some of the models were rather simple and others opted for more refined approaches. Bringing all of the studies together, the scientists reported that for all of the selected air pollutants (PM2.5, NO2, NOx & CO), there were correlations between a higher exposure and an increased risk of dementia. The team, however, qualified their findings by explaining that it is also possible that other factors, such as socioeconomic status, could play a role.


SCIENCE WATCH
14 August: Researchers identify a new mechanism for hippocampal lesion formation in Alzheimer’s disease

On 14 August, Dr Jing Tian and colleagues published a paper in Science Translational Medicine, showing that Ghrelin receptor interacts with dopamine receptors during the development of hippocampal lesions in Alzheimer’s disease (AD).

The hippocampus is one of the earliest brain structures to be affected in the development of AD: connections between synapses are progressively lost, causing cognitive deficits. Although Ghrelin, known as the “hunger hormone”, is produced in the stomach, its receptors are present at high levels in the hippocampus. Intriguingly, researchers have recently shown that Ghrelin receptors can directly interact with receptors for dopamine, a neurotransmitter that is dysregulated in AD. This suggests that Ghrelin may have a physiological function in the brain - however studies have yet to determine what its role may be during the development of AD.

To answer this question, Dr Tian and colleagues studied brain samples donated by people with AD and performed experiments using mouse models of AD. In both models they observed a direct interaction between amyloid beta (Aβ) and the Ghrelin receptor (GHSR1α). This interaction caused the Ghrelin receptor to be dysfunctional, in turn preventing it from linking with the DRD1 dopamine receptor. To see whether losing this link had a functional effect, researchers studied mice in which the GHSR1α receptor has been genetically removed. They observed that these mice had similar hippocampal lesions and memory deficits to AD mice. Interestingly, treatment of AD mice with two drugs that selectively stimulate the Ghrelin and DRD1 receptors reduced AD symptoms in these animals. However, treatment with each drug in isolation did not have the same beneficial effect, suggesting that activating both receptors at the same time is key. Based on these findings, the researchers hypothesised that higher TREM2 may have a protective effect in the brain, suggesting that therapies which stimulate TREM2 activity may be beneficial for people in the early stages of AD.

https://stm.sciencemag.org/content/11/505/eaav6278

28 August: Alzheimer’s Disease Neuroimaging Initiative study shows slower cognitive and clinical decline in participants with increased TREM2 in cerebrospinal fluid

On 28 August, Dr Michael Ewers and colleagues published a paper in Science Translational Medicine, showing that people with higher cerebrospinal fluid TREM2 levels experienced slower cognitive decline during the development of Alzheimer’s disease (AD).

TREM2 is a protein that sits on the surface of microglia, specialised cells that orchestrate inflammatory responses in the brain. TREM2 is thought to regulate the behaviour of microglia, controlling whether they adopt pathological or beneficial characteristics. However, studies have yet to conclusively show whether TREM2 affects cognitive decline in people with AD.

To answer this question, researchers turned to the Alzheimer’s Disease Neuroimaging (ADNI) Initiative, a longitudinal multicentre study which collects and shares data from participants with pre-symptomatic and symptomatic AD. Since 2004, ADNI has collected annual brain scans, genetic profiles, blood and cerebrospinal fluid (CSF) samples from hundreds of participants with mild cognitive impairment (MCI), early AD or advanced AD, sharing them with bona fide researchers upon request.

Using CSF samples from ADNI, Dr Ewers and his two joint first authors, Dr Franzmaier and Dr Suarez-Calvet, assessed the levels of TREM2 in 385 participants. Aiming to understand whether baseline levels of TREM2 could predict cognitive decline during the development of symptomatic AD, they found that participants with higher baseline soluble TREM2 (sTREM2) showed a slower decline in cognitive test scores over time. When they looked at the levels of p-Tau181, a well-known biomarker of AD, they observed that participants with a higher ratio of sTREM2 to p-Tau181, showed a slower conversion from MCI to symptomatic AD. This was associated with a slower development of hippocampal shrinkage over time, measured by analysing the annual MRI scans collected from ADNI participants. Based on these findings, the researchers hypothesised that higher TREM2 may have a protective effect in the brain, suggesting that therapies which stimulate TREM2 activity may be beneficial for people in the early stages of AD.

https://stm.sciencemag.org/content/11/507/eaav6221.full

29 August: Preclinical study shows links between dysfunctional calcium transport by mitochondria and Alzheimer’s disease

On 29 August, Dr Pooja Jadiya and colleagues published a paper in Nature Communications, showing that cognitive decline in animal models of AD is linked to calcium overload in dysfunctional mitochondria within brain cells.

Mitochondria are often described as the powerhouses of cells, responsible for generating energy-rich molecules by breaking down sugars, lipids and other compounds within the cell. A single cell can contain up to 2000 mitochondria, with the number of mitochondria varying according to the size, function and energetic requirements of the cell. In addition to their energy-generating function, mitochondria also play an important role in the regulation of calcium transport in and out of the cell. This, in turn, impacts the ability of mitochondria to fulfil their other functions. For example, when mitochondria are overloaded with calcium they aren’t able to properly generate energy, leading to the production of...
damaging free radicals. Interestingly, previous studies have shown that calcium accumulates inside neurons during the development of AD. Researchers have theorised that this calcium overload may promote the formation of amyloid plaques – and that amyloid, in turn, may cause further calcium disturbances, creating a vicious cycle of calcium dysregulation and amyloid accumulation that ultimately leads to neurodegeneration and memory loss.

In their new study, Dr Jadiya and colleagues set out to examine the role of mitochondrial calcium uptake in the development of AD, using animal models of disease to genetically dissect the function of specific calcium-regulating proteins. To check for genes that were relevant to human disease, the researchers first looked at brain samples donated by people with AD or healthy volunteers. They noticed that brain samples from people with AD had substantially lower levels of a gene called NCLX, which encodes a protein that helps transport calcium out of mitochondria. Moving into mouse models of AD, they showed that levels of NCLX gradually reduced as AD mice aged: at the same time, calcium accumulation in the mitochondria of brain cells gradually increased. When the NCLX gene was removed in AD mice, animals developed signs of cognitive impairment at a much faster rate than normal, associated with increased amyloid plaque formation. However, when NCLX was restored, mice regained cognitive function and their mitochondria were found to be normal, without the high levels of calcium accumulation observed in mice lacking NCLX.

Based on these findings, Dr Jadiya and colleagues suggest that mitochondrial calcium overload may be a starting point for AD development, with amyloid plaque formation happening partly as a result of mitochondrial dysfunction.

https://www.nature.com/articles/s41467-019-11813-6#author-information

9 September: ACADIA Pharmaceuticals announces positive results from Phase III trial of pimavanserin for dementia-related psychosis

Pimavanserin is an antipsychotic drug, approved by the US Food and Drug Administration (FDA) for the treatment of Parkinson's disease psychosis, which could soon be expanded for dementia-related psychosis.

On 9 September, ACADIA Pharmaceuticals announced positive results from its Phase III HARMONY trial of pimavanserin aiming to evaluate the efficacy and safety of pimavanserin by comparing it with placebo in preventing a relapse of psychotic symptoms in people with dementia-related psychosis. HARMONY was designed as a double-blind and placebo-controlled trial enrolling people with dementia-related psychosis in US and Europe. After an open-label stabilisation period of 12 weeks where participants received pimavanserin once daily, they were randomised to continue their pimavanserin dose or switched to a placebo control. Participants were then followed for up to 26 weeks or until a relapse of psychosis occurred. For the purpose of the study, relapse was defined as hospitalisation due to dementia-related psychosis, deterioration of symptoms, withdrawal from the study due to lack of efficacy, or the use of anti-psychotic medications.

The drug met its primary endpoint of delaying relapse of psychosis in people with dementia-related psychosis compared to placebo in a planned interim efficacy analysis. Upon the recommendations of the independent data monitoring committee based on statistical criteria of positive efficacy, ACADIA Pharmaceuticals said that it would end the study early.

Results will be presented at upcoming conferences. ACADIA Pharmaceuticals is planning to initiate discussions with the FDA regarding a regulatory pathway to approve this indication for the treatment of dementia-related psychosis. There is currently no FDA-approved drug for the treatment of dementia-related psychosis and if approved, pimavanserin would be the first one.

http://bit.ly/2mDfQGj

9 September: Axon Neuroscience announces positive results from Phase II ADAMANT trial of AADVac1, an anti-Tau immunotherapy

On 9 September, Axon Neuroscience announced positive top line results from their Phase II trial of AADVac1, showing good safety profiles and substantial reduction in neurodegeneration biomarkers in participants treated with AADVac1. AADVac1 is a tau vaccine that functions by priming the immune system to attack and clear damaging tau proteins that accumulate during the development of Alzheimer’s disease (AD) and other neurodegenerative disorders. Unlike other immunotherapy approaches, AADVac1 specifically targets disease-associated, misfolded tau proteins. A previous randomised, placebo-controlled Phase I clinical trial of AADVac1 showed a favourable safety profile and excellent immunogenicity in participants who received repeated doses of AADVac1. The ADAMANT Phase II trial aimed verify these safety results in a larger participant population, whilst also assessing efficacy in terms of clinical and biomarker outcomes. ADAMANT was designed as a randomised, double-blind, placebo-controlled trial, enrolling 196 participants with mild AD from 8 centres across Europe. Over a period of 24 months, participants received a total of 11 doses of AADVac1 or a placebo control. Endpoint analysis confirmed the results of the previous Phase I trial, showing an excellent safety profile for AADVac1. AADVac1 was also able to induce a robust immune response, with anti-Tau antibodies detected in 98.2% of participants receiving the vaccine. Significant results from biomarker tests were also reported: participants who received AADVac1 showed slower increases in neurofilament light chain (a marker of neurodegeneration) compared to those who received the placebo control. Positive signals from cognitive endpoints were reported in younger ADAMANT participants,
Although it should be noted that Axon did not provide details of the statistical measures used here. Based on these positive results, Axon Neuroscience hope to continue the development of AADVac1 in further clinical trials.


**9 September: Neurotrope announces results from confirmatory AD drug Phase II study**

On 9 September, Neurotrope, a company focused on developing drugs to treat neurodegenerative diseases including Alzheimer's disease (AD), announced top-line results from its confirmatory Phase II study of Bryostatin-1, an investigational treatment for moderate to severe Alzheimer disease (AD). This potent modulator of protein kinase C could stimulate synaptic growth factors, amyloid-beta degrading enzymes, and prevent Tau transformation into neurofibrillary tangles.

The confirmatory Phase II clinical trial was designed to assess the safety and efficacy of Bryostatin-1 in people with moderate to severe AD not receiving memantine treatment. Participants were randomised to receive 20µg of Bryostatin-1 or placebo over 12 weeks.

The company reported that its Phase II study of Bryostatin-1 failed to meet its primary endpoint of change from baseline to week 13 in the Severe Impairment Battery (SIB) total score. Similarly, Bryostatin-1 did not show any significant difference in the secondary outcome measures, which were changes from baseline to week 5, 9 and 15 in the SIB total score. Neurotrope is conducting a full review of the data.


**9 September: Cassava Sciences announces results from its Phase II clinical trial of PTI-125 in mild-to-moderate AD**

On 9 September, the biopharmaceutical company Cassava Sciences, developing novel solutions to detect and treat neurodegenerative diseases such as Alzheimer’s disease (AD) announced positive results of its lead drug candidate PTI-125. It is a small molecule drug targeting the altered form of filamin A found in the AD brain to restore its normal shape and function.

The Phase Ila clinical study was an open-label and multicentre trial evaluating the safety, pharmacokinetics and effect on biomarkers of PTI-125 in people with mild-to-moderate AD. The study was conducted with support from the National Institutes of Health (NIH). A total of 13 US participants (50-85 years old) received 100 mg oral tablets of PTI-125 twice a day for 28 days.

The company reported that all participants responded to the experimental drug, achieving thus a 100% responder rate. PTI-125 has been found to significantly decrease key biomarkers of AD pathology, neuroinflammation and neurodegeneration. The total Tau and the neurogranin, a marker for cognitive decline, decreased significantly by 20% and 32% respectively in participants.

It is anticipated that data will be presented at upcoming meetings, such as the Clinical Trials on Alzheimer’s disease (CTAD) conference (San Diego, December 2019). Furthermore, the company plans to initiate a Phase Ib study of PTI-125. Approximately 60 participants with mild-to-moderate AD will receive PTI-125 (50 or 100 mg) or placebo twice daily for 28 days.


**10 September: Research identifies areas in the retina that may indicate changes in mild AD**

On 10 September, an international team of researchers published an article on areas in the retina that could indicate changes in mild Alzheimer’s disease (AD) in the journal Nature.

The team analysed the differences in 10 retinal layers between 19 patients with mild Alzheimer’s disease (AD) and a control group of 24 volunteers.

The mean thickness of each individual layer was compared. This showed the researchers that the outer segment layer of patients with AD showed significant thinning.

The researchers reported that when the layers were compared point-by-point, patients with AD showed statistically significant thinning, in comparison with the control group, in irregular regions of total retina and nerve fibre, ganglion cell, inner plexiform, inner nuclear and outer segment layers. These findings may have future implications for the improvement in diagnostic procedures of AD.

http://dx.doi.org/10.1038/s41598-019-49353-0

**11 September: UK Biobank announces ground-breaking GBP 200M project to sequence the genomes of 500,000 UK Biobank participants**

On 11 September, the UK Biobank unveiled their £200M Whole Genome Sequencing (WGS) project, which will sequence the genomes of all 500,000 UK Biobank participants. This project is jointly funded by UK Research & Innovation (£50M), the Wellcome Trust (£50M) and four large pharmaceutical companies (Amgen, AstraZeneca, GlaxoSmithKline and Johnson & Johnson), which together are providing £100M in funding.
The UK Biobank was established in 2006 and collects longitudinal health data and biological samples from 500,000 participants aged between 40-69 years. The electronic health records of participants are directly linked to the UK Biobank database, providing information on disease events, drug prescriptions and deaths. UK Biobank also collects imaging data and is aiming to obtain MRI scans from 100,000 participants by 2020. From the outset, UK Biobank has shared its anonymised data with *bona fide* health researchers. To date, 802 papers using UK Biobank data have been published in peer-reviewed journals, identifying new risk factors for disease and paving the way for improved, targeted therapies.

WGS involves sequencing the entire genome, which in humans consists of over 3 billion base pairs of DNA. After a brief exclusive access period for the pharmaceutical company funders, WGS data will be released to researchers in two tranches: 125,000 sequences in March 2021, and the remaining sequences at the end of 2022. The addition of WGS data to UK Biobank will make it the most comprehensive resource of its kind in the world. By linking this genetic information with clinical data from participants, UK Biobank hopes to provide insights into why certain people develop life-changing diseases, and why others do not.


**13 September: Eisai and Biogen stop two Phase III clinical studies of elenbecestat in early Alzheimer’s disease**

On 13 September, Eisai and Biogen announced the decision to discontinue two Phase III clinical studies based on data safety monitoring board recommendation.

The MISSION AD1 and MISSION AD2 Phase III studies were multicentre, placebo-controlled, double-blind and parallel-group trials designed to assess the efficacy and safety of elenbecestat, a BACE inhibitor, in a total of 2.100 people with mild cognitive impairment or mild Alzheimer’s disease (AD). Participants were assigned to receive either placebo or 50mg of elenbecestat daily for two years.

Elenbecestat was the last active BACE inhibitor tested for AD in clinical trials. The decision to discontinue the Phase III studies is based on the results of a safety review, which suggested an unfavourable risk-benefit ratio. Data is expected to be presented at upcoming conferences.

The long-term extension of the Phase II trial of elenbecestat, will also be discontinued. The companies reported that the discontinuation of the MISSION AD program will not affect the ongoing Phase III Clarity AD trial of BAN2401, an anti-amyloid-beta monoclonal antibody, in participants with early AD.


**18 September: Researchers identify a new mechanism for tau-induced neuronal dysfunction in people with frontotemporal dementia**

On 18 September, Dr Peter Dongmin Sohn and colleagues published a paper in *Neuron*, showing that tau proteins associated with frontotemporal dementia prevent neurons from functioning properly by sequestering EB3 proteins in the AIS region of neurons within the brain.

The proper functioning of neurons is dependent on their “excitability”: their ability to create, propagate and terminate electrical signals. The axon initial segment (AIS), a specialised area located at the axon root, is where many electrical signals originate before travelling down the axon fibre. The AIS is extremely plastic: depending on the activity of the neuron, it can remodel itself, becoming longer or shorter. This “plasticity” enables normal signal propagation. However, in diseases such as frontotemporal dementia (FTD) neuronal excitability is altered - neurons become “hyperexcitable”, mis-firing electrical signals and causing cognitive dysfunction. Interestingly, recent studies suggest that tau proteins may help regulate the structure and function of the AIS. However, it is not yet clear how the mutated tau proteins associated with FTD interact with the AIS, or whether this influences the neuron ‘hyperexcitability’ that causes cognitive decline in FTD.

To investigate these questions, Dr Sohn and colleagues created an *in vitro* model of FTD using human neurons derived from cells donated by people with FTD. The donor cells produce a mutated form of the tau protein, called tau\textsuperscript{V337M}. Using advanced microscopy techniques to compare the FTD neurons with healthy ones, the researchers observed that tau\textsuperscript{V337M} neurons had much shorter AIS regions. In addition, stimulation of FTD neurons did not cause any changes in AIS length or structure, as was seen in healthy neurons. Detailed analysis of electrical traces from tau\textsuperscript{V337M} neurons showed a very spiky, hyperactive pattern: the FTD neurons fired up to 6 times more often than their healthy counterparts. To try to understand how tau\textsuperscript{V337M} was causing this hyperexcitability, Dr Sohn and colleagues took a closer look at structural proteins within the AIS. They saw that tau interacted with a protein called EB3, which helps stabilise the microtubule scaffolding within the AIS. In normal neurons, this interaction was much less strong than in tau\textsuperscript{V337M} neurons: as a result, much more EB3 was clustered in the AIS of FTD neurons compared to healthy cells. The quantity of EB3 in the AIS region was correlated with neuronal hyperexcitation: the more EB3 there was, the more electrical mis-firing occurred. Importantly, reducing EB3 restored normal function to the AIS, allowing it to elongate and shorten in response to electrical signals.
Together, these results suggest that the EB3 protein might play an important role in the neuronal dysfunction that characterises FTD.

https://www.cell.com/neuron/fulltext/S0896-6273(19)30692-0

DEMENTIA IN SOCIETY

18 September: Pope Francis highlights dementia during General Audience address

During his General Audience on 18 September 2019, Pope Francis raised the issue of dementia, highlighting the need for people with dementia, as well as their families and carers, to be supported.

Additionally, Pope Francis announced that 21 September 2019 marked World Alzheimer’s Day, calling for better attention for people affected by dementia worldwide, as well as the need to remove stigma around dementia.

Pope Francis stated: "Next September 21st is World Alzheimer’s Day, a disease that affects many men and women, who, due to this disease, are often victims of violence and abuse that trample their dignity. We pray for the conversion of hearts and for those affected by Alzheimer’s disease, for their families and for those who lovingly care for them. I also associate them with prayer, the memory of those suffering from cancer, so that they are also increasingly supported, both in the prevention and treatment of this disease." (The remarks were made in Italian – the translation has been taken from ADI’s website).

A video of the Pope’s comments, in Italian, can be found here:
https://www.youtube.com/watch?v=EcXuPYNoA8s

LIVING WITH DEMENTIA

19 September: Thomas Maurer, member of the EWGPWD, writes about “Shaping the world”

For my sixty-sixth birthday, I have given myself a very special present: the participation at the Tokyo Marathon 2019. It was the last remaining marathon out of the seven "Major Marathons of the World", all of which I completed during my sports career. At the same time, I combined the race with a "farewell trip" to my old home country of Japan. A country in which I lived and worked for several years at the beginning of the 1980s, as a local Chief of Staff of a Swiss company. I planned a trip together with my former wife, a Japanese woman who has been living in Switzerland for many years by now, and our two grown-up sons.

The friendliness and courtesy of the Japanese is unique. You are welcomed with a shy smile everywhere and greeted with a deep bow. No hustle and bustle, no stress, no aggression towards strangers. As a foreigner, you can move around completely safe and carefree. Nobody wants anything from you, you are not looked at in a weird way or even harassed by anyone. There is a serenity, modesty and peace, which would often do us and our Western lifestyle more than just a little good. A culture which opens your eyes and senses to the beautiful, the playful, the detail and the ultimately crucial and decisive things in life.

However, it is not very easy to get in contact with the locals. The reluctance of the Japanese is well-known. People are reserved even among family and friends, which makes social contacts more difficult. Still today, the country is some kind of another planet to me. I have come to know and appreciate many things from Japan and its people.

At the same time, this journey made me realise how small the world is. When I returned to my hometown of Bern, I found a letter in my mailbox written by a former well-known Swiss long-distance runner. He congratulated me on my run in Tokyo. It was an amazing feeling to realise that others can focus on my performance and my adventures, rather than on my illness. To experience, enjoy and help shape this small world and make it a home is the most beautiful and most important challenge I can imagine.

21 September: Idalina Aguiar, member of the EWGPWD, takes part in World Alzheimer’s Day events in Madeira

As part of the celebrations for World Alzheimer's Day, which took place on 21 September, Machico City Hall marked the event through the “Memory Ride”, in an awareness-raising action on Alzheimer's disease. I had the opportunity to actively participate as a person living with dementia, sharing with the public some of my experiences of living with this disease. As a member of
Alzheimer Portugal and of the EWGPWD, I was very pleased to lend my support to this event. Together with my daughter Nélida, I also wanted to represent ANCI (National Association of Informal Caregivers).

The municipality also organised the Exhibition “Reviving Memories”, a lecture where Alzheimer’s disease was the focus. Also, a panel was placed, “Machico Friend in Dementia” in the City Hall. It was a joint action that emphasised the importance of a society that is friendly to people with dementia in the fight against stigma, with the motto that "the Person is much more than Dementia."

We also had the opportunity to actively participate in the Friends of Dementia campaign, in gathering new friends and promoting the campaign, an initiative of Alzheimer Portugal.

It was an excellent opportunity provided by the municipality of Machico (Machico City Council) which, in this way, gave a clear example of citizenship in the dissemination of information on such a current topic. Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English.

NEW PUBLICATIONS AND RESOURCES

20 September: Alzheimer’s Disease International (ADI) publishes World Alzheimer Report

Alzheimer’s Disease International (ADI) have published “The World Alzheimer Report 2019: Attitudes to dementia”, following analyses of a large online survey on attitudes to dementia, which gathered the views of 70,000 people from across 155 countries and territories. The survey covered four demographic groups: people living with dementia, carers, healthcare practitioners and the general public. Analysis of the study, which collected responses from a range of stakeholders, was carried out by the London School of Economics and Political Science (LSE).

From the report, some key findings included:

- Almost 80% of the public are concerned about developing dementia and 1 in 4 people believe that nothing can be done to prevent dementia.
- 35% of carers across the world said that they have hidden the diagnosis of dementia of a family member.
- More than half of carers globally say their health has declined as a result of caregiving, even whilst expressing positive sentiments about their role.
- Almost 62% of healthcare providers worldwide think that dementia is part of normal ageing.
- 40% of the general public think doctors and nurses ignore people with dementia.

The full report can be downloaded at: https://www.alz.co.uk/research/world-report-2019
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>1-2 October</td>
<td>MOPEAD Project Meeting (Cologne, Germany)</td>
<td>Jean and Chris</td>
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<tr>
<td>7 October</td>
<td>Neuronet Project Meeting (Diegem, Belgium)</td>
<td>Jean, Angela, Chris</td>
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<tr>
<td>8 October</td>
<td>BBDiag Meeting (Milan, Italy)</td>
<td>Jean</td>
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<tr>
<td>10-11 October</td>
<td>AMYPAD General Assembly (Barcelona, Spain)</td>
<td>Jean and Cindy</td>
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<tr>
<td>21-22 October</td>
<td>European Alzheimer’s Disease Consortium (Amsterdam, Netherlands)</td>
<td>Jean</td>
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<td>22 October</td>
<td>Project proposal meeting (The Hague, Netherlands)</td>
<td>Dianne and Ana</td>
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<tr>
<td>23 October</td>
<td>Second meeting of AE working group on the ethics of involving people with dementia in research (The Hague, the Netherlands)</td>
<td>Dianne</td>
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<td>23 October</td>
<td>Interdem meeting (The Hague, Netherlands)</td>
<td>Ana</td>
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<tr>
<td>23 October</td>
<td>Neuronet Scientific Coordination Board Meeting (The Hague, Netherlands)</td>
<td>Chris and Angela</td>
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<tr>
<td>23 October</td>
<td>Alzheimer Europe Board (The Hague, Netherlands)</td>
<td>AE Board and staff</td>
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<tr>
<td>23 October</td>
<td>Alzheimer Europe Annual General Meeting (The Hague, Netherlands)</td>
<td>AE Board, members and staff</td>
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<tr>
<td>23-25 October</td>
<td>29th Alzheimer Europe Conference “Making valuable connections” (The Hague, Netherlands)</td>
<td>AE Board, members and staff</td>
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### CONFERENCES 2019

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<thead>
<tr>
<th>Date</th>
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<tbody>
<tr>
<td>5-7 November</td>
<td>14th UK Dementia Congress, <a href="https://careinfo.org/event/uk-dementia-congress/">https://careinfo.org/event/uk-dementia-congress/</a></td>
<td>Doncaster, UK</td>
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<tr>
<td>5-7 November</td>
<td>First dementia conference Krems, “Timely Detection of Dementia”, <a href="http://www.donau-uni.ac.at">www.donau-uni.ac.at</a></td>
<td>Krems, Austria</td>
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<td>26-29 March 2020</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://cony.comtecmed.com/">http://cony.comtecmed.com/</a></td>
<td>London, UK</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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