First of all, it is with great sadness that I share the news that Professor Dieter Ferring died unexpectedly this month. As a member of the Alzheimer Europe Expert Advisory Panel, he contributed to the abstract selection process for a number of our conferences and was a wonderful keynote speaker at our 20th Annual Conference in Luxembourg, in 2010. We have also had the great pleasure of working with him in the context of the EU project MinD, in which he played an important part. His wisdom and kind nature will be sorely missed by all who worked with him.

On a brighter note, I trust you have all had a good summer. There has been plenty of sunshine here, but AE has not been idle! We have been busy preparing our 27th annual conference (#27AEC) in Berlin and I would advise you to book soon if you have not already done so, as spaces are filling up fast. Special rates are available for people with dementia, students, delegates from lower and middle-income countries and members of the German Alzheimer association’s regional branches. You can find more information on our website.

We have also been busy making preparations for the European Working Group of People with Dementia (EWGPWD) meeting in Münbsbach, Luxembourg, which starts this weekend. We are looking forward to welcoming the members of the group, who will be making preparations for 27AEC, as well as sharing their thoughts on aspects of the ROADMAP project during a consultation. As always, we are indebted to the members of the group for their input.

Our Clinical Trials Watch service has also been updated during the summer, with five new trials being added! Check out the AE news section and our website for details.

In mid-July, I was delighted to be able to attend this year’s Alzheimer’s Association International Conference (AAIC17) in London. It was great to be able to network with upwards of 5,000 dementia researchers. Some of the main stories can be found in our “AAIC Watch” section. Five of the EU projects in which we are involved (AMYPAD, EPAD, EMIF MOPEAD and PredictND) were presenting at AAIC17 and it was great to see them gaining recognition on the global stage. You can read reports from all these projects about their time at AAIC in our “EU Projects” section. Also on the subject of EU projects, on 19 July the Innovative Medicines Initiative launched two new calls including topics for Alzheimer’s disease. It is fantastic to see the continuing support dementia research is getting from this initiative and at EU level in general.

Our members are now busy preparing for September now and we look forward to reporting on their activities around World Alzheimer’s Day (21 September) in the next edition.

Jean Georges
Executive Director
On 3 August, AE received confirmation that the recommendations on lay summaries by the clinical trials expert group, of which AE Project Officer Ana Diaz was a member, have been published by the European Commission. The “Summaries of Clinical Trial Results for Laypersons”, which were approved in January 2017 can be found in EudraLex - Volume 10 - Clinical trials guidelines: https://ec.europa.eu/health/documents/eudralex/vol-10_en

In September 2016, Alzheimer Europe (AE) launched the Clinical Trials Watch (CTW) – a service with up-to-date, accessible information on clinical trials. In July and August 2017, AE added more clinical trials to the service:
- COGNITE study (AZTherapies)
- CREAD2 study (Hoffmann-La Roche)
- DAYBREAK-ALZ study (Eli Lilly)
- MissionAD1 & MissionAD2 studies (Eisai)
- SYMBAD study (University of Sussex).

This online resource for anyone interested in clinical trials for the prevention and treatment of dementia and/or Alzheimer’s disease (AD) provides accessible and up-to-date information on phase III clinical trials that are investigating drugs for both conditions. All the clinical trials included are currently recruiting participants in at least one European country.

Further information about the CTW is available on: http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch

For more information about the CTW please contact Cindy Birck, Project Officer: cindy.birck@alzheimer-europe.org

You can register for the 27th Alzheimer Europe Conference (#27AEC) in Berlin until 22 September. The full conference registration fee includes:
- Admission to all scientific sessions
- Delegate bag and final programme including the abstract book
- Opening ceremony and welcome reception on 2 October
- Scheduled coffee breaks on 3 and 4 October
- Scheduled lunches on 3 and 4 October

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

Follow the event on twitter #27AEC

Elmar Gräßel is professor of Medical Psychology and Medical Sociology and head of the Centre of Health Services Research in Medicine at the Department for Psychiatry and Psychotherapy, University Hospital Erlangen, Germany.

His main research interests are caregiver research, health services research in dementia and non-drug therapies in dementia. Gräßel and his team developed and evaluated the multi-component non-pharmacological group therapy “MAKS” for persons with MCI, mild or moderate dementia – used in nursing homes and day-care centres.

He is a founding member of the German Alzheimer Society.

Elmar Gräßel is one of the speakers in Plenary 1, on 3 October. http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Elmar-Graessel
Kate Irving
Kate Irving is a Professor of Clinical Nursing in Dublin City University and the Health Service Executive. Her PhD was completed in Curtin University of Technology, Western Australia, 2001: Case studies in the use of restraints and her doctoral thesis focused on the care of people with dementia in acute medical wards. For the last decade, Prof. Irving has focused on research in the area of dementia prevention and treatment. Funded research projects include, IN MINDD (Innovative Midlife Intervention for Dementia Deterrence), several studies looking at the application of technology to augment dementia care cognitive stimulation therapy and strengths based approaches to dementia care. She led the Irish National Dementia Skills Elevator programme, was chair of the North Dublin Alzheimer’s Café, and was Clinical Lead in the DCU Memory Works Clinic a service to the community to help people make sense of and respond to the memory problems they are having. Kate Irving is one of the speakers in Plenary 3, on 4 October. http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Kate-Irving

Pierre Meulien
Pierre Meulien is Executive Director of the Innovative Medicines Initiative (IMI), a EUR 5 billion public-private partnership between the European Union and the European pharmaceutical industry. At IMI, he is responsible for the overall management of the program, which works to improve and accelerate the drug development process by facilitating collaboration between the key players involved in health research. Previously, Mr Meulien was President and CEO of Genome Canada, where he raised money and oversaw the launch of novel projects and networks in the field of genomics-based technologies. Prior to that, he was chief scientific officer for Genome British Columbia and was the founding CEO of the Dublin Molecular Medicine Center. Mr Meulien also worked with the French biotechnology company Transgene and with Aventis Pasteur (now Sanofi Pasteur).

He has a Ph.D. in molecular biology from the University of Edinburgh and carried out a postdoctoral fellowship at the Institut Pasteur in Paris. Pierre Meulien is one of the speakers in Plenary 4, on 4 October. http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Pierre-Meulien

Winfried Teschauer
Dr Winfried Teschauer studied biology, biochemistry and gerontology and has a diploma and PhD in neurobiology from the Technical University of Munich. His scientific work focused on protein-biochemistry, cancer research and management of emergency medicine at Ludwig-Maximilians-University of Munich.

Around the turn of the millennium, it became clear that his mother had Alzheimer’s disease, so he became involved in the work of the German Alzheimer’s Association and the Ingenium-Foundation where he has been working for about 15 years. The main focus of his work is people with dementia in acute hospital setting, dementia and delirium and challenging behaviour.

Winfried Teschauer is one of the speakers in Plenary 4, on 4 October. http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Winfried-Teschauer

Myrra Vernooij-Dassen
Prof. Myrra Vernooij-Dassen trained as a medical sociologist. She had a chair on psychosocial aspects of care for frail elderly people and was director of the Radboud Alzheimer Centre. She is principal investigator at the Radboud University Medical Centre Nijmegen and is affiliated to the scientific Institute of Quality of healthcare. She has performed a large body of research on quality of care, especially on dementia care and palliative care and on organisation of healthcare. She has supervised 22 PhDs and is currently supervising 10 PhD students. She published more than 250 (inter)national peer reviewed articles. Prof. Vernooij-Dassen is Chair of Interdem, a pan-European research group on detection and timely INTERvention in DEmentia. She is chairing the Research Funding board of Alzheimer UK and is a member of the Scientific Advisory Board of the European Joint Programming Initiative for Neurodegenerative Diseases (JPND).

Prof. Vernooij-Dassen is an honorary visiting professor of the School of Health of Bradford University and visiting professor at the Gadjah Mada University in Yogyakarta, Indonesia. She received the Dutch royal honour of being promoted to Officer in the order of Orange-Nassau. She also received the IPA 2016 distinguished service to the field of psychogeriatrics award.

Myrra Vernooij-Dassen is one of the speakers in Plenary 4, on 4 October. http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Myrra-Vernooij-Dassen
Anders Wimo

Anders Wimo’s research areas are geriatric health economy and epidemiology. He is the coordinator of the steering committees of the population project Swedish National study on Aging and Care (SNAC) and a member of the Swedish dementia quality assurance register (SveDem).

Professor Wimo has written several reports for the National Board of Health and Welfare and he was one of the experts of the Swedish Dementia national guidelines in 2010 as well as its ongoing update. He is also a member of the European Alzheimer Disease Consortium (EADC) and is on the Expert Advisory Panel of Alzheimer Europe.


He has participated in several EU projects and has written more than 300 scientific papers, reviews, book chapters and reports. Anders Wimo is one of the speakers in Plenary 2, on 3 October.


EU PROJECTS

6 July: AETIONOMY project Work Package 2 holds Virtual Dementia Cohort workshop

On 6 and 7 July 2017, Work Package 2 (WP2) of the AETIONOMY project executed a Virtual Dementia Cohort (VDC) workshop on the Aix-Marseille Université (AMU) campus, at the Institut de Neurosciences des Systèmes (INS).

The main focus of the meeting was the next steps towards generating the VDC. Both research developments, the 3D brain simulation of Prof. Viktor Jirsa’s team (AMU) and the longitudinal disease models for Alzheimer’s and Parkinson’s diseases of Prof. Martin Hofmann-Apitius group (Fraunhofer SCAI) are going to be integrated to generate virtual patients. A broad spectrum of methods, metrics and time scales were discussed. WP2 is planning to generate data representations of the longitudinal progress of the diseases including biomarker measurements, which are related to disease specific mechanisms.

During the workshop, AMU presented the “functional dynamics” and “functional connectivity dynamics” (FC, FCD) methods, which enable WP2 to complete missing imaging data from the Alzheimer’s Disease Neuroimaging Initiative (ADNI) cohort for its virtual patient model. This will increase the set of (currently) 15 virtual patients (with full imaging data) to a cohort of 916, which will be the basis for the further generation of a huge, truly ‘similar’ cohort. In the next steps, project partners Fraunhofer and AMU will generate an ADNI merge file including the main features and their related brain regions before implementing links between imaging and molecular/genetic data.

AETIONOMY is a five-year project, running from early 2014 to 2019. It aims to identify subgroups of dementia and Parkinson’s disease, based on the underlying genetic or molecular causes of the variants, in order to allow for tailored therapies.

Work Package 2 deals with all data and knowledge management activities; WP2 is therefore the place where the AETIONOMY knowledge base is being designed, implemented and productively operated. WP2 is co-led by academic partner University of Luxembourg and EFPIA partner Boehringer Ingelheim (BI).

6 July: INDUCT project is researching palliative care as a complex health technology for people with dementia

Rose Miranda (INDUCT Early Stage Researcher 11) is researching palliative care as a complex health technology for people with dementia. She has written the following report:

The Interdisciplinary Network Using Current Technology (INDUCT) is a forerunner in pushing boundaries for research and innovation by studying how complex health technologies can improve dementia care. A complex health technology is a complex intervention characterized by multiple interacting components related to its content, context, implementation, and varying effects on target population. An example of this technology is palliative care, which is the focus of INDUCT Project 11. The Early Stage Researcher Rose Miranda is conducting her research on palliative care for people with dementia at the End-of-Life care Research Group in Vrije Universiteit Brussels and Ghent University.

Palliative care is an approach that aims to improve the quality of life of patients and their families facing problems associated with life-limiting illness such as dementia, through the prevention and relief of suffering. The great benefits of palliative care to people with dementia are gaining massive importance in recent years. However, providing optimal palliative care to this population remains a huge challenge to health systems in Europe and beyond.
Rose is therefore investigating the quality of palliative care for community-dwelling people with dementia in Belgium, Italy, and Spain by using well-tested indicators of quality. This study revealed how care at the end-of-life is managed for people with dementia across countries, which can provide useful insights on specific aspects of care where improvements can be made. The results of this research will be presented and discussed in the upcoming Alzheimer Europe Conference in Berlin this October (Presentation 25.4, 4 October, 10:30-12:00). For any question regarding this project in particular, please contact Rose Miranda (rose.miranda@vub.be). For more information about INDUCT, please visit: www.dementiainduct.eu

7 July: The MinD project holds public design workshop

This time the MinD team met in The Netherlands again, where the team is hosted by three partners, University of Twente, Panton Healthcare Design and Zorggroep Sint Maarten, who are reflecting the interdisciplinary and cross-sectoral nature of the project. The main aim of the visit was to continue to work on the design development to identify the most urgent areas for design intervention and relevant design solutions.

The team worked on mapping existing design products and services as well as design ideas developed by the MinD team against the design themes, which had emerged from the data collection. This allowed to identify 7 ‘Transition areas’ where people with dementia and their carers are most concerned with adapting to change. Under the guidance of colleagues from Panton, the team also developed ‘Personas’ – examples representative of different groups of persons with dementia and carers – which are used to make key issues experienced more tangible.

On Thursday 6 July, hosted by Panton Design, the MinD team held a design symposium and workshop with external experts on dementia to show them the current state of our work and collect ideas, opinions and comments. Prof Kristina Niedderer gave an introduction to the MinD project. This was followed by the keynote of Prof Tischa van der Cammen, from Delft University on design for ageing.

After lunch, Ingeborg Griffeon form Panton Design introduced the Design workshop part of the day. Participants from both healthcare and design were given the opportunity to review and comment on the results of the MinD project so far and to join into the design development activities. The tasks generated lively discussion and great results offering public engagement and contributions to the MinD project as well as knowledge transfer for participating experts and students.

12 July: EPAD project launches animated video about amyloid

The European Prevention of Alzheimer’s Dementia (EPAD) project has launched its second video, which tries to explain what we currently understand about amyloid and how it relates to dementia. EPAD Research Participants may be invited to take part in a clinical trial if test results suggest abnormal levels of a protein called amyloid. If abnormal levels are present, it may mean that person has a higher risk of developing Alzheimer’s dementia in later life. The three-minute-long animation is available on the EPAD YouTube channel (IMI EPAD), which also includes the project’s introduction movie launched in March 2017. Both videos have been developed in English as well as additional languages.

15 July: MOPEAD Consortium meets in London

The MOPEAD Consortium met for the third time on 15 July 2017, in London. The AAIC17 conference was an opportunity to gather all project partners present at the conference. An update on each of the patient recruitment processes was given (especially around the common protocol for patient evaluation to ensure comparison between participating countries and the professional training protocols. Discussions were also held on the metrics and analysis of recruitment results. The communication and dissemination activities were presented and discussed.

The four models of patient engagement are: Citizens Science, Open House, primary care-based engagement, tertiary care (endocrinologists)-based engagement).

The recruitment will take place in five countries: Germany, Slovenia, Spain, Sweden and the Netherlands.
The next Consortium meeting will take place on, 5 October 2017, in Berlin, Germany, in the wake of Alzheimer Europe’s Annual Conference.

16 July: Predict ND attends Alzheimer Association International Conference 2017

The 2017 Alzheimer’s Association International Conference (#AAIC17) meeting was held from 16-20 July in London, UK.

The PredictND team is delighted to have been actively involved in such an important global event as the AAIC, with four project abstracts accepted this year. As well as the four presenters themselves, the project was also represented by several consortium members and project partners in attendance, including Alzheimer Europe.

A lot of attention was given to the potential of biomarkers to identify people at risk of developing Alzheimer’s dementia and of preventative approaches (both pharmacological and lifestyle interventions) to halt or delay the progression to Alzheimer’s dementia in persons with positive biomarkers for Alzheimer’s pathology.

The PredictND achievements were well received and centred on four key presentations: There were two papers PredictND presented:

- Hanneke Rhodius-Meester gave an oral presentation on the subject: “Prognosis of Clinical Progression in Subjective Cognitive Decline Using a Clinical Decision Support System”
- A poster on the topic of “Data-Driven Diagnosis of Dementia Disorders: The PredictND Validation Study” by Marie Bruun (Rigshospitalet)
- A poster on the topic of “Detecting Cognitive Disorders Using Muistikkko Web-Based Cognitive Test Battery – Validation in Three Cohorts” by Teemu Paajanen, (University of Easter Finland – UEF)
- A poster on the topic of “Computed Rating Scales for Cognitive Disorders from MRI” by Jyrki Lötjönen.

During the conference, project partner Combinostics was represented with a booth and demonstrated some of the tools to which the PredictND project has contributed. The project was discussed multiple times with conference delegates visiting the booth and increased the visibility of the PredictND consortium at this key conference in the Alzheimer’s and related disorders field.

AAIC18 will be held from 22-26 July 2018, in Chicago, US.

17 July: MOPEAD communication team publishes infographic

On 17 July, the communication team of the MOPEAD project has released their first infographic.

It emphasizes general information on the project’s background, motivation and objectives. Its aim is to raise interest in the project and provide a first step towards engagement of potential study participants.

The motivation behind MOPEAD is the challenge of late diagnosis, which creates a barrier to access available treatments and support services, as well as enrolment in Clinical Trials in very early stages. The project focuses on the importance to encourage a cultural shift towards making a timely diagnosis of Alzheimer’s disease at its initial stages.

MOPEAD therefore provides information on how to improve the consistency of diagnosis and communication as soon as symptoms begin.

Take a look at the infographic on the website: https://www.mopead.eu/

21 July: AMYPAD features prominently at AAIC Conference in London

The Alzheimer’s Association International Conference (AAIC) took place in London from 16 to 20 July. This conference, the world’s largest forum dedicated to advancing dementia science, was a great opportunity to present the “Amyloid imaging to prevent Alzheimer’s disease” (AMYPAD) project, which featured prominently in a number of key communications:

- An AMYPAD Meet&Greet event was organised by GE Healthcare and Piramal on 17 July. There, Gill Farrar (GE Healthcare) introduced the project, followed by Nicola Raffa (Piramal) and Craig Ritchie (UEDIN) who presented the Diagnostic Utility and the Prognostic Natural History Studies. Frederik Barkhof (VUmc) led the interesting discussions and closed the session.
- AMYPAD was invited to join “The Imaging Dementia-Evidence for Amyloid Scanning” (IDEAS) forum lunch meeting on 18 July and was briefly presented by Giovanni Frisoni (Université de Geneve).
- The AMYPAD partner IXICO organised an expert symposium dedicated to Imaging and digital biomarkers in Alzheimer’s disease clinical development on 18 July. AMYPAD was well represented with two oral presentations gave by Frederik Barkhof and Elisabetta Grecchi (IXICO).
- Three posters focusing on the AMYPAD project were presented:
  1. Frederik Barkhof and Gill Farrar (pictured) presented a high-level overview of the AMYPAD project.
  2. Juan Domingo Gispert (BBRC) presented the WP2 goals as well as results already obtained.
  3. Giovanni Frisoni described the WP3 work.

For more information on the AMYPAD presentations at AAIC, read here: http://amypad.eu/news/recent-news/amypad-features-prominently-at-aaic-conference-in-london/
21 July: EPAD announces a second wave of Trial Delivery Centres

EPAD is establishing a Europe-wide cohort of over 6,000 participants, of which 1,500 will be invited to participate in a trial to test new treatments for prevention of Alzheimer’s dementia.

The EPAD Longitudinal Cohort Study (EPAD-LCS) opened for recruitment in May 2016. It is a core part of the EPAD project that links participants in other cohorts and registers across Europe. A first wave of Trial Delivery Centres (TDCs) opened in Edinburgh (UK), Barcelona (Spain), Toulouse (France) and Amsterdam (The Netherlands). EPAD is delighted that one-year follow-ups are already under way at the Edinburgh TDC and participants are returning to have the full set of assessments done again.

EPAD is also very pleased to announce that the LCS study has begun Wave 2 of its TDCs, with centres opening for recruitment in San Sebastian (Spain) and Stockholm (Sweden). As of 21 July 2017, 276 research participants have been entered into the EPAD-LCS across six TDCs in five European countries. Other additional centres are already certified and will open shortly.

You can read the testimonial of the first San Sebastian research participant enrolled in the CITa Foundation here. For more information on the EPAD initiative and to keep up to date with our progress, visit http://ep-ad.org/ and also follow us on Facebook https://fr-fr.facebook.com/IMIEPAD/ and Twitter (@IMI_EPAD).

27 July: EMIF reports on presenting project progress at AAIC 2017

Prof. Sir Simon Lovestone (pictured), recently knighted for his contribution to neuroscience, Professor of Translational Neuroscience at Oxford University, and academic coordinator of EMIF presented a plenary at Alzheimer’s Association International Conference (AAIC) 2017, on Tuesday 18 July, entitled, “The Future of Electronic Health Records and Big Data in Dementia Research”. Prof. Lovestone outlined the work conducted by EMIF to date, inclusive of an AD cohort catalogue and a technology and governance platform for the discovery, assessment and reuse of de-identified AD records data. He also highlighted confluent work with partners such as UK-CRIS, and DP-UK in aggregating relevant data for researchers on accessible platforms.

Prof. Lovestone commented, “EMIF-AD has given us a tremendous opportunity to conduct research which would ordinarily have taken considerable time, resources and money to better characterise and understand earlier Alzheimer’s disease, and without it we would be much further back in our progress”. EMIF-AD has already developed what Prof. Lovestone denoted as ‘impossible cohorts’, the EMIF 500 and EMIF 1000, combining from multiple cohorts across Europe de-identified health data, access to samples and diagnostic results to support blood based correlates of AD progression using more invasive or expensive biomarkers, as just one example of progress. This has involved all three guiding objectives of EMIF – making data findable, assessable and reusable - and many of the tools EMIF has developed to achieve these aims.

The AAIC 2017 meeting is a preeminent meeting of over 5600 of the world’s leading researchers, next generation investigators, clinicians and the care research community to share discoveries in basic and translational research that will lead to methods of prevention and treatment, and improvements in diagnosis for Alzheimer’s disease and other dementias. Dr Pieter Jelle Visser, Academic Lead for EMIF-AD and Clinical Epidemiologist, Maastricht University and VU Medical Centre Amsterdam, commented, “We are very proud that EMIF-AD has twenty presentations at AAIC 2017, reinforcing the contribution of this unique collaboration in Alzheimer’s Disease research to the knowledge base”.

In the spirit of such collaboration, Prof. Lovestone portrayed a possible future where multiple, international platforms for dementias research could support target identification; proof of concept clinical trials; efficacy trials (feasibility to recruitment); regulatory and payer approval requirements for new therapeutics; phase IV studies, as key milestones for therapeutic development against dementias. Prof. Lovestone added, “We have to work together and EMIF-AD, UK-CRIS, DPUK, EPAD, GAIN, and many others are in an ideal position to do so, providing a global framework for dementias research that will make a critical difference to addressing the increasing threat to individuals, families and society of these awful diseases”.

Also attending AAIC 2017 was Jelle Praet, AD Cohort Engagement, EMIF-AD, who is working with cohorts to expand the cohort catalogue, as well as support cohort custodians with the process to on-board the EMIF-AD platform. He suggested, “EMIF-AD is providing real benefit already with the 46 cohorts that are within the catalogue, but we need to expand on the diversity, quality and quantity collaborating. We are introducing new technologies to harmonise AD research data and to open up the opportunity for AD/dementias researchers to explore European cohorts and datasets”. So far eight cohorts are confirmed as on-boarding into the EMIF-AD platform, with eleven expressing significant interest in doing so during AAIC 2017.

Looking forward to the future, Bart Vannieuwenhuyse, Industry Coordinator for EMIF, is one of many collaborating with the EMIF-AD research community, along with Prof. Lovestone, working on a sustainable platform beyond the IMI programme phase. He proposed, “Dementias research is very challenging, and Alzheimer’s disease is a very complex challenge, and a major threat to our society, which has meant few therapeutic options to date”. He added, “we will only
address this with a sizeable collaboration of multiple, diverse stakeholders, from patients and their carers to clinicians, academics, and the Industry to meet such a societal challenge, supported by common platforms and technologies”.

EMIF-AD colleagues would be keen to hear from those across the European research community who would wish to work together on establishing a sustainable future for the EMIF-AD platform, and to combine initiatives requiring access to real world data, samples or patient recall, while driving the research priorities for the near future.

More information on EMIF-AD can be found here:
http://www.emif.eu/about/emif-ad

More on the Cohort Catalogue here:
www.emif.eu/about/emif-platform/emif-catalogue

A copy of Prof. Lovestone’s keynote presentation from AAIC 2017 is available here:

To contact EMIF-AD: http://www.emif.eu/contact or if you are an AD cohort and wish to collaborate, contact Jelle Praet: jpraet1@its.jnj.com

31 July: EPAD gets a great media coverage

The European Prevention of Alzheimer’s Dementia (EPAD) consortium is increasing in optimism regarding the success of its project that had some great media coverage during the summer.

On 24-27 June, the third Congress of the European Academy of Neurology (EAN) took place in Amsterdam. Sean Knox, EPAD WP6 co-lead, attended the event and was interviewed by Touch Neurology. He presented the EPAD project, its aims, its progress to date and where further information can be found on this important project.

The interview filmed at the 3rd EAN can be watched on the EPAD YouTube channel (see link at bottom).

On 20 July, research in dementia prevention was covered in BBC on its main 6 o’clock news bulletin (see link at bottom - from 19 min 50 sec) and on BBC Radio 4 (see link at bottom - from 17 min 10 sec). Prof Craig Ritchie, EPAD co-coordinator, was interviewed by the BBC and talked about both the PREVENT Dementia study and the EPAD project, led from the University of Edinburgh Centre for Dementia Prevention.

On 31 July, The Times Scotland published an article entitled: “Everyday pill to stop dementia in its tracks is tested in Scotland”, in which the EPAD project was featured. In this article, written by health reporter for The Times in Scotland Helen Puttick, Prof. Ritchie explains dementia prevention and mentions that changes in the brain may precede symptoms of Alzheimer’s dementia by many years, or even decades.

EAN interview:

https://www.youtube.com/watch?v=6ycxGyLzm-g&list=PLHIJXSw8nVdz2SPmelEK-yizq7Mqx5BKDQ&index=2

BBC TV news bulletin:
http://www.bbc.co.uk/programmes/b08xd148

BBC radio 4 segment:
http://www.bbc.co.uk/programmes/b08xdq7

The Times Scotland article can be read on the EPAD website.

24 August: The ROADMAP project updates us on recent progress

The ROADMAP project partners are staying active in pursuing the evaluation of the value of Real-World Data in Alzheimer’s disease (AD) to provide the foundation for an integrated data environment and framework for Real-World Evidence in AD. For that purpose, they engage in meetings with key stakeholders, such as the Innovation Task Force (ITF). They present the project as well as the challenges in optimising Real-World evidence for AD to open a forum of discussion and research in this innovative context.

On 29 June, ROADMAP Consortium representatives from NICE, Biogen, Eli Lilly and Novartis went to London for an ITF briefing meeting held at the European Medicines Agency (EMA) to discuss the project’s activities.

On 16 July, ROADMAP Coordinator Professor John Gallacher (University of Oxford / Dementias Platform UK) presented a poster at the Alzheimer’s Association International Conference (AAIC), held this year in London.

2017 also presents forthcoming opportunities for members of the consortium to report on insights from their recent work, and to shape as well as challenge these in collaborating with key stakeholders.

On 4 and 5 September, the Outcome definition team will engage with Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) to consult on their current scientific work and gain not only insights on research leading approaches, but also on how to integrate their expert views on topics raised within the work stream.

The next occasion to meet the ROADMAP team is at the 27th Alzheimer Europe Conference (#27AEC), being held in Berlin from 2-4 October. ROADMAP will be represented on 4 October, at a symposium convened by Eli Lilly. The symposium, entitled: “Engaging with patient organisations within IMI consortia to inform quality, relevance and value in Alzheimer’s research – insights from MOPEAD, EPAD and ROADMAP”, will explore how these three initiatives are tackling AD across the disease continuum. The panellists will provide their perspectives regarding the rationale for each project, engaging in a discussion on the concrete multishared actions to improve timely diagnosis through citizens’ participation, pioneering novel approaches to clinical trials and providing evidence regarding the value of new medications.
Following the AE Conference, ROADMAP will be represented at the Clinical Trials in Alzheimer’s Disease (CTAD) conference in Boston, USA from 1-4 November. ROADMAP Consortium members from Eli Lilly, Novartis and the University of Oxford will be introducing the “Challenges in Optimising Real World Evidence for Alzheimer’s Disease”.

Finally, ROADMAP will be holding a poster presentation at the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Annual Congress in Glasgow, UK from 4-8 November. This international event will be an opportunity for ROADMAP consortium members to communicate about how the project will play a role in challenging current paradigms in the assessment of novel treatments by decision makers and describe innovations for assessing new therapies to treat AD.

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 116020 (“ROADMAP”). This Joint Undertaking receives support from the European Union’s Horizon2020 research and innovation programme and EFPIA.

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

The projects in this newsletter, with IMI 2 funding are:
- AETIONOMY- grant agreement 115568
- AMYPAD - grant agreement 115952
- EMIF - grant agreement 115372
- EPAD - grant agreement 115736
- MOPEAD- grant agreement 115985
- ROADMAP - grant agreement 116020

A number of the projects in which Alzheimer Europe is a project partner are received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration (FP7).

The projects in this newsletter, with FP7 funding are:
- PredictND - grant agreement 611005

In Memoriam Dieter Ferring, 1958 - 2017

It is with great sadness that we share the news that Professor Dieter Ferring died unexpectedly, on 3 August. He would have turned 60 next year.

Prof. Ferring was a founder member of the University of Luxembourg and one of the Faculty of Psychology's most prominent researchers. As an internationally renowned developmental psychologist, he made a major contribution to the University’s reputation for research in psychology and social psychology. He also directed the Master’s in Gerontology and the Institute for Research on Generations and Family.

As a member of the Alzheimer Europe Expert Advisory Panel, Prof. Ferring contributed to the abstract selection process for a number of our conferences and was a wonderful keynote speaker at our 20th Annual Conference in Luxembourg in 2010. We have also had the great pleasure of working with him in the context of the MinD project, in which he played an important part. His wisdom and kind nature will be sorely missed by all of us, who worked with him.

We are deeply saddened and shocked by the news of his sudden passing and would like to extend our heartfelt condolences to his family, friends and colleagues.

Alzheimer Europe Networking

On 3 and 4 July (Berlin, Germany), Gwladys and Jean made a field visit for the 27th Alzheimer Europe Conference.

On 10 July (Glasgow, UK), Cindy attended an EPAD TDC certification visit.

On 14 July (London, UK), Jean attended a workshop on “Involving the public and patients in research - sharing global practice and evidence”.

On 15 July (London, UK), Jean attended a consortium meeting for the MOPEAD (Models of Patient Engagement in AD) project.

On 15 July (London, UK), Jean participated in a joint GAP/EPAD (Global Alzheimer’s Platform/European Prevention of Alzheimer’s Dementia) workshop.

From 16 to 20 July (London, UK), Jean attended the Alzheimer’s Association International Conference.

On 11 August, Kate and Vanessa attended “Media Materials - World Alzheimer’s Month 2017” (ADI) by teleconference.

On 21 August, Dianne, Ana and Chris took part in a teleconference in connection with WP2 of ROADMAP.

On 22 August, Dianne took part in a telephone conference in connection with WP 8 of ROADMAP.

On 24 August, Dianne, Ana and Kate took part in a telephone conference with DEXIC in connection with SMART4MD.

On 25 August, Dianne took part in a WP8 telephone conference in connection with PACE.

On 28 August, Dianne took part in a telephone conference with the organisers of the symposium on big data for the health forum in Gastein.
Members of the European Alzheimer’s Alliance

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

**Austria:** Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP). **Belgium:** Mark Desmesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brentem (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomalašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (S&D); Mipa Kumpula-Natri (S&D); Merja Kyllönen (Greens/EFA); Sirpa Pietikäinen (EPP). **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Frédérique Ries (ALDE); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Costas Chrysogonos (Greens/EFA); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D). **Holland:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Ian Duncan (ECR); Theresa Griffin (S&D); Richard Ashworth (ECR); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudgton (Greens/EFA); Jason Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alny Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

**EUROPEAN ALZHEIMER’S ALLIANCE**

29 August: MEP Heinz K. Becker member of the European Alzheimer’s Alliance - action on dementia

MEP Heinz K. Becker (Austria) has been a member of the European Alzheimer’s Alliance since 2011. He recently attended Alzheimer Europe’s European Parliament lunch debate in June 2017 “The current and future treatment of Alzheimer’s Disease”. Mr Becker will co-chair the next lunch debate entitled “Dementia care in the European Union” on 5 December 2017 with MEP Olga Sehnalová (Czech Republic).

AE asked Mr Becker: From a policy maker’s perspective, why do you think it is important to bring the challenge of Alzheimer’s disease to the front and centre of the European Parliament and what could be done to meet this public health challenge?

Following the efforts of the Slovakian EU-Presidency as well as Netherland’s presidency, it is tremendously important to deliver strong signals to the Maltese Presidency to keep dementia and in particular Alzheimer’s disease at the top of Europe’s health agenda. At the same time it is important to continuously remind the Commission not to slow down in realizing their ambitious objectives, described in the Commission’s Communication on Alzheimer’s disease and other neurodegenerative disorders, adopted in 2009.

As one of the most widespread forms of dementia, Alzheimer’s disease is also one of the most common neurodegenerative diseases - causing tremendous problems to millions of Europeans and enormous costs to the EU-health systems. To date, no curative treatment exists and access to services, treatment and support is still unequal between the
EU member states. It is evident that a European strategy on Alzheimer’s disease is desperately needed.

The current situation does not only lead to severe difficulties in the person with dementia’s life, but also in the indispensable work of their formal and informal carers, friends and relatives. We cannot stand by any longer whilst this situation remains unchanged.

A European strategy on Alzheimer’s disease should focus on EU-wide cooperation on research on the root cause of Alzheimer’s disease as well as ways of early diagnosis of Alzheimer’s disease and other forms of dementia. Furthermore, the free and direct access to any form of necessary health care for European citizens with Alzheimer’s disease as well as professional support for their informal carers must be secured for everybody.

By showing patients respect and dignity as well as decreasing fear and stigma associated with the disease, we can increase their level of participation in society and a higher level of independence as well as streamline the public healthcare spending.

http://alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance

EU DEVELOPMENTS

19 July: IMI launches two new Calls, including topics on Alzheimer’s disease

On 19 July, the Innovative Medicines Initiative (IMI) launched two new Calls for proposals with topics on Alzheimer’s disease, big data, vaccines, autoimmune disease, the blood-brain barrier, drug development, and the exploitation of IMI project results. The total budget for the two Calls stands at just over EUR 130 million. Around half of this comes from the European Commission’s Horizon 2020 programme. The other half comes from EFPIA companies as well as IMI Associated Partners.

Call on Alzheimer’s disease and technologies:

People in the earliest stages of Alzheimer’s disease experience declining cognitive and functional abilities, making it harder for them to remember things and places, carry out simple calculations, use a phone/computer, drive, and adhere to medications. This topic aims to develop a digital platform that draws on smartphone, wearable and/or home sensor technologies to detect changes in cognitive and functional abilities. Ultimately, information from this platform will make it easier to assess how well new dementia treatments work.

The Deadline for submitting short proposals is 24 October 2017.

For more information, read the full press release, here:

http://www.imi.europa.eu/content/imi2-call-11-and-12-launch

20 July: Commission launches public consultation on Health and Care in the Digital Single Market

The European Commission has launched a public consultation on how Europe should promote digital innovation in health and care, for the benefits of citizens and health systems in Europe.

The consultation will collect information on three main pillars:

- Citizens’ secure access to their health data and the possibility to share it across borders, clarifying citizens’ rights and enhancing interoperability of electronic health records in Europe;
- Connecting and sharing data and expertise to advance research, personalise health and care, and better anticipate epidemics;
- Using digital services to promote citizen empowerment and integrated person-centred care.

Welcoming the initiative Vice-President Andrus Ansip (pictured) and Commissioners Vytenis Andriukaitis, Mariya Gabriel and Carlos Moedas stated: “We are dedicated to improving European citizens’ quality of living by improving Europe’s health, care and research systems by using digital technologies to their full potential. This consultation will help us identify ways to offer citizens, medical professionals and researchers better access to health data, prevention, rapid response to pandemic threats, personalised treatments and care. We are considering new digital initiatives to deliver on the free movement of patients and data, to support the modernisation of national health systems, and to bring together scattered evidence and innovative knowledge from across Europe. At the heart of our policies, citizens and their wellbeing are our first priority.”

Citizens, patient organisations, health and care professionals, public authorities, researchers, industries, investors, insurers and users of digital health tools are all invited to share their views via an EU Survey open until 12 October 2017.

The survey can be found here:

https://ec.europa.eu/eusurvey/runner/Public_consultation_Transformation_Health_Care_DSM

1 August: 19 cities bid to host the European Medicines Agency (EMA)

Nineteen countries have officially lodged applications to host the European Medicines Agency (EMA), once the UK leaves the European Union in March 2019.
The EMA is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. Currently based in Canary Wharf, London, it is home to about 1,000 staff and welcomes 40,000 visitors a year.

These are the cities bidding to host the EMA, as of 1 August 2017: Amsterdam, Athens, Barcelona, Bonn, Bratislava, Brussels, Bucharest, Copenhagen, Dublin, Helsinki, Lille, Malta, Milan, Porto, Sofia, Stockholm, Vienna, Warsaw, Zagreb.

Further details on each country’s individual bid can be found here:

**22 August: European Disability Forum launch new video campaign for Accessibility Act**

The European Disability Forum (EDF) has launched a new video campaign for a better European Accessibility Act (EAA).

The final debate on the EAA will take place in the European Parliament on Wednesday 13 September 2017. The final vote will go to the plenary session on 14 September, in which all 751 Members of the European Parliament (MEPs) can vote on whether it will adopt the Internal Market and Consumer Protection Committee (IMCO) report as it is, or with changes, or if it will reject it.

EDF was not happy with the IMCO report and is campaigning for MEPs to make changes to the text to improve it, but this will be very difficult. In order to now influence MEPs, EDF has drafted proposed amendments.

EDF has also defined its most important priorities “red lines” when it comes to the vote. If those priorities are not included in the report, EDF recommends to MEPs to reject the adoption of the report completely. These priorities are:

- A binding clause on the built environment (Article 3 (10))
- A clear reference to the applicability of the accessibility requirements to other Union acts such as public procurement or the EU Structural Funds (Article 1(3))
- Obligations for all businesses, including for microenterprises and SMEs (Art. 12)
- An ambitious and comprehensive Annex I with clear requirements (Annex I)
- Requirements for all transport modes that clearly go beyond existing legislation

The video can be viewed here:
https://www.youtube.com/watch?v=ALtmGkBYu10

Further details can be found here:
http://www.edf-feph.org/european-accessibility-act-1

You can read the Internal Market and Consumer Protection Committee (IMCO) report here:

**29 August: Join the European Health Parliament**

The European Health Parliament is a platform gathering young professionals, to work together in order to change the future of healthcare in Europe. Are you below 35 and you want to participate in the third edition of the EHP? Apply now and let’s make health great again!

http://www.healthparliament.eu/

**MEMBERS’ NEWS**

**15-16 June: Hungary’s Social Cluster Association reports on its Common Speaking Experts 2017 conference**

On 15 and 16 June, the Social Cluster Association held the Common Speaking Experts 2017 conference in Budapest, Hungary. The 2-day-long conference focused on inter-professional long-term care with presentations in both English and Hungarian language (via simultaneous translation) and with the participation of more than 150 experts from more than 10 countries.

Many highly acclaimed professional honoured the conference either as audience members or presenters, including some of the members of Alzheimer Europe, such as Charles Scerri who gave a presentation both on day 1 – the plenary session providing an international outlook – and day 2, in one of the 6 sections.

The opening speech was given by Ledia Lazëri, Head of the WHO Country Office in Hungary, highlighting the significance of this event. At the end of the first day, a consensus paper was approved by the participants regarding important guidelines for the improvement and optimisation of care services.

Dementia was a major focus point of the conference, and as a result we devoted a whole section to Hungarian Alzheimer Cafés, where the participants got to know the Slovenian good practices as well, through the presentation of Stefanija L. Zlobec. Other important themes, among many, included the actualities of geriatrics, incontinence, palliative care, and education. The importance of inter-professional and international cooperation and the development of coherent strategies in order to find the best solutions, was addressed.

By the end of the conference – which we would be happy to repeat in the future - we all gained a lot of useful information and valuable experience we hope to utilise in the field of care.

English language presentations:
http://socialcluster.hu/Documents-m104
10 July: Alzheimer’s Society (UK) writes about its participation in Pride festivals across the UK

At Alzheimer’s Society we embrace the opportunity that Pride festivals across England, Wales and Northern Ireland give us to reach the lesbian, gay, bisexual or trans (LGBT) community, using the events as a platform to celebrate our united against dementia message. This year’s events are even more exciting because our vibrant new brand will guarantee that we are noticed and remembered.

Pride events normally consist of a parade through the city, which we are able to enter with our Dementia Community Roadshow Vehicles and staff, and an area for community organisations to exhibit, where we can host an information stand. Over the summer we’ve entered parades in Birmingham, London and Manchester with hundreds of staff and volunteers alongside our colourful Roadshow vehicles. Further to the parades we’ve held information stalls at the Belfast, Cardiff, Bristol, Colchester, Manchester, and London Pride festivals to provide information about dementia, the work of Alzheimer’s Society, and to showcase our brand new LGBT publications.

We have a factsheet for anyone caring for or supporting an LGBT person with dementia, to help them understand the challenges the person might face and how to support them. Then for LGBT people living with dementia we have a booklet explaining what dementia is, and the ways that it might affect you as an LGBT person. They’ve both been reviewed by LGBT people affected by dementia, and we’ve had input from members of the LGB&T partnership and Opening Doors London.

The response we get from the public is excellent and our staff love to be involved because Pride festivals are colourful, fun and full of positivity. Over 1 million people watched the London Pride Parade on 10 July and working there was one of the highlights of the summer. We can’t speak highly enough of our participation and we can’t wait to represent ourselves at even more Pride festivals in 2018!

11 July: Spominčica reports on 1st dementia-friendly spot in Slovenia

On 11 July, Štefanija L. Zlobec, President of Spominčica - Alzheimer Slovenija and Slovenian Human Rights Ombudsman, Vlasta Nussdorfer officially opened the first “dementia-friendly spot” in Slovenia. This is a place where persons with dementia, their care partners, public workers (retailers, pharmacists, post workers, firemen, policemen, etc...) and other citizens can get proper information about dementia. The dementia-friendly spot provides help for those, who show signs of dementia, who are lost or confused. If someone meets a person showing first signs of dementia (disorientation, confusion, distress, nervousness), they can seek advice and support at the dementia-friendly spot. The spot has a multifunctional role: to raise public awareness about dementia, offer information about dementia, contribute to better recognition of the disease in the community and reduce stigma. On the other hand, with dementia friendly spots we facilitate social inclusion of individuals with dementia in the community.

At the opening, a press conference was organised at the Ombudsman of Human Rights office. Spominčica introduced Tomaž Gržinič, a member of the Slovenian dementia working group, who impressively presented his experience of living with dementia. In the main evening TV news this event was presented to the public and Ms L. Zlobec also gave a live interview.

In the coming months Spominčica will open more dementia friendly spots across Slovenia, at important junctions: shopping centres, daily centres for the elderly, at post offices, at centres for social work and elsewhere. All these spots will be marked with a sticker and a label Dementia friendly spot. Pictured: Štefanija L. Zlobec, president of Spominčica and Vlasta Nussdorfer, Slovenian Human Rights Ombudsman opening the first Dementia friendly spot at the Human Rights Ombudsman building.

20 July: Free application for people with MCI and mild dementia released in Greece

The Greek not-for-profit organization Science For You (SciFY) in collaboration with Alzheimer Athens has developed the smartphone application DiAnoia to propose practical ways to help people with memory problems to improve cognitive functions, mood, everyday function and quality of life. Currently the app is in Greek, but there are more steps ahead...

DiAnoia is a free smartphone application for the caregivers of people with mild cognitive impairment and at the early stages of dementia. Family carers and health professionals have in hand an everyday helper that:

- Offers printable cognitive exercises ready for use to train memory, attention, language etc, in a familiar way for the elderly (paper and pencil).
- Makes exercises more attractive using storytelling
- Proposes ways to spend quality time together
- Reminds key points not to forget
- Allows keeping track of the exercises performed.

200,000 people live with dementia in Greece and this number is dramatically increasing in the years to come. Caregivers’ psychological and financial burden of dementia is huge.
Scientists have made it clear that early intervention is crucial. Non-pharmacological interventions such as DiAnoia play an important role, but are not widespread and cannot be used by people living far from Dementia Day Centers and similar institutions. That is why DiAnoia is an accessible and free solution for crisis-stricken people with dementia and their families in Greece.

The project "DiAnoia" has been implementing under the "Points of Support" program, which is co-funded by TIMA Charitable Foundation, John S. Latiris Public Benefit Foundation, Hellenic Hope charity and Bodossakis Foundation. SciFY and Alzheimer Athens also plan to enrich it and launch a version for iOS in autumn.

You can download DiAnoia on your android smartphone or search “dianoia” on Google Play) https://goo.gl/h6n4r5
For more info: Vassilis Giannakopoulos, vgia@scify.org, +30 211 400 4192, +30 697 20 58 648
http://www.scify.org/

26 July: New edition of ”Living with dementia at home” guide for dementia care partners published in Slovenia

On 26 July Spominčica issued 1,000 copies of the 2nd, revised edition of the guide "Living with dementia at home". It was prepared by partners Spominčica-Alzheimer Slovenia and Aldring og helse, Nasjonal kompetansetjeneste and funded by Norway Grants and Merck Sharp & Dohme. The Norwegian partner also donated the illustrations.

Most of the contents of the guide are dedicated to recognition of dementia, problems associated with the disease, how to care for person with dementia, communicate with them, keep active physically and cognitively. This edition also focuses on the ethical and legal issues, social care rights of care partners and techniques that help people with dementia stay mobile and autonomous as long as possible. As Dr. Milica Gregorič Kramberger, the Slovenian neurologist wrote, this guide is indispensable in any manner of speaking: for closest family, relatives and friends, who constantly seek advice, guidance, new information and any kind of support to make everyday life with individuals with dementia easier. What professionals think about the guide is best illustrated by a quote from Prof. Dr. Zvezdan Pirtoshek from the Neurology Clinic of the University Medical Centre Ljubljana, professor in the Faculty of Medicine, University of Ljubljana:

"It is a tiny blue booklet, which offers useful information about dementia. It can help us understand how the disease influences every dimension of our life. Despite all obstacles closest ones are facing when caring for loved one with dementia, a disease can still awake an inner human note. With a positive attitude, approach and knowledge even an incurable disease could become an opportunity for optimism and bringing faith to life."

10-11 August: Jersey holds annual Battle of Flowers event

The Battle of Flowers is one of the most important cultural events in Jersey each year, and this year Jersey Alzheimer’s Association has the privilege of being the official Battle of Flowers Charity.

First staged in 1902 in celebration of a Royal Coronation, the Jersey Battle of Flowers has since grown over the past century and more to become one of the largest floral carnivals in Europe and without doubt a major highlight in Jersey’s varied summer calendar of festivals and events.

On 10 and 11 August Parades took place at which many volunteers linked to Jersey Alzheimer’s Association sold programmes and collected donations from the many thousands of people who attended the events. The charity is very grateful to the organisers of the Battle of Flowers for allowing nearly 50 people to board Le Petit Train, itself a very well-known Jersey tourist attraction, and take part in the Thursday afternoon Parade. We were overwhelmed by the support of the enthusiastic crowds who waved and applauded as the Train went by. The 50 people on the Train in the Battle of Flowers Parade comprised people with dementia and care providers.

Jersey Alzheimer’s Association has a fantastic opportunity as the Battle of Flowers Charity, to raise awareness of dementia and raise much-needed funds towards the cost of our services this year.

Pictured: Le Petit Train decorated and ready to enter the Parade arena!

23 August: The Alzheimer Society of Ireland publishes new booklet “Eating Well with Dementia”

The ASI will shortly be launching a new booklet called “Eating Well with Dementia”. The booklet offers practical tips and helps families and carers to understand how dementia can affect a person’s appetite and experience with food; how to meet nutritional needs of someone with dementia; and how people with dementia can enjoy and be involved in meal preparation and mealtimes.

Research has shown that the majority of people living with dementia in Ireland are struggling to eat properly – according to new research on the relationship between diet and nutrition and the condition. The research also highlighted challenges with shopping and cooking.

The booklet offers practical tips and helps families and carers to understand how dementia can affect a person’s appetite.
and experience with food; how to meet nutritional needs of someone with dementia; how people with dementia can enjoy and be involved in meal preparation and mealtimes; and how to deal with weight loss, weight gain and other issues.

Basic tips, which are included in the booklet, including keeping the table setting simple, establishing a routine, allowing sufficient time to eat, being flexible around food choices and not worrying about neatness, will be of huge assistance to family members and carers across Ireland.

The booklet is now available from The Alzheimer Society of Ireland by ringing the Alzheimer National Helpline on 1800 341 341 or by emailing helpline@alzheimer.ie

23 August: New leaflet on how to live with dementia published in Croatia and Slovenia

As part of the EU project “Improving the quality of life of people with dementia in the Istrian cross-border area between Croatia and Slovenia - Demenca acROsSLO, Alzheimer Croatia led the creation of a promotional leaflet "What is dementia and how to live with it". The aim of this leaflet is to raise public awareness of dementia, the need for its de-stigmatisation and to familiarise readers with support possibilities. The leaflet briefly covers symptoms and diagnoses of dementia, and how people with dementia and their family caregivers can have better quality of life.

23 August: Jersey reports on its experience at this year’s ADI conference

Mark Blamey, Manager of Jersey Alzheimer’s Association, travelled to Kyoto in Japan in late April in order to support Sarah Blake who is a Senior Occupational Therapist working for HSSD. Sarah had been awarded a poster exhibition concerning the award-winning Splashchat swimming activity at a major Conference on Dementia run by Alzheimer’s Disease International (ADI) at which there were 4,000 delegates present.

Splashchat takes place every Thursday at AquaSplash, a popular Swimming Centre in St Helier, Jersey thanks to support from Sally Minty-Gravett MBE, who also travelled to Japan, the OTs, the Memory Assessment Centre and The Bar & Canteen.

The purpose of our trip to Japan was to raise awareness of the unique nature of Splashchat. We promoted the partnership working between public, private and voluntary sectors. And we wanted to inspire others to set up similar groups. In addition we were able to demonstrate how Splashchat helps to make Jersey a ‘dementia friendly community’. Dementia friendly community was one of the principal themes of the Conference.

In the ancient and beautiful city of Kyoto we learned a lot about Japan’s experience of dementia. Japan is the inspiration for the Alzheimer Society’s ‘Dementia Friends’ programme in the UK. Our visit enabled us to network with many people. We heard about best practice in other parts of the world, as JAA does each year by attending the Alzheimer Europe Conference, and the Alzheimer’s Show in London.

We returned to Jersey eager to share the latest developments in dementia care. The three of us were interviewed on BBC Radio Jersey about our trip on 19 May. The two key messages we heard at the Conference were the need for much more collaboration and education across all parts of society.

Finally at its most basic level attending Conferences of this kind shows support for the millions of very courageous people who either live with dementia or provide care.

Details of the fantastic ADI Conference in Kyoto can be found via this link: https://www.alz.co.uk/ADI-conference-2017

Pictured (left to right): Sally Minty-Gravett MBE, Sarah Blake, and Mark Blamey in front of Sarah’s poster.

28 August: The Alzheimer Society of Ireland works on a new research strategy

The Alzheimer Society of Ireland (ASI) is developing a new research strategy for the next three years.

Policy and Research Manager Dr Bernadette Rock aims to explore the possibility of ASI addressing gaps that exist in dementia research and forging a stronger role within the dementia research landscape in Ireland.

To this end, various stakeholders are taking part in a consultation that will help map and plan a new research strategy for ASI.

29 August: The Alzheimer Association of Finland publishes information leaflet about memory-friendly environments

The “Quick-guide to the memory friendly environment” raises awareness and gives practical ideas how to design easily accessible and clear environments. Memory friendliness helps people with cognitive impairment or memory diseases to live independently as long as possible.

The leaflet highlights ways to make environments more memory friendly: for example, good lightning, clear signs, a quiet sound environment and logical and familiar ways to design spaces. On the other hand, people with memory diseases might need more time and support from us all. Memory friendly environments are based on understanding and acceptance of diversity.
29 August: World’s top athletes come together in Zagreb, to help raise awareness of dementia

The world's top athletes joined together at the IAAF World Challenge Meeting in Zagreb on August 29, creating an event to help raise awareness of dementia. They erased data from images of their biggest successes, emphasising the memory loss caused by Alzheimer’s dementia. They emphasised the importance of a healthy lifestyle and of sport, to help ward off the illness.

With this action, organised by Alzheimer Croatia together with the organisers of the IAAF event, Croatia kicked off “World Alzheimer Month” (September), aiming at supporting early diagnosis of dementia causes. A roundtable on that topic was attended by members of the Management Board of Alzheimer Croatia, representatives of the Zagreb Health Office and organisers of the IAAF World Challenge Meeting. They highlighted key benefits of early detection of Alzheimer’s disease and the need to adopt the proposed Croatian National Dementia Plan, as a prerequisite for a systematic approach to this growing public health problem.

In the concluding note on sport and Alzheimer’s disease, Maria Kušan Jukić, psychiatrist, a member of Management Board of Alzheimer Croatia, said: "Sport is beneficial for the body but also for the brain, as the brain and muscles as well as thought and movement are inseparable."

29 August: Alzheimer’s Society (UK) writes “Why businesses and organisations should be more dementia-friendly”

Dementia costs UK businesses GBP 1.6 billion per year (EUR 1.72 billion) (CEBR, 2014) and over 89% of employers believe that dementia will become a bigger issue for their organisation and their staff (Employers for Carers, 2014). However we found that 73% of UK adults do not think that businesses and organisations are geared up to deal with dementia (Alzheimer’s Society, 2013). With the UK statutory retirement age increasing, and the number of people with dementia expected to rise to 1 million by 2021, we will see many more people developing dementia or becoming a carer whilst still in employment. Businesses need to future proof their organisations, as consumers want businesses which value their customers. A key benefit to organisations in becoming dementia-friendly is that when a business gets it right for people with dementia, it gets it right for everyone.

Alzheimer’s Society’s dementia-friendly business pilot engaged 10 major businesses to test the viability of a framework for businesses to become dementia friendly. These included Heathrow, BT, British Gas, Sainsbury’s and Barclays. An assessment was made on how they support employees, customers or clients in key areas including HR processes/procedures, training and awareness, customer support and physical environments.

The findings were made into a Dementia Friendly Business Guide. This guide supports all organisations through guidance, best practice case studies and sector specific actions, looking at how businesses can support their staff and customers affected by dementia. It highlights why businesses need to train their staff to be aware of the impact of dementia, that they must adapt their products and processes to tackle the challenges customers and staff face, and review public facing buildings to ensure accessible environments include dementia.

The resource looks at three key areas that can be adopted by any organisation – large or small.

People:
- Training and awareness
- Supporting staff affected by dementia

Processes:
- Customer and client support
- Information provision and signposting

Places:
- Reviewing their physical environment.
- Community engagement.

Please feel free to download a copy of the Dementia Friendly Business Guide for your own reference:
https://www.alzheimers.org.uk/info/20079/dementia_friendly_communities/361/dementia_friendly_businesses

30 August: Scottish Dementia Working Group reports on its work to spread knowledge about Scotland’s new strategy

The last few months have been an exciting time for the Scottish Dementia Working Group, with the launch of Scotland’s new Dementia Strategy and the growth of our group, as we welcome a number of new members.

The new Dementia Strategy overlaps with the SDWG’s current campaigning priorities – Diagnosis, Post-Diagnostic and Continuing Support; supporting a well trained workforce; building capacity of SDWG; and Working in Partnership: Local, National, International – in a variety of ways, thanks in large part to our members’ contributions throughout its development. A priority for us over the summer has therefore been working hard to ensure our members are aware of the new strategy and able to hold their representatives to account on its commitments: our recent General Meetings in the West of Scotland and the North East of Scotland focused on Post-Diagnostic Support and Building Capacity respectively, and included guest presentations from professionals on specific aspects of the strategy as well as opportunities for members to share and discuss their thoughts.
Our Building Capacity priority has been a particular focus for us over the summer, as we have taken time to bring together the many new members we have welcomed over the last six months at our “New Members Meeting”, as well as delivering a training programme for our committee which has so far covered “Understanding Dementia” and ‘Dementia and Equalities’.

31 August: Alzheimer Bulgaria member wins “Best man of Plovdiv” award

Kolyo Bonev (pictured, right), a member of Alzheimer Bulgaria, every day takes care of his wife, who has been diagnosed with Alzheimer’s, and he helps other people in a similar situation. He has been awarded a prize, “Best man of Plovdiv”, given by the municipality.

The event was held for the fifth consecutive year together, with the National Alliance for People with Rare Diseases and the Social Assistance Agency of the Municipality of Plovdiv and with the help of the students from the Vocational High School of Food Technologies and Equipment, who were on duty at the “Spot for Goodness” – a place where the citizens could share stories about relatives and friends - their example of moral goodness and empathy. Deputy Mayor Georgi Titoukov congratulated the winners and the participants personally and gave them their awards.

The other prizewinners in this year’s edition of the “Best man of Plovdiv” are Dr Georges Pelev, obstetrician-gynaecologist who helped a woman with health problems to have a healthy child, Tanya Kalcheva, a devoted nurse, Asya Atanasova, Natalie Peneva, Tanya Arizanova for their help at the "Hagi Geoka Pavlov" Home for the Elderly with Physical Disabilities and Jana Beleva, a children's songwriter who spends her time working in orphanages and children with disabilities where she teaches them, discovers their talent and gives them hope and courage.

POLICY WATCH

22 July: Polish report on Care for people with Alzheimer’s disease and support for their families presented in Parliament

On 22 July, the Polish Alzheimer’s Association informed us that a report, “Care for people with Alzheimer’s disease and support for their families”, by the Polish Supreme Audit Office had been presented in Polish Parliament on the Senior Policy Committee.

The Polish Alzheimer’s Association evaluates this report, and the public opinion survey commissioned for it, as very useful. The report was widely discussed in the Polish media and evaluated as being much-needed.

You can also find the entire presentation online (in Polish):
https://www.nik.gov.pl/kontrole/P/16/067/

25 July: Switzerland reviews medical service provision, potentially to the detriment of people with dementia

In Switzerland, the system of tariffs for medical service (TARMED) (accounting system for medical services) has been revised. In a former version of the document proposed by the Swiss Federal Council, different limits have been introduced. Among those, particularly limits of consulting time in absence of the patients caused resistance from associations of physicians of different specialisations.

Alzheimer Switzerland also drafted a statement entitled “TARMED discriminates against people with dementia”, in which it argues that people with dementia would be especially affected by the limits proposed. But older people in general and also those with mental illness would experience serious disadvantages. With its report, Alzheimer Switzerland, as representative of patients and their relatives, was one of two national societies participating in the public consultation, which do not profit from the medical tariffs. Two main arguments were raised:

- A sound diagnosis of dementia is complex and therefore takes time. Also, in many cases information of other service providers or family members will be necessary, which cannot be addressed in the presence of the patient.
- The Swiss National Dementia Strategy formulates clearly defined goals and objectives in order to promote the quality of life for people with dementia, underlining the necessity of an early and differentiated diagnostic process. So the limits proposed stand in contradiction to those demands and goals.

At the end of August, the Federal Council decided that the new payroll accounting system will become operational on 1 January 2018, but in an amended version:

The originally proposed limits have been withdrawn in important parts: People 75 years and over, children and people with mental illness will be excluded from the limits of services in absence of the patients. This can be seen as a success, in no small part thanks to the contribution of Alzheimer Switzerland, in this important political process.

The Federal Council will formally adopt the act this autumn. As soon as the definitive version of the tariff system is published, Alzheimer Switzerland will have to have a closer look at whether people with dementia are definitely amongst those groups excluded from limits on services and will continue to be committed to the protection of the rights of people with dementia.
21 August: Flying the flag for dementia at the UN Committee on the Rights of Persons with Disabilities

On 21 August, the UN Committee on the Rights of Persons with Disabilities opened its 18th session in Geneva. On the agenda were the Constructive Dialogues with the governments of Montenegro, Latvia, Luxembourg and the UK.

The Committee will also adopt the List of Issues for Slovenia, Russia and Bulgaria. The committee meets to re-evaluate how well countries are implementing the UN Convention on the Rights of Disabled People.

The UNCRPD has been hearing evidence from disabled people’s organisations (DPOs), charities, and NGOs. It has also been hearing from governments.

Alzheimer’s Society UK Ambassador Keith Oliver (pictured) was there to fly the flag on behalf of everyone affected by dementia. Putting rights at the heart of UK dementia policy and campaigning work is a key priority for people with dementia – and the CRPD investigation into the UK is an excellent opportunity to do this.

As a result of a recent workshop, Alzheimer Society UK produced a report which has been submitted to the UN as part of their investigation. The Dementia Policy Think Tank have also produced a report, and it is hoped that together these reports show the Committee how important it is for them to address dementia in their investigation.

The CRPD investigation has been a really significant opportunity for Alzheimer Society UK to raise awareness of the rights of people with dementia and the need for action. In the next few months, the Committee will produce recommendations for the UK government on what they must do to protect disability rights in the UK, and Alzheimer Society UK want to make sure that people affected by dementia are part of this.

29 August: What has Greece done so far, to implement its Dementia Action Plan?

Dr Paraskevi Sakka of the Athens Alzheimer’s Association tells us:

According to the latest figures, there are 200,000 people living with dementia in Greece and 400,000 family carers looking after them.

Recognising the magnitude of the dementia issues and the total lack of services offered in our country, in 2013 the Greek Minister of Health assigned a working group, which developed a comprehensive National Dementia Action Plan covering all aspects of dementia.

In December 2014, the Greek Parliament established the National Observatory for Dementia and Alzheimer’s disease, to ensure the implementation of the plan, which was approved by the whole spectrum of political parties within the Greek Parliament.

So far, the implementation of the Dementia Action Plan includes the following:

- A national dementia registry is underway by the Greek National Health Service Organization.
- A rating system to measure the impact of dementia on families is being developed, taking into account the severity of the disease, socioeconomic status, access to health and social care services. This will be used by the State to establish financial benefits for persons with dementia and their families accordingly.
- Six Memory Clinics have been organised, in Psychiatric or Neurological Departments of General Hospitals in Greek cities.
- Seven Dementia Day Care Centres in big cities and nine Day Care Centres in collaboration with Municipalities in smaller cities have been opened throughout the country.
- Five hospices are under construction in various locations throughout Greece.

The above actions are funded by the National Strategic Reference Framework 2014-2020.

SCIENCE WATCH

11 June: Probiodrug announces phase 2a results for its experimental AD drug

On 11 June, Probiodrug, a biopharmaceutical company developing novel therapeutic solutions to treat Alzheimer’s disease (AD) announced encouraging results of its phase 2a SAPHIR clinical trial study in early AD participants.

This clinical trial was a 12-week, randomised and double-blind study conducted in 7 European countries and assigned for participants with early AD. The purpose was to evaluate the safety, tolerability and efficacy of a highest dose of PQ912 (800 mg) compared to the placebo. Probiodrug’s experimental AD drug PQ912 blocks the activity of Glutaminyl Cyclase, an enzyme that participates in the Aβ formation.

The treatment appeared safe but some skin and gastrointestinal adverse effects during the first period of the treatment were reported. The researchers plan to test several doses in future trials. A highly significant inhibition in pGlu-Aβ oligomers, a specific Aβ type, was observed in the treatment group as well as a strong trend for reduction of markers of synaptic dysfunction and inflammation. A neuropsychological test to access the working memory reported a statistically significant effect of PQ912 while other cognitive assessments showed no significant differences.
5 July: Researchers identify the structure of Tau filaments

In a study published in the journal Nature on 5 July, researchers from the MRC Laboratory of Molecular Biology (UK) and Indiana University School of Medicine (US) revealed for the first time the structure of Tau filaments, a protein linked to Alzheimer’s disease (AD). Scientists extracted tau protein filaments from the brain of someone who died with AD. They analysed and imaged the filaments’ structure using a specific technique called Cryo-Electron Microscopy (Cryo-EM) as well as a software for modelling protein structures at the atomic level.

The findings revealed that Tau proteins were arranged in two types of filaments. Although one was more symmetrical than the other, both types of filaments had identical amino acids in their core region. Researchers believe that the analysis of these filaments will help to prevent their formation in AD and other neurodegenerative diseases involving Tau.

Sjors Scheres, a senior author on the paper, explained: “It’s very exciting that we were able to use this new technique to visualise filaments from a diseased brain as previous work depended on artificial samples assembled in the laboratory”.

http://www.nature.com/nature/journal/v547/n7662/full/nature23002.html

17 July: Axsome Therapeutics launches phase 2/3 trial of its AD agitation drug

On 17 July, the company Axsome Therapeutics, which develops therapies for the management of central nervous system disorders, announced the enrolment of the first participant in its ADVANCE-1 study. The purpose of this phase 2/3 trial is to evaluate the efficacy and safety of AXS-05 in the treatment of agitation in people with Alzheimer’s disease (AD).

The study was previously approved by the US Food and Drug Administration (FDA). The investigational product AXS-05 is an oral AD agitation drug combining dextromethorphan and bupropion. Approximately 435 US participants will be randomly assigned to receive AXS-05, placebo, or bupropion for five weeks.

19 July: FUJIFILM Corporation AD drug fails to meet its primary endpoints in Phase 2 study

On 19 July, FUJIFILM Corporation announced results of its Phase 2 clinical trial in people with Alzheimer’s disease (AD). The experimental drug T-817MA developed for the AD treatment is described to have potent neuroprotective effects and strong efficacy in animal models.

The drug failed to meet is primary study endpoints of cognition and global clinical function in its Phase 2 trial conducted in the US on people with mild to moderate AD. In addition, no significant differences were observed in the secondary outcomes.

25 July: Neuronix announces positive results for the treatment of mild to moderate AD

The company Neuronix, which develops new methods to promote a medical treatment for Alzheimer’s disease (AD) and to improve the quality of life of people with dementia, has announced results from its NeuroAD therapy system. It is a non-invasive therapeutic device for the cognitive improvement of people with AD. It uses both magnetic stimulation and cognitive training.

Several clinical studies where participants received the therapy for six weeks, five times per week, during a one-hour session per day, showed significant cognitive and behavioural improvements.

Neuronix implemented its system in London (UK) earlier this year and all the 16 participants with mild to moderate AD treated with NeuroAD showed significant improvements in cognitive function. These results were in accordance with studies conducted in Europe, Asia and US.


27 July: Regular evaluation of Quality of Life is the foundation of good care of people with dementia, study finds

On 27 July, a paper on “Factors associated with the quality of life of people with dementia and with quality of life-improving interventions: Scoping review” was published in the journal Dementia, aiming to synthesise current research exploring the factors and interventions associated with the quality of life of people with dementia. The study concluded that a regular evaluation of Quality of Life (QoL) is the foundation of good care of people with dementia.

The primary evaluators of QoL are the people themselves. As the disease progresses, the focus of evaluation shifts to family members and/or social and healthcare professionals. However, even then, the view of the person with memory related diseases must always be taken into account through Advances Directives. Due to the nature of the disease, it is important to discuss the individual factors affecting QoL and to record them in an advanced directive during the first year following diagnosis, the study authors say.


31 July: FDA approves Phase 1 trial for AD drug PTI-125

On 31 July, Pain Therapeutics, a drug-development company based in Texas, US, announced that it received the clearance from the US Food and Drug Administration (FDA) regarding its drug candidate PTI-125 to treat Alzheimer’s disease (AD). Previous findings showed that PTI-125 could significantly improve AD neurodegeneration in AD mouse models as well as in post-mortem brain tissue from people with AD.
In order to get an overview of the life cognitive relationships within the participating population, the research participants completed cognitive tests that measured memory and problem-solving abilities. After verifying that average age, years of education, and APOEε4 status did not differ between the two groups, the sample was stratified by race. Then stress-cognition relationships within African American and white subgroups were looked at. The analyses revealed that for all study participants a greater number of stressful events was associated with poorer late-life cognitive function. African Americans experienced over 60 percent more stressful events than non-Hispanic whites during their lifetimes. These experiences predicted poorer memory and thinking skills in older age. The researchers determined that, in African Americans, each stressful experience was equivalent to approximately four years of cognitive aging.


16 July: Studies reveal the AD diagnostic value of PET scans

The accumulation of β-amyloid is described as a hallmark of Alzheimer’s disease (AD), which can be visualized in the brain by a nuclear medicine neuroimaging tool called Positron Emission Tomography (PET).

Results from different studies highlighted the clinical value of amyloid-β PET scans were presented at AAIC 2017 in London. Additionally to report that PET scans could enhance the AD diagnosis, studies also revealed an underutilization of amyloid-β PET imaging contributing to AD misdiagnosis.

An ongoing study conducted at Oslo University, Norway, mentioned that amyloid imaging was a key contributor to diagnose or exclude an AD diagnosis in all the 50 participants with cognitive complaints.

In a study involving 135 participants with memory problems performed at Karolinska Institute in Stockholm, Sweden, researchers underlined that PET scans could improve the dementia diagnosis in up to two-thirds of cases.

An ongoing meta-analysis evaluating the value of amyloid PET in more than 1,100 participants with cognitive impairment was presented by GE Healthcare. Preliminary results revealed that amyloid PET scans led to a change in diagnosis in 20% of people.

One other study, led by a research team from the Indiana University School of Medicine in Indianapolis, analysed the results of a survey conducted in 510 participants with cognitive impairments and their caregivers. The study concluded that many participants were frustrated by the limited access to PET imaging and that more that 80% were receptive to do PET scans if they were recommended by their doctor.

A study also presented at AAIC2017 by researchers from Icahn School of Medicine at Mount Sinai in New York, US, reported that 62% of dementia cases are missed based on Medicare claims, which are commonly used to identify people with dementia.


16 July: Agent clears toxic proteins, reduces inflammation and improves cognition in engineered Alzheimer’s disease (AD) mice

Research presented at the Alzheimer’s Association International Conference on 16 July, adds to the body of knowledge how a future treatment of neurological
diseases might be developed. The research team from Georgetown University, led by Chabrel Moussa (pictured) investigates cellular, biochemical and pathological mechanisms that underlie neurodegenerative diseases including Alzheimer’s disease (AD) and Parkinson’s disease (PD).

On one hand, the scientists have found cell receptors abnormally overexpressed in the brains of deceased people with PD and AD. On the other hand, they not only found that these can be suppressed in AD mice models to clear the toxic protein build up, but also that they may reduce brain inflammation. Additionally, the mice had improved cognition after treatment.

This discovery has been the first time that the potential targets against cancer, so called “discoindin domain receptors” (DDRs) were identified as an actor in PD and AD. “Activation of these cell receptors appear to prevent brain cells from cleaning out the trash – the toxic buildup of proteins, such as alpha-synuclein, tau and amyloid, common in neurodegenerative diseases,” says the study’s senior author, Charbel Moussa, MBBS, PhD, director of Georgetown’s Laboratory for Dementia and Parkinsonism, and scientific and clinical research director of the GUMC Translational Neurotherapeutics Program.


16 July: Social interaction could help people with dementia

On 16 July, at the Alzheimer’s Association International Conference (AAIC) in London, researchers presented data demonstrating that social interaction can improve quality of life for people with dementia. The study, led by the University of Exeter, King’s College, included more than 800 participants with dementia living in 69 nursing homes in the UK.

The findings showed that good staff training and one hour a week of social interaction can improve the life and reduce agitation of people with dementia. This effective care can also reduce the health care costs. Researchers hope to see this programme adopted in all care homes in the UK.

“70% of people living in care homes have dementia, so it is vital that staff have the right training to provide good quality dementia care”, comments Doug Brown, Director of Research for Alzheimer’s Society.

https://www.sciencedaily.com/releases/2017/07/170716111209.htm

17 July: Hearing loss adds to the growing body of potential early signs of future risk of memory and thinking problems

On 17 July, findings presented at the Alzheimer’s Association International Conference added further knowledge on potential early sings that people might develop memory and thinking problems in future. Researchers from the University of Exeter presented finings examining memory and thinking skills of 783 cognitively healthy participants of late middle age, of which over 30% had one or two parents that had previously been diagnosed with Alzheimer’s disease (AD).

In order to learn about the connection between hearing abilities and cognitive functioning the participants conducted a wide range of cognitive tests over a period of four years. After taking into account other risk factors, the analyse revealed, that those participants with hearing loss at the beginning of the study were exposed to a likelihood twice as high to develop mild cognitive impairment four years later than those without hearing problems.

Taylor Fields, a PhD student at the University of Wisconsin who led the research, said that the findings suggest hearing loss could be an early warning sign that an individual might be at greater risk of future cognitive impairment - but added more research was necessary to unpick the link.


17 July: People with healthier diets at lower risk of cognitive impairment

On 17 July, a group of US scientists presented results from analyses of almost 6,000 study participants of the Health and Retirement Study at the Alzheimer’s Association International Conference 2017. Among the healthy people that took part in the study, those who followed the specially designed MIND diet and Mediterranean diet were at a 30 to 35 % lower risk of cognitive impairment. In addition to that, people with healthier diets also exhibited meaningful preservation of cognitive function.

Although, these findings are contributing to the body of evidence that having a healthy lifestyle contributes to better health, the impact of a diet in the context of such a study can also be overestimated. When interpreting such results limitations should be taken into account. In this case most of the data has been self-reported and is part of an observational study.

Further studies are required to elucidate the role of diet on change in cognition during aging.


17 July: Sleep disordered breathing may be a modifiable risk factor for Alzheimer’s disease (AD)

During the Alzheimer’s Association International Conference (AAIC) in London on 18 July, different research analyses have presented findings on significant associations between sleep
disordered breathing (SDB) and the accumulation of biomarkers for AD.

Taking the overall message of these findings into account, it becomes more and more probable, that SDB might be a modifiable factor in the pursuit of lowering the risks of dementia and disease progression.

SDB is expressed by repeated episodes of under breathing and not breathing during sleep. The most common form of not breathing during sleep occurs when the upper airway closes partially or fully during sleep, but efforts to breathe continue. This occurs in about 3 of 10 men and 2 of 10 women.

In this realm, research presented at the AAIC pointed out findings that showed that episodes of not breathing during sleep were associated with increased brain β-amyloid deposition, decreased cerebrospinal fluid (CSF) and increased tau protein levels. These are all associated with a higher risk of developing dementia.

Data from the Alzheimer’s Disease Neuroimaging Initiative (ADNI) showed in addition to that, that SDB accelerated the accumulation of brain β-amyloid both in cognitively normal individuals and individuals with mild cognitive impairment.


17 July: Study reveals nine lifestyle changes that may help to prevent dementia

At London’s Alzheimer’s Association International Conference (AAIC) on July 2017, researchers from the University of Wisconsin School of Medicine and Public Health presented the socioeconomic status of 1,479 people living in poor and wealth areas. In this study, they analysed the cognitive performance through memory, verbal and learning tests.

They found that living in the suburbs could protect people from dementia. With a score around 25% below the average clinical scores in the tests, people from deprived areas had worse cognitive performance and an increased risk to develop dementia. Scientists believe that pollution, limited access to healthy food and stress have negative effects on the brain.

Additional results underlined that participants from poorer areas had unusually high levels of a protein involved in Alzheimer’s disease.

18 July: RA2 presents a revised pipeline analysis of Alzheimer’s drugs

On 18 July at the Alzheimer’s Association International Conference (AAIC), ResearchersAgainstAlzheimer’s (RA2), an UsAgainstAlzheimer’s network of more than 450 Alzheimer’s researchers in the United States and abroad, reported the number of clinical trials in progress or expected over the next five years.

The presentation illustrated a revised pipeline analysis of Alzheimer’s therapies. 27 Alzheimer’s drug in phase 3 and 8 in phase 2 are currently on track to be launched in the next five years. In addition to the estimated launch date, researchers reported also the estimated trial completion and the estimated regulatory filing. The analysis described the drugs by mechanism of action. As an example, 23 drugs in phase 2 and 3 target amyloid protein while 28 drugs target the neurotransmission. Interestingly, the analysis included some data showing the percentage increase of phase 2 clinical trials from 2016 and the number of drugs in phase 3 in 2017 compared to 2016.

19 July: Study reveals nine lifestyle changes that may help to prevent dementia

In a study published in the journal The Lancet on 19 July, a panel of 24 international experts led by the University College London, UK, identified 9 lifestyle changes that could prevent a third of dementia cases. This study was also presented at the Alzheimer’s Association International Conference (AAIC) in London.

Researchers listed nine factors that could be linked to an increased risk of dementia including lack of education, hearing loss, smoking, physical inactivity, obesity, hypertension, depression, social isolation and type 2 diabetes. These lifestyle factors can play a role in increasing or reducing the risk of dementia. Although not all of the factors identified are easily modifiable, some lifestyle changes might help reduce dementia risk. The study suggested that 35% of dementia cases could potentially be prevented. Better education in early live, addressing hearing loss and stopping smoking could reduce the incidence of dementia by 22%.

"Although dementia is diagnosed in later life, the brain changes usually begin to develop years before," said lead author Prof. Gill Livingston.

LIVING WITH DEMENTIA

24 August: Idalina Aguiar, member of the EWGPWD, writes about her recent activities

My month of June was full with some opportunities to talk about dementia and raising awareness about it.

First, I had the pleasure to give a talk with my daughter, Nélida, in Café Memória da Madeira, on 24 June. Many participants already knew us but our testimony inspired each one of them. I felt a little bit nervous, but I talked in my own language and I was well prepared in my previously cognitive stimulation sessions, that I attend every week at Alzheimer Portugal, Delegation of Madeira. Nélida talked about how her life and that of the entire family became very different, and I talked how my life became an everyday challenge. Together we talked about how kindness, patience and love have made it possible to overcome everyday challenges.

Last 27 June, I met some students from Geriatric Assistant Training. I read a text about myself, previously prepared with Lucílía and Gonçalo in my cognitive stimulation sessions. I talked with the students about how it was to be diagnosed with dementia, how I am dealing with it and how can I live with dementia and why am I participating in EWGPWD, more recently. I know the students felt touched by my testimony and they told me that it was a pleasure to meet me and that I have changed the way they view people with dementia.

These were the main different things I have done in June. In everything else I am doing what Idalina always does: read, play cards, going to concerts, enjoy time with family and friends, gardening.

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

28 August: Helga Rohra, member of the EWGPWD, writes “Dementia goes to school”

Advocates in dementia all over Europe have a strong wish: let young people know that a diagnosis of dementia is never the end.

There are still valuable existing resources that can be activated!

My aim as a former Chair and current member of the European Working Group of People with Dementia (EWGPWD) is raising awareness among youngsters, taking away the fear of this diagnosis and having a dialogue.

To be able to do this, please follow in my steps. It is rewarding for both sides: people with dementia and youngsters. It is innovative and it is a MUST – please LISTEN to us.

First you need a list of schools in your area - in your county. Decide what the best age is to talk about what pupils have learned from books, seen in the media or have lived in their family.

I advise that the best age is youngsters starting from the age of 14/15 years and older.

Please consider that the way you explain dementia can also influence their future field of study, even the profession they take.

Next step: you contact the Head of the school or perhaps, with luck, you know a teacher personally.

Are you yourself a person with dementia, who worked at a school or institute? It will be get easier for you, if so!

You will get many answers like: the time table is overloaded - the staff see no point in having a person with dementia at their school - the pupils are too young! Be prepared to answer, and adopt a firm attitude. Soon a flyer of the EWGPWD, under the guidance of Alzheimer Europe, will be online to help you!

Next step – now you know the age of your pupils, you have to know how many hours the topic of dementia was discussed in class - then you contact the teacher in charge and the Head too. Now a plan has to be discussed between the teacher and you; the person with dementia and your care partner. The teacher will go into details of dementia in a special class, either sociology or ethics. Then after some weeks you may even be announced in the daily press: "Person with dementia ... (name) in dialogue with the school...grade...", Stay tuned for the report to follow...

The special day arrived: In the big hall of the school - pupils gather. You are welcomed like someone precious! All are very silent and curious! Teachers feel a bit embarrassed. Youngsters do not show any emotions at all at the beginning.

My attitude: make them feel I AM still the person - the teacher I once was. Communication on the same level from the very start. They get involved, I prepared work cards. We split into groups - a vivid interaction develops. And after 2 hours my gift of the day:

"Now I have a new view on dementia - I learnt that people with dementia can even be optimistic and challenging too. I think I would like to study in the dementia field - it is fascinating!"
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>3-5 September</td>
<td>Meeting of the EWGPWD (Munsbach, Luxembourg)</td>
<td>Dianne, Ana and Chris</td>
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<tr>
<td>6 September</td>
<td>2nd ethics working group meeting on disability (Luxembourg, Luxembourg)</td>
<td>Dianne and Jean</td>
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<td>8 September</td>
<td>Carers’ survey meeting (Amsterdam, Netherlands)</td>
<td>Ana and Jean</td>
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<tr>
<td>11 September</td>
<td>Essity expert panel meeting on continence care (Florence, Italy)</td>
<td>Dianne</td>
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<td>11-14 September</td>
<td>WHO Regional Committee 67 (Budapest, Hungary)</td>
<td>Vanessa</td>
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<td>14-15 September</td>
<td>EPAD mid-term review (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>19-20 September</td>
<td>Patients’ and Consumer’s Working Party of European Medicines Agency (London, UK)</td>
<td>Jean</td>
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<tr>
<td>20 September</td>
<td>Meeting to discuss IMI project proposal (Brussels, Belgium)</td>
<td>Dianne and Ana</td>
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<tr>
<td>26 September</td>
<td>Scientific Advisory Board of Centre of Excellence in Digital health and Personalised Medicine (Esch/Belval, Luxembourg)</td>
<td>Jean</td>
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### CONFERENCES

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<thead>
<tr>
<th>Date</th>
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<tr>
<td>2-5 September</td>
<td>30th European College of Neuropsychopharmacology Congress, <a href="http://2017.ecnp.eu/">link</a></td>
<td>Paris, France</td>
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<td>4-5 September</td>
<td>7th International Conference on Geriatrics &amp; Gerontological Nursing, <a href="http://geriatrics-gerontology.conferenceseries.com/">link</a></td>
<td>Edinburgh, Scotland</td>
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<td>11-12 September</td>
<td>18th International Conference on Alzheimer’s Drug Discovery, <a href="https://www.alzdiscovery.org/events/event/18th-international-conference-on-alzheimers-drug-discovery">link</a></td>
<td>New Jersey, USA</td>
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<td>11-13 September</td>
<td>2nd World Congress &amp; Expo on Dementia &amp; Neuroscience, <a href="http://scientificfederation.com/neuro-science-2017/">link</a></td>
<td>Miami, Florida, USA</td>
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<td>11-14 September</td>
<td>42nd Federation of European Biochemical Societies (FEBS) Congress, <a href="https://2017.fbscienceconference.org/">link</a></td>
<td>Jerusalem, Israel</td>
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<td>16-21 September</td>
<td>XXIII World Congress of Neurology, <a href="http://www.2017.wcn-neurology.com/">link</a></td>
<td>Nice, France</td>
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<td>16-18 September</td>
<td>6th Croatian Neuroscience Congress (6CNC), <a href="https://www.contres.hr/en/6cnc/preliminary-scientific-programme/">link</a></td>
<td>Osijek, Croatia</td>
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<td>17 September</td>
<td>Innovations and state of the art in dementia research, <a href="http://alzheimers-dementia.org/">link</a></td>
<td>Rome, Italy</td>
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<td>20-22 September</td>
<td>13th International Congress of the EUGMS, <a href="http://www.eugms.org/2017.html">link</a></td>
<td>London, UK</td>
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<td>28-29 September</td>
<td>IMI Stakeholder Forum 2017, <a href="https://goo.gl/IDGnsA">link</a></td>
<td>Brussels, Belgium</td>
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<td>2-4 October</td>
<td>27th Alzheimer Europe Conference “Care today, cure tomorrow”, <a href="http://www.alzheimer-europe.org/conferences/berlin-2017">link</a></td>
<td>Berlin, Germany</td>
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<td>9-10 October</td>
<td>16th International Conference on Neurology and Neuro Cognitive Disorders, <a href="http://neurocognitivedisorders.conferenceseries.com/">link</a></td>
<td>London, UK</td>
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<td>16-18 October</td>
<td>9th International Conference on Alzheimer’s Disease &amp; Dementia, <a href="http://alzheimers-dementia.conferenceseries.com/">link</a></td>
<td>Rome, Italy</td>
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<td>16-17 October</td>
<td>17th Global Neuroscience Conference, <a href="http://neuroscienceconferenceseries.com/">link</a></td>
<td>Osaka, Japan</td>
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<tr>
<td>17-20 October</td>
<td>Alzheimer’s Australia National Conference, <a href="http://dementia2017.org/">link</a></td>
<td>Melbourne, Australia</td>
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<tr>
<td>20-21 October</td>
<td>9th Dementia Conference, ASK 2017 for dementia friendly society, <a href="www.spominicina.si">link</a></td>
<td>Termécsképze, Slovenia</td>
</tr>
<tr>
<td>1-4 November</td>
<td>Clinical Trials on Alzheimer’s Disease (CTAD), <a href="http://www.ctad-alzheimer.com/">link</a></td>
<td>Boston, USA</td>
</tr>
<tr>
<td>3-5 November</td>
<td>20th Asia Pacific Regional Conference of Alzheimer’s Disease International, <a href="www.alzi.or.id">link</a></td>
<td>Jakarta, Indonesia</td>
</tr>
<tr>
<td>11-15 November</td>
<td>47th Annual Meeting of the Society for Neuroscience, <a href="https://goo.gl/6nWv1a">link</a></td>
<td>Washington DC, USA</td>
</tr>
<tr>
<td>27-30 November</td>
<td>CNS Summit, <a href="http://cnssummit.org/">link</a></td>
<td>Florida, USA</td>
</tr>
<tr>
<td>17-19 January 2018</td>
<td>12th Human Amyloid Imaging, <a href="http://www.worldeventsforum.com/hai/">link</a></td>
<td>Miami, Florida, USA</td>
</tr>
<tr>
<td>15-16 Feb 2018</td>
<td>8th International Conference on Pharmacoconomics of Alzheimer’s Disease (IPECAD), <a href="www.ipecad.org/">link</a></td>
<td>Paris, France</td>
</tr>
<tr>
<td>22-23 Feb 2018</td>
<td>11th International Conference on Vascular Dementia, <a href="http://vasculardementia.conferenceseries.com/">link</a></td>
<td>Paris, France</td>
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<tr>
<td>1-3 March 2018</td>
<td>Nutrition and maintaining functions with aging (IANA 2018)</td>
<td>Miami, USA</td>
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<tr>
<td>15-18 March 2018</td>
<td>AAT-AD/PDTM Focus Meeting on Advances in Alzheimer’s and Parkinson’s Therapies</td>
<td>Torino, Italy</td>
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<tr>
<td>22-25 March 2018</td>
<td>12th World Congress on Controversies in Neurology (CONy)</td>
<td>Warsaw, Poland</td>
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<tr>
<td>7-11 July 2018</td>
<td>11th FENS Forum of Neuroscience, <a href="http://www.forum2018.fens.org/">link</a></td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>26-29 July 2018</td>
<td>33rd International Conference of Alzheimer’s Disease International, <a href="https://www.alzdiscovery.org/events/event/18th">link</a></td>
<td>Chicago, USA</td>
</tr>
<tr>
<td>3-6 October 2018</td>
<td>Croatian Congress on Alzheimer’s Disease with International participation, CROCAD-18</td>
<td>Novigrad, Croatia</td>
</tr>
<tr>
<td>Date/Year</td>
<td>Event Description</td>
<td>Location</td>
</tr>
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<tr>
<td>29-31 October 2018</td>
<td>28th Alzheimer Europe Conference “Making dementia a European priority”</td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>22-25 October 2019</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague, Netherlands</td>
</tr>
</tbody>
</table>

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

Alzheimer Europe Board:
Chairperson: Iva Holmerová (Czech Republic); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: James Pearson (UK - Scotland); Honorary Treasurer: Maria do Rósario Zincke dos Reis (Portugal). Members: Stefanie Becker (Switzerland), Helen Rochford-Brennan (Ireland), Marie-Odile Desana (France), Sabine Henry (Belgium), Sabine Jansen (Germany), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Štefanija Lukič Zlobec (Slovenia).

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27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017
www.alzheimer-europe.org/conferences  #27AEC