I hope everyone who joined us at our Annual Conference in The Hague has returned home energised by the event and by the valuable connections it helped to make. I also hope you enjoyed the latest edition of our Dementia in Europe magazine, which was included in delegates’ bags and is now available on our website. We have had a very busy month and are still hard at work in the aftermath of the conference – our most successful one yet, with close to 1,000 delegates. We have received great feedback and I want to thank everyone for being so positive and for being so active on social media - the overall statistics are impressive, with over 25 million tweet impressions for #29AEC!

Congratulations to the winners of the poster awards: Gillian Council, Thea Debono, Marjolein Scholten and Monika Wilhelmi. Last but not least, thank you to our co-hosts at Alzheimer Nederland for a fantastic collaboration and great team work. Next year, we head to Bucharest for #30AEC!

To coincide with our conference, we were also brought together the members of our ethics working group on inclusive research and held our Annual General Meeting. 33 of our 35 full members were represented - a great turnout! Our INTERDEM colleagues held their annual meeting in The Hague as well and I was honoured to be invited to speak, as part of the network’s 20th anniversary celebrations. The Neuronet project was also heavily featured at #29AEC and showcased the entire portfolio of neurodegeneration projects of the Innovative Medicines Initiative.

Aside from events in The Hague, this month saw a very important announcement from Biogen about its plan to file for FDA regulatory approval for aducanumab, based on new analysis of its two clinical studies. Full results will be presented at the December CTAD conference and we will be following developments on this potentially ground-breaking announcement very closely.

On the policy front, we have great news from Spain, where the Government has approved the National Alzheimer’s Plan. Congratulations to our colleagues at Confederación Española de Alzheimer and Fundación Alzheimer España who have worked hard to achieve this. Rather less positive is the news from Belgium, which is considering stopping reimbursing existing dementia drugs. This controversial move was made by France in 2018. The proposed measure in Belgium is rightly being contested by the Alzheimer Liga Vlaanderen and the Ligue Alzheimer.

To end on a high note, I would like to extend a warm welcome to two new members of the European Alzheimer’s Alliance, MEPs Sergei Stanishev and Manuel Pizarro. Their support brings the total number of members to 93. We appreciate their support and hope to see them at our upcoming lunch debate in Brussels, on 10 December.

Jean Georges
Executive Director
ALZHEIMER EUROPE

12 September: Dianne Gove presents Alzheimer Europe’s 2018 ethics report on intercultural care for “Dementia and Migration” webinar

On 12 September 2019, Dianne Gove, Director for Projects, presented Alzheimer Europe’s 2018 report on “The development of intercultural care and support for people with dementia from minority ethnic groups”, during a webinar on the topic of “Dementia and Migration”. Gabriele Kreutzner and Sümeyra Öztürk from Demenz Support Stuttgart also presented the project “DeMigranz” during the webinar, which was part of a series organised by the European Foundations’ Initiative on Dementia (EFID).

Participating practitioners at the EFID webinar of 12 September discussed daily challenges related to the work on dementia and migration.


Watch the recording of the webinar, here: https://youtu.be/GHKRatLn9kg

21 October: European Working Group of People with Dementia involved in RADAR-AD website section on Patient Engagement

This month, the RADAR-AD project, in which Alzheimer Europe is a partner, has launched a Patient Engagement section on its website. The section includes information about the Patient Advisory Board (PAB), which is composed of members of the European Working Group of People with Dementia (EWGPWD) and supporters. There is a “core” group of six, which is more involved, and they are featured on the website. They are: Helen Rochford-Brennan, Chris Roberts and Stefan Eriksson (all three are EWGPWD members). The other three “core” members are Janni (Stefan’s daughter and supporter), Jayne (Chris’ wife and supporter), and Nélida Aguiar (EWGPWD member Idalina Aguiar’s daughter and supporter).

The sections were developed by Alzheimer Europe and members of the core PAB, with input from the other members of RADAR-AD’s work package 3. The PAB was set up in March 2019, since when the members and the core group have done a lot of work, which is featured on the website. You can see the RADAR-AD website section on Patient Engagement, here: https://www.radar-ad.org/why-and-how

23 October: 31st edition of Dementia in Europe magazine published

We are pleased to present the 31st edition of our Dementia in Europe magazine. This edition, published in time for our Annual Conference in The Hague, provides an update on our efforts to make dementia a policy priority in Europe. We share progress made in reconvening the European Alzheimer’s Alliance, a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament. Two new EU-funded projects in which Alzheimer Europe is actively involved, Alzheimer’s Disease Detect and Prevent and VirtualBrainCloud, are also presented and members of our ethics working group discuss Alzheimer Europe’s report on making services and support for people with dementia appropriate for people from all ethnic communities.

The Policy Watch section presents a “who’s who” of some of the key leaders and decision-makers in the EU. It also includes an update on the Governmental Expert Group on Dementia, which met for the second time in June 2019. We take a look at the ins-and-outs of data-sharing in clinical research projects and the section concludes with a piece about the policy outcomes of a recent Spominčica - Alzheimer Slovenija conference.

The Dementia in Society section takes a look at the outcomes of policy campaigning at local and national levels. Then, Debbie Abrahams MP, Co-chair of the UK Government’s All Party Parliamentary Group (APPG) on Dementia, reveals some of the key findings of the group’s report, “Hidden no more: Dementia and disability”. In Iceland, a new working group of people with dementia was formed at the start of the year. You can read about the group’s aims and progress made so far. Finally, project officers Angela Bradshaw and Cindy Birck look into the potential benefits of gene therapy for Alzheimer’s disease (AD).

This 31st edition of Dementia in Europe is our Annual Conference edition and the final section shines a spotlight on the Netherlands and on Alzheimer Nederland. Alzheimer Nederland co-hosted the 29th Alzheimer Europe Conference “Making valuable connections” (#29AEC) in The Hague. As well as looking at the history and work of our co-hosts, this section also includes an interview with people living with dementia who share their reflections following the Dementia Event – a national gathering for and by people with dementia. We are
also delighted to have an interview with the Dutch Health
Minister, as well as an update on the country’s national
dementia strategy - the Deltaplan Dementie.
In addition to the magazine, we have published a supplement
on clinical trials.
You can buy the magazine via our E-shop: http://alzheimer-
europe.org/Publications/E-Shop.
Past issues can be freely downloaded here: http://alzheimer-
europe.org/Publications/Dementia-in-Europe-magazines

23 October: Alzheimer Europe holds its 2019 Annual Meeting in The Hague

Prior to its Annual Conference (#29AEC) in The Hague, Alzheimer Europe held a Board meeting on 22-23 October and an Annual General Meeting (AGM) on 23 October. 33 out of 35 full member organisations were in attendance or represented at the AGM, at which Alzheimer Europe celebrated its achievements in 2018 and shared its plans for 2020. Some of the organisation’s main achievements from 2018 were:

1. carrying out a mapping exercise of national working groups of people with dementia and providing a report with the results, as well as identifying good practices
2. reinstituting the European group of governmental experts on dementia and organising a first meeting of the group, with representation from 17 national ministries, the European Commission, the OECD and the World Health Organization
3. publishing the 2018 Dementia in Europe Yearbook with a comparison of 21 national dementia strategies in European countries
4. developing a report on intercultural care and support for people with dementia from minority ethnic groups as part of its European Dementia Ethics Network, and
5. publishing the results of a survey of 1,409 carers’ experiences of a diagnosis in the Czech Republic, Finland, Italy, the Netherlands and the United Kingdom (Scotland) in a report and publishing a scientific article in the International Journal of Geriatric Psychiatry thanks to an educational grant from Roche.

The meeting also focused on the recent European Parliament elections and looked at ways to try and ensure dementia is a priority of the next EU Health and Research Programmes.
Policy Officer Owen Miller presented some preliminary findings from the European Dementia Movement survey, carried out this year. He was pleased to share that, based on responses from 55% of member organisations, the network already includes 592 local and regional branches, 3,910 staff members, and that its 2018 expenditure was approximately EUR 220 million.

23 October: Ethics working group on inclusive research meets for second time in The Hague

The second meeting of Alzheimer Europe’s working group on ethical challenges affecting the involvement of people with dementia in research was held on 23 October in The Hague. The working group, which was chaired by Dianne Gove, brought together experts from Belgium, the Netherlands, Luxembourg, Italy, the United Kingdom and Sweden.
During the day, members of the working group participating in this meeting (Saloua Berdai Chaouni, Ann Claeys, Krista Tromp, Jenniffer van den Broeke, Corinna Porteri, Mohammed Akhlak Rauf, Karen Watchman and Ingrid Hellström) went through the latest draft and debated key issues on the topic of “overcoming ethical challenges affecting the involvement of people with dementia in research”, in the context of Public and Patient Involvement (PPI) and as research participants. The emphasis was on inclusive research, on understanding multiple and intersecting characteristics/identities and on challenging barriers to the involvement of a diverse group of people with dementia in research.
The final report, which will be a discussion paper containing recommendations, will be targeted at researchers, funders and ethics committees and will be available at the beginning of next year (2020).

23-25 October: Alzheimer Europe holds its most successful Annual Conference yet

The 29th Alzheimer Europe Conference (#29AEC) “Making valuable connections” was held in The Hague on 23-35 October 2019. 954 participants from 46 countries attended the conference, which boasted 287 speakers and 241 poster presentations, sharing their research, projects and experiences in an atmosphere of collaboration.
Iva Holmervová, Chairperson of Alzheimer Europe, opened the conference, extending a special welcome to the 36 people
with dementia who were among the delegates, as well as their supporters. Following Iva Holmerová’s opening speech, delegates were also welcomed by Gerjoke Wilmink, Executive Director of Alzheimer Nederland; Myrrha Vernooij-Dassen, Chairperson of INTERDEM (Early detection and timely INTERvention in DEMentia); Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD); Kavita Parbhudayal, Deputy Mayor of The Hague; and Theo van Uum, Director of Long-term Care at the Dutch Ministry of Health, Welfare and Sport.

Gerjoke Wilmink referred to Alzheimer Nederland’s 35th anniversary, and drew delegates’ attention to the organisation’s role as one of the co-founders of Alzheimer Europe and as hosts and co-organisers of the 1st Alzheimer Europe Conference, in Friesland. She also mentioned Alzheimer Nederland’s national “Dementia Event”, held earlier the same day. Myrrha Vernooij-Dassen emphasised the importance of taking responsibility to move the field forward, mentioning three ways in which this could be done: developing more individualised interventions, based on a better understanding of ways in which people are affected by dementia, and of the mechanisms of change underlying effective interventions; developing models of co-production in dementia research and in implementation of findings; and mentoring and educating the next generation of dementia care researchers. Next, Helen Rochford-Brennan addressed delegates from her perspective as a person living with dementia, highlighting the value of the voice of people living with dementia, in particular drawing attention to the benefits of patient and public involvement (PPI). She also stressed that researchers need to branch out beyond their current pool of contacts, to move things forward. Kavita Parbhudayal, Deputy Mayor of The Hague, responsible for Care, Youth and Public Health took the floor next, extending a warm welcome to delegates from her perspective as a person living with dementia who were among the delegates, as well as their supporters. Following Iva Holmerová’s opening speech, delegates were also welcomed by Gerjoke Wilmink, Executive Director of Alzheimer Nederland; Myrrha Vernooij-Dassen, Chairperson of INTERDEM (Early detection and timely INTERvention in DEMentia); Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD); Kavita Parbhudayal, Deputy Mayor of The Hague; and Theo van Uum, Director of Long-term Care at the Dutch Ministry of Health, Welfare and Sport.

“What next? Post-diagnostic support” was chaired by Gerjoke Wilmink (Netherlands) and opened with a presentation on “Improving the diagnosis, post-diagnostic support, care and inclusion of people with dementia: the findings of the 2nd European Joint Action on Dementia”, given by Geoff Huggins, the Director of the NES Digital Service. The second speaker was je van der Flier, head of clinical research at the Alzheimer Center Amsterdam at Amsterdam UMC, presenting “Research leading to better diagnosis and care in memory clinics – findings from the ABIDE project” (ABIDE = Alzheimer’s Biomarkers In Daily practice). Henry Brodaty, Professor of Ageing and Mental Health, at the University of New South Wales (UNSW Sydney) was last to take the floor in this session, delivering a presentation on “After the diagnosis... what next? Post-diagnostic support for people with dementia and their families”. The first plenary ended with an award ceremony. ZonMw - The Netherlands Organisation for Health Research and Development, gave an award to the ABIDE project. The award was presented to Wiesje van der Flier, principal investigator, by Henk Smid, Director of ZonMw and Saskia Danen, patient representative from Alzheimer Nederland. The project was funded by ZonMw and Alzheimer Nederland. A short video about the project was also shown.

“eHealth as effective support for family carers”, she emphasised the need for a more balanced view of dementia and its impact. While the dominant view on dementia places much emphasis on suffering and loss and while there is no cure for the disease, it does not mean that people with dementia are without hope, or lost. “There can certainly be room for positive experiences and a meaningful life despite the illness”, she said, and eHealth can contribute to this. It enables a more affordable and personalised delivery of care by increasing socio-economic inclusion, patient empowerment, and access to services and information in daily life. She stressed that the main hindrance to the use of eHealth interventions in daily dementia practice is a lack of research into its implementation. This, coupled with a number of implementation barriers, needs to be overcome in order to move forwards.

On 24 October, the first plenary session on “Diagnosis and post-diagnostic support” was chaired by Gerjoke Wilmink (Netherlands) and opened with a presentation on “Improving the diagnosis, post-diagnostic support, care and inclusion of people with dementia: the findings of the 2nd European Joint Action on Dementia”, given by Geoff Huggins, the Director of the NES Digital Service. The second speaker was je van der Flier, head of clinical research at the Alzheimer Center Amsterdam at Amsterdam UMC, presenting “Research leading to better diagnosis and care in memory clinics – findings from the ABIDE project” (ABIDE = Alzheimer’s Biomarkers In Daily practice). Henry Brodaty, Professor of Ageing and Mental Health, at the University of New South Wales (UNSW Sydney) was last to take the floor in this session, delivering a presentation on “After the diagnosis... what next? Post-diagnostic support for people with dementia and their families”. The first plenary ended with an award ceremony. ZonMw - The Netherlands Organisation for Health Research and Development, gave an award to the ABIDE project. The award was presented to Wiesje van der Flier, principal investigator, by Henk Smid, Director of ZonMw and Saskia Danen, patient representative from Alzheimer Nederland. The project was funded by ZonMw and Alzheimer Nederland. A short video about the project was also shown.
The second plenary session, which took place later the same day, focused on “Technology and e-health” and was chaired by Charles Scerri (Malta). The opening presentation, by Wijnand IJsselsteijn, Professor of Cognition and Affect in Human-Technology Interaction at Eindhoven University of Technology, looked at “Warm technology and co-design with people with dementia”. Dag Aarsland took the floor next, for his presentation “What role for ‘wearables’ in the detection of people at risk of dementia and in monitoring disease progression?”. Dag Aarsland is Head of Department of Old Age Psychiatry at the Institute of Psychiatry, Psychology and Neuroscience at King’s College London. His presentation included an introduction to the RADAR-AD project (Remote Assessment of Disease And Relapse - Alzheimer’s Disease), in which Alzheimer Europe is a partner. Marco Blom, Scientific Director and Head of National Services at Alzheimer Nederland, was up next. He gave a presentation on “Identifying the needs and views of carers of people with dementia: the online platform of Alzheimer Nederland”. Emma Ferguson-Coleman, who is a Deaf research associate within the Social Research with Deaf People (SORD) group at the University of Manchester, closed the second plenary session, giving delegates some insight into “Navigating everyday challenges of life-story work with Deaf sign language users with dementia”.

The third plenary session took place on 24 October. “Making our societies more dementia-inclusive” was chaired by Jim Pearson (Scotland, UK) and opened with a presentation by
Bernd Heise, a member of the EWGPWD, who shared his expectations from dementia-inclusive communities, with the audience. Mohammed Akhlak Rauf, Founder & Director of Meri Yaadain CIC, used his presentation to discuss “Embedding intercultural care to support dementia care amongst minority ethnic communities”. Julie Meerveld, Manager of Regional Support and Advocacy at Alzheimer Nederland, presented “The Dutch National Programme for a dementia-inclusive society – a collaboration involving national and local authorities, associations and companies”. Elina Suzuki, an Advisor to the Director of Employment, Labour and Social Affairs at the Organisation for Economic Co-operation and Development (OECD), was the final speaker at this plenary session. She presented on the state of dementia care and dementia-friendly initiatives across OECD countries.

The last plenary session posed the question “How can research lead to better prevention?” and was chaired by Marco Blom (Netherlands). It began with a presentation on “Multidomain lifestyle interventions to prevent cognitive impairment and dementia: From FINGER to World-Wide FINGERS”, given by Tiia Ngandu, Research Manager and leader of the Dementia Prevention group at the Finnish Institute for Health and Welfare in Helsinki. Next, Meike Vernoij, Professor of Population Imaging at the Erasmus University Medical Center, discussed “The role of imaging in epidemiological studies: findings of the Rotterdam Scan Study”. Sebastian Köhler, Associated Professor at the School for Mental Health and Neuroscience at Maastricht University and Senior Researcher at the Alzheimer Centrum Limburg at Maastricht UMC+ used his session to stress the importance of immediate action, where dementia prevention is concerned.

The second keynote presentation was delivered by Debby Gerritsen, Professor of Wellbeing among Frail Elderly People and People with Chronic Illnesses in Long-term Care, at the Department of Primary and Community care of the Radboud University Medical Center in Nijmegen. Her presentation, “Empowerment and wellbeing among people with dementia”, emphasised that the healthcare sector and healthcare professionals need to focus more on people’s strengths and their need to feel useful, rather than on what they are no longer capable of. She also highlighted the importance of specifying what empowerment means and includes for people with dementia, and how it can be shaped in the relationship between the individual and the people in their environment.

The three-day conference also featured 32 parallel sessions on diverse topics for delegates to choose from. The three-day conference was formally closed by Iva Holmerová and Geert van Laer, who thanked speakers and poster presenters for sharing their research, projects and experiences. Iva Holmerová thanked Alzheimer Nederland for co-hosting the 29th Alzheimer Europe Conference and said a special thank you to the various sponsors of the conference: The European Union Health Programme (2014-2020), Roche, Eisai, Biogen, Janssen, Amgen, Otsuka, the Alzheimer Europe Foundation, The Hague Convention Bureau, The City of The Hague, Skyteam, Lufthansa.

She then invited all delegates to mark the dates of the next Alzheimer Europe Conference (#30AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 20 to 22 October 2020. The 29th AE Conference in The Hague received funding under an operating grant from the European Union’s Health Programme (2014-2020).

24-25 October: Special symposia held during #29AEC in The Hague

On 24 and 25 October 2019, during the 29th Alzheimer Europe Conference (#29AEC), several special symposia were held, including:

**European Working Group of People with Dementia (EWGPWD): “Inspired by connections”**

Members of the EWGPWD discussed how people with dementia connect to their communities and looked at the importance of these connections for maintaining a meaningful and full life and for continuing to contribute to society. One of the areas mentioned several times during the session was transport. Members of the group feel strongly that this is a key factor in living well with dementia, as it affects whether or not they can maintain social connections, access medical appointments and other important events, and remain as independent as possible.

The symposium was chaired by Helen Rochford-Brennan (Ireland). Angela Pototschnigg (Austria), Stefan Eriksson (Sweden) and Chris Roberts (United Kingdom) gave presentations during the session, while Tomaz Gržinič (Slovenia), Petri Lampinen (Finland), Idalina Aguiar (Portugal) and Geert van Laer (Belgium) made their contributions via the medium of video clips filmed at the group’s most recent meeting. The group hopes that their short speeches and video clips will inspire people with and without dementia, to find new ways to connect with each other.

The four videos are now available on Alzheimer Europe’s YouTube channel: www.youtube.com/AlzheimerEurope
Clinical trials in Alzheimer’s disease

This Special Symposium, which was sponsored by a grant from Janssen, focused on the past, present and future of clinical trials in Alzheimer’s disease. To complement the Special Symposium, conference bags included a copy of the Clinical Trials Supplement, accompanying the October 2019 edition of our Dementia in Europe magazine. The Symposium was chaired by our Executive Director, Jean Georges.

The speakers were Brian Inglis, Simon Lovestone and Philip Scheltens. Brian Inglis, a Scottish participant in the EPAD (European Prevention of Alzheimer’s Disease) longitudinal cohort study, spoke about his experiences of this clinical study and about what motivated him to participate in research. Simon Lovestone, Professor of Translational Neuroscience at the University of Oxford, and one of the academic partners of the EPAD consortium, took stock of what we have learned from unsuccessful clinical trials for Alzheimer’s disease (AD). Philip Scheltens, Director of the Alzheimer Center Amsterdam at Amsterdam UMC, discussed new avenues for AD research.

Data sharing in dementia research

This Special Symposium, which was sponsored by a grant from Gates Ventures, was chaired by Angela Bradshaw, Project Officer at Alzheimer Europe. The session aimed to provide a broad overview of the state-of-the art on health data sharing, from clinical research to data protection and, finally, the views of patients.

The speakers were Pieter Jelle Visser, Manuela Mayrhofer and Nicola Bedlington. Pieter Jelle Visser, Associate Professor at the Alzheimer Center of Amsterdam University Medical Center, highlighted the lack of effective drug therapies for Alzheimer’s disease (AD) and underlined the importance of accessing large clinical datasets to speed up research. He discussed a number of recent initiatives aimed at facilitating data sharing, including Dementias Platform UK (DPUK), the Netherlands Consortium of Dementia Cohorts and the European Medical Information Framework - Alzheimer’s disease (EMIF-AD) project. Manuela Mayrhofer of the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) focused on the legal frameworks that underpin responsible data sharing in health research. She outlined one of the central ambitions of the General Data Protection Regulation (GDPR): to strike a balance between the protection of individuals’ personal data, whilst also enabling the free movement of this personal data. She also looked at the scope of the GDPR and discussed some recent data scandals, outlining how the EU are handling these situations to ensure data is held, processed and shared securely. Nicola Bedlington of the European Patients’ Forum (EPF) shared the views of patients and the general public on data sharing, presenting the work that the EPF has undertaken with its member organisations. She introduced delegates to the “Data Saves Lives” initiative, a multi-stakeholder platform hosted by the EPF that aims to provide up-to-date information about health data in an accessible format.

The achievements of the 2nd European Joint Action on dementia

Since its inception in 2016, the 2nd European Joint Action on dementia – “Act on Dementia” has been promoting collaboration among EU Member States to improve the lives of people living with dementia and their carers. Act on Dementia comes to a close this year and this symposium was an opportunity to showcase its results and findings.

The symposium was jointly presented by Geoff Huggins, Director of the NES Digital Service (which is part of NHS Scotland and has responsibility for developing Scotland’s National Digital Platform); David Nuttall, Department of Health and Social Care, UK Government; Pierre Krolak-Salmon, Institut du Vieillissement, Lyon, France; Nicola Vanacore, National Institute of Health, Italy; Oyvind Kirkevold, Aldring og Helse, Olso, Norway; Mireia Espallargues and Vicky Serra-Sutton, Avaluacio Sanitaries de Catalunya, Spain; and Gillian Barclay, Scottish Government, Edinburgh, UK.

Alzheimer Nederland symposia

Alzheimer Nederland, co-host of the 29th Alzheimer Europe Conference, held three special symposia, during the event.

The first was a special edition of an “Alzheimer Café”. Famous author Nicci Gerrard (pictured, centre) was interviewed about her latest book, “What Dementia Teaches Us about Love”. The book gained a lot of attention in the media and among the general public. After her own father dying from dementia, she set out to explore the illness. Her book is an attempt to understand and is filled with stories, both moving and optimistic, from people living with dementia to those planning for the end of life, from the scientists unlocking the mysteries of the brain to the therapists using art and music to enrich the lives of affected people; from the
campaigners battling for greater compassion in care to the families trying to make sense of dementia. The book explores memory, language, identity, ageing and the notion of what it truly means to care.

The second Alzheimer Nederland symposium focused on the Netherlands’ national dementia strategy, the “Deltaplan Dementie”. Speakers at the session were Philip Scheltens (Deltaplan Dementie), Marianne De Visser (ZonMW Program Committee), Dinant Bekkenkamp (Alzheimer Nederland) and Karlijn Kwint (Vilans). All four speakers are closely involved in the implementation of the Deltaplan. The Deltaplan was launched in 2012, to address and manage the growing problem of dementia in the Netherlands. This second national strategy was launched by the Ministry of Health, Welfare and Sports and comes to an end next year. The Deltaplan Dementie is also a cooperative network with member organisations in the fields of science, education, healthcare, healthcare insurance and business, as well as patient organisations.

The third and final symposium was “Innovations in dementia care in the Netherlands”. The speakers were Bere Miesen (The Hague), Bernadette Willemsen (Reigershoeve), Simone De Bruin (RIVM – Netherlands National Institute for Public Health and the Environment) and Willem Draaisma (Participe). The Dutch innovations examined during this session were: the “Alzheimer Cafe”, new developments in small-scale housing and care farms; and “Odensehuizen” (a Danish creation, picked up and developed into a new facility in the Netherlands).

25 October: Alzheimer Europe Foundation awards prizes for #29AEC posters

At Alzheimer Europe’s 29th Annual Conference (#29AEC), the Alzheimer Europe Foundation awarded a prize to the top four poster presentations, as voted by conference participants via an online survey. For each full day of the conference (24 and 25 October), a runner-up and a winner were selected:

- 24 October runner-up: Gillian Council for “The Tipi Project: connecting people to nature”
- 24 October winner: Thea Debono for “The Effects of Animal-Assisted Therapy (AAT) on the behaviour of older persons living with dementia within a Maltese Long Term Care (LTC) facility”
- 25 October runner-up: Marjolein Scholten for “Green Care Farms, a new old housing concept?”
- 25 October winner: Monika Wilhelmi for “Hands-on Dementia. The interactive way to understand dementia. A method to feel the symptoms of dementia”.

Congratulations to all four of them! Winners will receive EUR 750 and runners-up get EUR 250.

The Alzheimer Europe Foundation would like to thank all conference delegates who voted and all poster presenters for their excellent contributions at the conference.

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Alzheimer Europe networking

On 16-19 September (Copenhagen Denmark), Owen attended the 69th session of the WHO Regional Committee for Europe.

On 30 September (Brussels, Belgium) Owen attended the European Commission’s “EU Health Programme High Level Conference.”

On 1-2 October (Cologne, Germany), Jean and Chris attended the Models of Patient Engagement for Alzheimer’s Disease (MOPEAD) project’s 5th and final General Assembly meeting.

On 7 October (Brussels, Belgium), Jean, Angela and Chris attended the 3rd Neuronet consortium meeting.

On 8 October (Milan, Italy), Jean attended a meeting of the BBDiag project and present the findings of Alzheimer Europe’s Carers’ survey.

On 10-11 October (Barcelona, Spain), Cindy and Jean attended the AMYPAD General Assembly Meeting.

On 11 October (London, United Kingdom), Jean attended the sustainability working group of the EPAD project.

On 16 October (Brussels, Belgium) Owen attended the MEP Alliance meeting entitled “Mental Health The EU and mental health – priorities and possibilities for action”.

On 21-22 October (Amsterdam, Netherlands), Jean attended the meeting of the European Alzheimer’s Disease Consortium.

On 23 October (The Hague, Netherlands), Dianne and Ana attended a meeting for a project proposal.

On 23 October (The Hague, Netherlands), Ana attended the INTERDEM meeting.

On 23 October (The Hague, Netherlands), the Alzheimer Europe Board met.

On 23 October (The Hague, Netherlands), Alzheimer Europe held its Annual General Meeting.

On 23 October (The Hague, Netherlands), Ange and Chris attended the Neuronet Scientific Coordination Board meeting.

On 23 October (The Hague, Netherlands), Dianne attended the second meeting of Alzheimer Europe’s ethics working group.

On 24 October (The Hague, Netherlands), Dianne attended the DZNE EU-atlas on dementia & migration workshop.

From 23 to 25 October (The Hague, Netherlands), Alzheimer Europe organised its 29th Annual Conference “Making valuable connections” with Alzheimer Nederland.
Researchers presented the work of the RADAR-AD project at the exhibition “Science is Wonderful!” on 25 and 26 September, which aimed at bringing science closer to the general public.

“Science is Wonderful!” was part of the Research and Innovation Days organised by the European Commission in Brussels. The exhibition targeted everyone passionate about science, research and innovation, ranging from education professionals, researchers, students, school children, the media and the general public. It presented an invaluable opportunity to showcase present scientific research to the public and engage wider audiences with scientific studies. The exhibition spanned a broad variety of EU-funded research projects, from moon rovers to bioplastic and others.

At the event, RADAR-AD was represented by Marijn Muurling (pictured, right), PhD student at the Amsterdam UMC and part of the clinical study, interested in how new technologies can help people with Alzheimer’s disease. Ms Muurling explained the goal, research and methods of RADAR-AD to the attendees. Together with Robbert Harms, a machine learning expert from Altoida Inc., they showed medical devices, such as the Altoida app. This is an app on a tablet, which includes a motor task and augmented reality task that screens people for early stage AD. Ms Muurling and Mr Harms explained how the project will use the application within the RADAR-AD study - namely, as a digital biomarker for visuospatial and executive function and spatial memory.

Moreover, attendees had the opportunity to interact with and app called “Mezurio”, which measures cognition. They were able to play several brain-training games on it and learn how these are applied within RADAR-AD’s research. Also, real-time data from a “Fitbit” smartwatch was shown, which is used in the RADAR-CNS study as well. RADAR-AD uses this smartwatch to measure sleep, movements and heartbeat during activities of daily living. Lastly, a video of a “smart home” in Greece was shown, which presents the idea of a specially-designed home, adapting to the needs of a person with Alzheimer’s dementia, thus supporting them to live more independently. This “smart home” will be used within RADAR-AD’s research as part of a small sub-study.

In addition to school children, researchers and families, representatives from partner and funder organisations also interacted with the project team and the devices being demonstrated. Among them was Pierre Meulien, Executive Director of the Innovative Medicines Initiative (IMI). IMI provides funding to RADAR-AD.

The researchers were happy to receive a positive response to the work done within RADAR-AD. Marijn Muurling commented:

“They were all very enthusiastic and curious about the devices and data, especially when they heard that they could play a game.”

2 October: The Models of Patient Engagement for Alzheimer’s Disease project gathers for final General Assembly meeting in Cologne

On 1 to 2 October, the MOPEAD consortium held its final General Assembly meeting in Cologne.

The main aim of the meeting was to reflect on outstanding actions needed for the successful completion of the project and to reflect on the project’s progression. This included planification of relevant publications about the project’s scientific findings.

The meeting was chaired by Mercè Boada (Project Coordinator, Fundació ACE) and Laura Campo (Project Leader, Eli Lilly). After a brief introduction by the host Frank Jessen (University Clinic of Cologne) and opening remarks by the project leadership, presentations and subsequent discussions kicked off.

The first day started with an overview of the necessary actions to ensure timely reporting. The following discussion focused on the brain imaging data which will be stored and validated at a partner site in Sweden.

Following on from this discussion, the partners from GMV provided an overview of the results of the different approaches the project had explored to identify people with mild cognitive impairment and dementia (providing an online test, open house days at a memory clinic, engaging with general practitioners but also diabetologists).

After that, the communication team co-lead provided an overview of some of their activities, including the project’s
participation in a World Alzheimer’s Month campaign on social media. The day concluded with a presentation about the Innovative Medicines Initiative by Elisabetta Vaudano.

On the second day, the partners presented mostly on topics which will be fully covered in future publications. These included:

- The technical features of the online testing
- Results from online testing (including costs per country in which media adverts were launched)
- A closing paper, bringing the main conclusions from the project together
- A paper on ethical issues and the opportunities of early diagnosis in the context of the project
- The open house days at memory clinics
- A survey with general practitioners on their attitudes towards early diagnosis of MCI and dementia
- Results from involving general practitioners in the screening of people with possible mild cognitive impairment respectively dementia
- An analysis on the cost effectiveness of each of the different approaches to identify people with mild cognitive impairment or dementia.

The day concluded with an overview and discussion on the timelines for the publication of the papers and subsequent closing remarks by the project leadership thanking each consortium partner for their dedication and good collaboration. Find out more about the project here: www.mopead.eu

7 October: Neuronet consortium meeting held at Johnson & Johnson headquarters in Belgium

On 7 October, Neuronet held its third consortium meeting at Johnson & Johnson headquarters in Diegem, Brussels. The consortium meeting aimed at providing an update on each of the five Neuronet work packages to the Neuronet consortium, coordinated by Synapse and led by Janssen. Attendees of the meeting included representatives from Alzheimer Europe, the UK National Institute for Health and Care Excellence (NICE) and several pharmaceutical companies (Roche, Eli Lilly, Janssen, Takeda and Sanofi).

As part of the consortium meeting, the following five work packages were discussed:

- **WP1 Project and impact analysis** (presented by Diana O’Rourke from NICE). This work package aims to profile Innovative Medicines Initiative projects in the neurodegenerative disease (NDD) area. WP1 is also collecting information on all NDD public-private partnerships worldwide. Consortium members discussed the progress on project data collection, which will form the backbone of a programme gap analysis.
- **WP2 Programme integration** (presented by Carlos Diaz from Synapse). This work package aims to support the integration of Neuronet NDD projects, creating a framework to support cross-project collaboration. After presenting an overview of the WP2 working groups on data sharing, sustainability, regulatory/HTA and patient privacy/ethics, discussions here focused on how Neuronet can encourage collaboration between NDD projects.
- **WP3 Tools and services** (presented by Nina Coll from Synapse). This work package aims to develop specific tools and services for areas where unmet needs have been detected. Discussions focused on the design, content of and access to a knowledge base (KB), which will be an online tool that brings together information on all Neuronet projects, including lists of publications, deliverables, project teams and timelines.
- **WP4 Dissemination & Outreach** (presented by Chris Bintener from Alzheimer Europe). This work package aims to promote synergy between project communication and dissemination activities, also acting as an ‘ambassador’ for the Neuronet portfolio. The Neuronet website and newsletter have been launched, as has a Twitter campaign publicising the projects and their objectives. Neuronet will hold four parallel sessions during the 2019 Alzheimer Europe Conference in The Hague where representatives of the different NDD projects will present.
- **WP5 Management & Sustainability** (presented by Sandra Pla from Synapse). This work package brings together all management and governance activities for the Neuronet consortium. Synapse provided the consortium with an update on deliverables, budget and the planning of following meetings, highlighting the upcoming IMI review of Neuronet.

10 October: The AMYPAD project holds its General Assembly meeting in Barcelona

On 10 and 11 October, the “Amyloid imaging to prevent Alzheimer’s disease” (AMYPAD) consortium gathered for its General Assembly meeting in Barcelona, Spain. The first day placed the emphasis squarely on the two AMYPAD sub-studies. A first session was dedicated to the Diagnostic and Patient Management Study (DPMS). As initially planned, eight European sites received the approval for the diagnostic study...
and are now active and running. The diagnostic study has reached the 50% recruitment mark with over 500 research participants recruited and over 300 amyloid PET scans performed. After that, a session was dedicated to the Prognostic and Natural History Study (PNHS). Five Wave-1 sites received approvals and are actively recruiting. In parallel, several Wave-2 sites have received approvals and have initiated their activation process. As of 14 October 2019, 548 subjects have been informed of which 310 consented. A total of 231 participants have been scanned so far.

Analysis of the data acquired in both studies has also started. The first and preliminary results were presented including the process for data harmonisation and request. A keynote lecture was then delivered on the Alzheimer’s disease drug development pipeline. Andrew Stephens gave a comprehensive overview of the recent clinical trial failures and agents currently being developed for the treatment of Alzheimer’s disease.

On the second day, the AMYPAD consortium gathered for a scientific session giving the stage to nine AMYPAD researchers to showcase their work. There was also sessions on the AMYPAD budget, sustainability and ethics. Cindy Birck continued with a talk on the AMYPAD communications. AE contributes as co-lead to the communication and dissemination activities for the AMYPAD project. Before the wrap-up session, the new IMI NEURONET project was presented along with the opportunities for AMYPAD. Gill Farrar and Frederik Barkhof then recapitulated the meeting’s discussions after which the meeting ended. Executive Director Jean Georges and Project Officer Cindy Birck attended the meeting.

23 October: INTERDEM network celebrates 20 years at its Annual Meeting in The Hague

INTERDEM is a network of researchers interested in psychosocial interventions. It is made up of 217 researchers and academics with different professional disciplines, spread across 23 countries (19 of which are in Europe). The INTERDEM network held its fully booked Annual Meeting on 23 October 2019, prior to the 29th Alzheimer Europe Conference (#29AEC), with 110 researchers attending. There were two sessions, the first of which was reserved for participants to share news of their ongoing research activities, and gave them the opportunity to give and receive feedback, as well as exploring opportunities for further collaboration.

The second session, focused on “New insights in caregiving and community”. Speakers from Germany and The Netherlands addressed caregiving challenges, social health and the role of the community.

During the meeting the 20th anniversary of the INTERDEM network was celebrated with the participation of Jean Georges, Executive Director of Alzheimer Europe, which is a key partner of INTERDEM. Ana Diaz, Project Officer, also attended the INTERDEM Annual Meeting on behalf of Alzheimer Europe.

On 23 October (The Hague, Netherlands), Neuronet (Efficiently Networking European Neurodegeneration Research) convened the second meeting of its Scientific Coordination Board coinciding with Alzheimer Europe’s Annual Conference.

Neuronet’s high-level, overarching Scientific Coordination Board is formed by 15 leaders of Innovative Medicines Initiative (IMI) projects in the area of neurodegeneration. The Scientific Coordination Board is responsible for Neuronet’s strategic decision-making as well as the creation of specific Working Groups and Task Forces in which projects will be able to collaborate.

The day started with an update on Neuronet’s latest and future activities by project leads Carlos Diaz (SYNAPSE Research Management Partners) and Lennert Steukers (Janssen Pharmaceutica NV). This provided the Scientific Coordination Board with the opportunity to give feedback and to shape the future priorities for Neuronet.

The following discussions focussed on an online tool entitled the “Knowledge Base”, which will bring together project information in an easily accessible way for project leaders.

Further, the group discussed Neuronet’s working groups. The focus of each group is on a topic of common interest. Neuronet will form these groups by expert members from the different projects, and involve invited experts from related...
initiatives. The framework currently focuses on four key areas: Data sharing and re-use, HTA/regulatory interaction, Patient privacy and ethics as well as one on Sustainability.

After that, the members discussed past collaborations between projects and what difficulties they encountered as well as lessons learnt. This led to a subsequent dialogue on opportunities for new collaborations and tangible Neuronet results. Next, the group discussed current gaps in the research portfolio and how to address these. After that, the chairs wrapped up the meeting with a recapitulation of the days’ main conclusions as well as the next steps.

https://www.imi-neuronet.org/scientific-coordination-board/

25 October: EPAD opens up its data access system to the entire research community

The European Prevention of Alzheimer’s Dementia (EPAD) project, a highly innovative programme aiming to streamline the testing and development of preventative treatments for Alzheimer’s disease, has announced the upcoming release of its first wave of data, including the baseline data from the first 500 research participants (V500.0). Researchers will now have access to the EPAD Research Access Process, designed to give academic researchers and institutions from all over the world a way of accessing the data collected in the EPAD Longitudinal Cohort Study. Study data access will be provided via secure online tools in order to facilitate collaboration between people and teams with similar research aims.

At the 29th Alzheimer Europe Conference, in The Hague, Professor Craig Ritchie (pictured), EPAD Project Coordinator, explained the rationale of the EPAD V500.0 dataset and emphasised the transparency of the data set being used by the project team. He announced that the first data set (V500.0) will be available from 18 November and invited institutions from all over the world to begin the application process. This would allow applicants to register online and complete their request with all the accompanying information. Data workspaces containing the V500.0 data set will be live from 18 November.

For detailed information on the process for access, visit http://ep-ad.org/erap/

The V500.0 data release represents the first formal public data release from the EPAD project for use by institutions worldwide. It will assist researchers to describe and compare their findings as well as in systematic reviews and meta-analyses. In the chosen nomenclature (V500.0); V:version, “500” is the number of sequentially recruited research participants in each dataset and ‘.0’ refers to the study visit the dataset includes up (visit 0 refers to the baseline data). Each Data set will have a DOI (Digital Object Identifier) to reference the source of the data in subsequent publications:

doi:10.34688/epadlcs_v500.0_19.05.10

25 October: Neuronet convenes annual event on European research collaboration in Alzheimer’s disease and beyond

Neuronet, a coordination and support action funded by the Innovative Medicines Initiative (IMI), brings together 15 IMI consortium projects working on neurodegenerative disease, encompassing over EUR 290 million in research funding.

The Neuronet programme held four parallel sessions as part of the Alzheimer Europe conference on 24 and 25 October, showcasing projects that are working to improve our understanding, diagnosis and treatment of neurodegenerative disease.

The first parallel session was chaired by Lennert Steukers from Janssen, and was entitled “European research collaboration in Alzheimer’s disease and beyond”. The three speakers in this session introduced the work of the IMI on neurodegenerative disease (Elisabetta Vaudano, IMI), presented an overview of the Neuronet project (Carlos Diaz, Synapse Research Partners) and highlighted the importance of meaningful patient and public involvement in IMI research projects (Ana Diaz, Alzheimer Europe).

The second parallel session was chaired by Craig Ritchie, Director of the Centre for Dementia Prevention at Edinburgh University, and was entitled “From risk to dementia: Understanding disease progression and its causes”. In this session, leaders of the ADAPTED (Maria Eugenia Sáez), PHAGO (Angela Hodges) and AETIONOMY (Martin Hofmann-Apitius) projects presented their work on characterising some of the key molecular drivers of Alzheimer’s disease (AD), such as the ApoE genetic risk factor and the innate immune receptors CD33 and TREM2.

The third parallel session was chaired by Jacoline Bouvy of NICE and was entitled “Improving data access and the development of predictive models”. Four IMI projects were presented in this session: EQIPD (Malcolm Macleod), EMIF (Pieter Jelle Visser), ROADMAP (John Gallacher) and IM2PACT (Dominique Lesuisse.) The EQIPD project is developing a framework for improving research quality, aiming to improve the drug development pipeline, while the EMIF and ROADMAP
projects showcased the new platforms and tools they have developed to help researchers visualise and access clinical research data and real-world evidence. This session finished with a presentation on the IM2PACT project, which is working to understand the blood-brain-barrier in health and disease. The fourth Neuronet session was chaired by José Luis Molinuevo, Neuronet Scientific Coordination Board member, and was entitled “Diagnosis, patient engagement and trials”. AMYPAD (José Luis Molinuevo) and EPAD (Craig Ritchie), two sister projects of the IMI neurodegeneration portfolio, highlighted their achievements in using amyloid-PET scans to diagnose AD (AMYPAD), and in creating clinical trial registries and cohorts of people at risk of developing Alzheimer’s dementia (EPAD). The leader of the MOPEAD (Mercè Boada) project then presented the four patient engagement models that they are currently testing, aiming to improve early patient engagement in clinical trials. The final Neuronet session was brought to a close with a presentation on the RADAR-AD (Dag Aarsland) project, which is exploring how digital technologies can be used non-invasively to measure the progression of disability associated with AD.


EU project acknowledgement

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

AMYPAD - grant agreement 115952
EPAD - grant agreement 115736
MOPEAD - grant agreement 115985
Neuronet - grant agreement 821513
RADAR-AD - grant agreement 806999

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 93, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance (EAA):

Austria: Monika Vana (Greens/EFA), Belgium: Petra de Sutter (Greens/EFA); Frédérique Ries (ALDE); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE), Bulgaria: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Sergei Stanichev (S&D). Croatia: Tonino Picula (S&D); Ruža Tomašić (ECR). Cyprus: Costas MAVRIDES (S&D). Czech Republic: Tomáš Zdechovsky (EPP). Denmark: Margrete Auken (Greens/EFA); Christel Schaldemose (S&D); Heidi Hautala (Greens/EFA); Mia Petri Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). France: François-Xavier Bellamy (EPP); Dominique Bilde (ENF); Nathalie Colín-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffrey Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Anne Sander (EPP). Germany: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). Greece: Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyriki (EPP); Elissavet Vozemberg-Vroniidi (EPP). Hungary: Tamás Deutsch (EPP); Ádám Kósa (EPP). Ireland: MattCarthy (GUE/NGL); Giáran Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke ‘Ming’ Flanagan (GUE/NGL); Billy Kelleher (ALDE); Séan Kelly (EPP); Mairead McGuiness (EPP); Grace O’Sullivan (Greens/EFA). Italy: Isabella Adinolfi (EFDD); Brando Benifei (S&D); Patrizia Toia (S&D). Lithuania: Vilija Blinkевичute (S&D). Luxembourg: Charles Goerens (ALDE); Christophe Hansen (EPP); Tilly Metz (Greens/EFA); Nicolas Schmit (S&D); Isabel Wieseler-Santos Lima (EPP). Malta: Roberta Metsola (EPP); Alfred Sant (S&D). Netherlands: Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). Poland: Elżbieta Łukacijewska (EPP); Jan Olbrycht (EPP). Portugal: José Gumsào (GUE/NGL); Marisa Matias (GUE/NGL); Manuel Pizarro (S&D). Romania: Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (S&D). Slovakia: Ivan Stanefec (EPP). Slovenia: Franc Bogovič (EPP); Milan Brežeg (S&D); Tanja Fajon (S&D); Klemen Groselj (ALDE); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). Spain: Iñakun Bilbao Barandica (ALDE); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA). Sweden: Jytte Guteland (S&D); Peter Lundgren (EFDD). United Kingdom: Martina Anderson (GUE/NGL); Theresa Griffin (S&D); Jude Kirton-Darling (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Julie Ward (S&D).
EUROPEAN ALZHEIMER’S ALLIANCE

15 October: European Alzheimer’s Alliance welcomes two new members

Alzheimer Europe is delighted to announce that two Members of the European Parliament (MEPs) have agreed to join the European Alzheimer’s Alliance (EAA). The two new members are:

Sergei Stanishev (S&D, Bulgaria) & Manuel Pizarro (S&D, Portugal)

We thank Mr Pizarro and Mr Stanishev for their support and look forward to working with both of them through the course of the current term, to make dementia a European policy priority.

Follow us on Twitter

EU DEVELOPMENTS

15 October: EDF publishes open letter to EU Commission

The European Disability Forum (EDF), along with eight MEPs and eight other disability organisations, have published an open letter calling for the European Commission’s unit in charge of disability to be moved to the Secretariat-General, with a sole focus on disability and to be strengthened in terms of financial and human resources.

The letter highlights that issues of freedom of movement, transport, digitalisation, EU funds, anti-discrimination laws, employment strategies etc. all significantly impact on persons with disabilities.

It goes on to welcome the commitment within the remit of the Commissioner-designate for equality in fulfilling the obligations of the EU in relation to the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The letter also highlights that, as the EU as an organisation ratified the UNCRPD, the obligations cover all its competences, meaning the unit in charge of disability should act as a focal point to ensure compliance.

The letter can be read here: http://bit.ly/32Z2qUS

15 October: European Parliament holds hearing for Commissioners-designate

The European Parliament has concluded its hearings into the initial proposed Commissioners-designate, who will make up the College of Commissioners for the next five years. Between the 30 September and 8 October 2019, MEPs questioned candidates on their experience and policy priorities for the future roles.

Of particular relevance to the work and priorities of Alzheimer Europe, as well as the wider dementia policy agenda, were the following nominees and positions:
- Margrethe Vestager – Executive Vice President – Europe Fit for Digital Age
- Valdis Dombrovskis – Executive Vice President – An Economy that Works for People
- Věra Jourová – Vice President for Values and Transparency
- Dubravka Šuica – Vice President for Democracy and Employment
- Helena Dalli – Commissioner for Equality
- Mariya Gabriel – Commissioner for Innovation and Youth
- Sylvie Goulard – Commissioner for the Internal Market
- Johannes Hahn – Commissioner for Budget and Administration
- Stella Kyriakides – Commissioner for Health

With the exception of Sylvie Goulard, all Commissioners-designate were approved by the relevant committees of the European Parliament. As such, France will now be required to submit a new name for consideration for the Internal Market portfolio.

A plenary vote of the European Parliament had been due to take place at the end of October to confirm the College, with an intended commencement date of 1 November. However, in light of the rejection of Ms Goulard (and two other candidates), the timescales are now less clear, as the new nominees will need to pass committee hearings, before the plenary vote can take place.

MEMBERS’ NEWS

21 September: Association Luxembourg Alzheimer (ALA) holds 18th Memory Walk

Memory Walks are organised by Alzheimer associations around the world, with the aim of informing and educating the general public. This year, the ALA Memory Walk took place on 21 September, on World Alzheimer’s Day. Many personalities such as Mrs Corinne Cahen, the Minister of Family, as well as Prime Minister Xavier Bettel, came to show their support.
From 11:00 to 18:00, visitors were able to get information about the services offered by ALA, and about Alzheimer’s disease and other forms of dementia, at the Place Clairefontaine in the city centre. An Alzheimer’s Café was organised, at which participants got an idea of the work that ALA is doing on a daily basis. In this relaxed atmosphere, the visitors were able to meet and connect with others, take part in various discussions, and enjoy many activities.

This year’s theme was around greater acceptance and tolerance. Dementia can cause personality and behaviour changes. This complicates life, because society does not know how to react to the people living with dementia. For better integration, more respectful relationships and more tolerance, it is important to inform the public about the disease. The Memory Walk is intended to help, in this respect.

As the name suggests, the Memory Walk is above all a walk. By walking with ALA, participants showed their solidarity with people with dementia. As the weather was good, many people took part in the three tours that went from the government district to the avenue Marie-Thérèse where the Austrian era was explained to them.

In short, Luxembourg’s 2019 Memory Walk was a great success.

21 September: Alzheimer’s Association of Larissa in Greece hosts a variety of World Alzheimer’s Day events

The Greek association of Alzheimer’s disease and related disorders of Larissa (Alzheimer’s Association of Larissa, EENAL), in response to the needs of its patients and fellow citizens, carried out original and innovative activities for World Alzheimer’s Day 2019. A gathering was held at the EENAL offices on the morning of 21 September, at which President Eleni Kamboa-Nifli and volunteers offered coffee and various delicacies to patients, their carers and friends of people with dementia. They discussed nutrition issues, pets and especially helper dogs. The volunteer and veterinary surgeon Athanasia Grammenoudi, with her dog Danae (a pinscher) standing alongside her, informed everyone about the usefulness of assistant dogs as a companion, to combat loneliness, as guides and as guard dogs. Later on, she began a cognitive enhancement laboratory with people with dementia, with the assistance of Danae. Danae, with her calmness and playfulness, held everybody’s interest and brought back memories of childhood, as well as adulthood experiences, resulting in each participant with dementia telling their own unique story. One of them, Katerina, walked with Danae at her side and told the story of her own pet, Lisa.

During the afternoon of the same day, the fountain in the city’s Central Square was lit in purple, a colour associated with the Alzheimer’s movement. With the purple fountain in Central Square as a starting point, EENAL’s 1st memory walk took place. The president of EENAL, volunteers, carers, Dementia Friends and Danae the dog walked together. Holding purple balloons, they strolled along the city’s sidewalks and streets, aiming to raise awareness of Alzheimer’s disease among different age groups, to evoke acceptance of those affected and to involve society. During the walk, volunteers shared balloons and people were eager to participate in this event. The walk was successfully completed at the city’s hill, from where the following message was sent:

“I get informed, I discuss it, I’m not afraid of the disease, I’m getting involved.”

People with dementia and their families were so pleased about the event and the positive message that was conveyed to the public, that they asked for the memory walk to be established as a means of empowerment. The President of EENAL thanked the volunteers and the participants and assured them that “we will always move forward together and forcefully”.

25 September: Greek Alzheimer association in Chalkida hosts “Alzheimer picnic”

On 25 September, the Greek Society of Alzheimer’s Disease of Chalkida, organised an intergenerational picnic event on the green space of Kanithos, Chalkida. The Greek Society of Alzheimer’s Disease of Chalkida supports a variety of activities to bring young and old people together in meaningful activities.

They called this picnic event “Walking - walking on the green
space”. Authentic interaction and fun between children and seniors were the aims of this activity. 85 pupils from the 9th Primary School “Giannis Skarimpas” (5th and 6th grades) and 60 seniors, including people with dementia and caregivers, joined teachers, volunteers and professionals to enjoy team activities and games. All participants were engaged meaningfully in several activities and it was a “feel-good” experience for all. Professionals and volunteers worked together to organise the event. The Greek Society of Alzheimer’s Disease of Chalkida wishes to thank everyone who made this event a success.

5 October: Bulgaria organises three events to promote the importance of physical activity for better physical and mental health

On 5 October 2019, in the South Park in Sofia, Bulgaria, Alzheimer Bulgaria and Foundation Compassion Alzheimer organised 5 km run, to mark World Alzheimer’s Day (21 September).

Their message, for the occasion, was “Health promotion and disease prevention through sport”.

Two other days dedicated by the international community to promoting physical and mental health among older people. These two further days, were the International Day of Older Persons (1 October) and World Mental Health Day (10 October).

5 October: Croatia holds its 1st Memory Run

On 5 October 2019, Alzheimer Croatia held its first Memory Run in the capital Zagreb, bringing together 400 participants. The 5-kilometer-long race began in the heart of the city and continued through the picturesque baroque Upper Town. This event attracted a great deal of public and media attention, raising public awareness of dementia and promoting Alzheimer Croatia, which, this year, marks its 20th anniversary of continually helping people with Alzheimer’s and their family carers. In addition, the race aimed to promote a sporty and healthy lifestyle as a way to help prevent central nervous system diseases, and to gain new Dementia Friends. The race was the final event in Alzheimer Croatia’s World Alzheimer’s Month 2019 calendar, and its primary goal was to draw attention to the diseases that cause dementia. According to estimates, they affect around 100,000 people in Croatia.

This race, which will become an annual tradition, was organised by Alzheimer Croatia and the Sljeme Athletic Club, with the support of the City of Zagreb and numerous sponsors.

15 October: German Alzheimer’s Association (DAIzG) answers more than 100,000 calls since telephone hotline was launched in 2002

More than 100,000 calls and e-mails have been answered by the consultants of Alzheimer Telephone, the Alzheimer and dementia hotline of the German Alzheimer’s Association (DAIzG), since the service was launched in January 2002. A multi-professional team provides advice from Monday to Friday at +49 30 259 37 95 14. On Wednesdays from 10:00 to 12:00, Turkish-speaking advice is also offered. Every year, between 5,000 and 6,000 people register, and the number of enquiries has risen steadily over the past few years, as has the duration of individual interviews.

The concerns of the callers are very diverse: the most common questions (around 20%) concern the treatment of people with dementia and the impact on relatives due to the care situation (about 14%). There are also enquiries about the symptoms of dementia, the diagnosis and treatment options, as well as legal provisions. Many callers also ask for concrete support and funding by long-term care insurance. Almost half of the callers who turn to the Alzheimer Telephone are adult children of people with dementia. About 20% of calls are from caregiving spouses who seek help and counselling using this hotline. The consultants on the Alzheimer Telephone have many years of experience and regularly expand their specialist knowledge through advanced training. In the discussions, they respond to all concerns individually. The service is free and anonymous if requested.

The Alzheimer Telephone is financially supported by the German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

21 October: Alzheimer’s Society partners with National Trust to make all 500 historic and countryside sites dementia-friendly

Alzheimer’s Society (UK) is working in partnership with the charity organisation the National Trust on an ambitious three-year project to make all of their 500 historic and countryside sites dementia-friendly.

In what is the largest collaboration of its kind, bringing heritage and dementia together, the organisations are joining forces to unlock some of the UK’s best-loved history and heritage for millions of people affected by dementia.

The new partnership, which will see one of the Alzheimer’s Society’s biggest roll-outs of its Dementia Friends’ programme within a heritage organisation, will focus on:
• upskilling the 74,000 people who work and volunteer for the National Trust
• improving the accessibility of the sites for all visitors and
• improving internal policies and processes to support members of staff and volunteers who may be affected by the condition.

It will also see improvements at some of the places, including improved signage, facilities and modifications to materials used on paths and car parks. The National Trust will also be developing dementia services (such as cafés, tours and social events), taking heritage to local care homes, hospitals, day centres and community groups. Hosting awareness-raising activities and making improvements for those living with the disease will also support the case for more dementia-friendly communities.

The power of historic connections
For people with dementia and their carers, historic spaces, collections and stories can prompt and stimulate discussion, encourage outdoor exploration, and offer a vital connection to the world around them.

Research from Alzheimer’s Society shows that day trips are one of the most likely and regular activities for people living with the condition and their carers. In comparison to other visitor attractions, people living with dementia also view heritage sites as ‘safe’ and familiar spaces.

"Visiting a heritage site can improve physical and mental health by helping people keep active. The importance of such venues increases as we get older, as a place to relax, recover and engage through multi-sensory stimulation of the space around us," said Jeremy Hughes, Alzheimer’s Society’s Chief Executive.

For more information: http://bit.ly/2PJGVDZ

30 October: Alzheimer’s Society attends and exhibits at UK political party conferences

In September and October, Alzheimer’s Society (UK) attended and exhibited at the Labour and Conservative Party Conferences - the two main political parties in the UK. Across both conferences Alzheimer’s Society spoke with over 100 members of parliament (MPs) and local councillors, drawing their attention to the issues people affected by dementia face in accessing and paying for care, and highlighting the policy recommendations from the “Fix Dementia Care” campaign.

At the Labour Party Conference the stall was visited by Leader of the Opposition Jeremy Corbyn MP (pictured, left) and Shadow Chancellor John McDonnell MP. They both agreed that the social care system needed urgent reform and the Alzheimer’s Society delegation shared some of their campaigner’s stories with them.

Later in the week the delegation was joined by volunteers with personal experience of the dementia care system. Philip Scott, whose mother has dementia, Sandra Briant and her husband Andy, whose mother also has dementia shared their stories with MPs and Councillors who visited the stand including with Labour’s care spokesperson, Barbara Keeley MP.

Philip Scott said: “It was a very useful platform to get the message across. I had several conversations in which I felt people clearly understood something has to be done.”

The following week at the Conservative Party Conference, Mr Scott joined them once again, alongside Howard Gordon who lives with dementia and is a member of the 3 Nations Dementia Working Group.

Alzheimer’s Society's stall was visited by Health and Social Care Secretary, Matt Hancock MP and Howard Gordon spoke with him about his own condition and the need for better and more affordable care. Matt Hancock reiterated that this issue remains a Government priority and that the Department of Health and Social Care will continue to speak with Alzheimer’s Society about its plans.

Throughout both conferences the Society’s delegation, including Chief Executive Jeremy Hughes, attended conference events, round tables and meetings to share Alzheimer’s Society’s policy and campaign messaging with politicians and other key stakeholders from the sector.

Alzheimer’s Society is now following up with the Councillors and MPs to ensure that people, like Howard Gordon, Philip Scott and Sandra Briant, urgently get the support they need and a properly-funded dementia care system.

DONATE NOW! Help us make dementia a priority
POLICY WATCH
10 October: Irish Government’s decision to provide funding for more Dementia Advisers is welcomed by The Alzheimer Society of Ireland

The Irish Government’s decision to provide funding for 10 more Dementia Advisers in Budget 2020 has been welcomed by The Alzheimer Society of Ireland (ASI) as a first step in dealing with the inadequate and glaring gaps in services and supports that have been identified across the country. This follows years of neglect of people with dementia in recent Budget Day announcements.

The ASI also welcomes the one million additional home care hours which will be provided in 2020, as home care was another key ask of its Pre-Budget campaign (pictured). This will help support people with dementia to live at home in an environment that is familiar to them and where the majority of people with dementia want to be.

This announcement is acknowledgment that there is finally some understanding at Irish Government level of the harsh realities faced by ordinary people up and down the country; people with dementia and their family carers are currently being left to put up with dementia service and supports black holes across Ireland.

In July, The ASI launched its Pre-Budget Submission 2020 “Dementia Supports Across Ireland – Still Asking, Still Waiting, Still Struggling” which called on the Government to fund vital community supports and home care that are so desperately needed to help thousands of people living with dementia and their struggling families across Ireland.

The Alzheimer Society of Ireland CEO, Pat McLoughlin said: “People with dementia and their family carers have been ignored in the Budget for years, so this announcement is the first positive step in the Government taking the dementia services crisis more seriously. We feel that given the challenge that dementia presents to Irish society, the condition should form an integral part of the overall health budget and should be considered and reflected in overall health considerations for the coming year.

“We have been calling for more Dementia Advisers for years and it was a key ask in our Budget 2020 Submission. Much more is needed to support those living with dementia and their carers. Dementia Advisers work with people with dementia, their families and carers to provide a highly responsive and individualised information and signposting service. They are a key community support for people.”

14 October: Belgium is considering halting the reimbursement of dementia drugs

The National Institute for Health and Disability Insurance in Belgium (RIZIV) is considering putting a stop to reimbursing medications used to treat the symptoms of Alzheimer’s disease (AD). The measure, which would mean that as of 1 July 2020 anyone diagnosed with AD would no longer be reimbursed by their health insurance for these drugs, is part of the RIZIV’s budget proposal for 2020.

The proposed measure in Belgium is being hotly contested by the Alzheimer Liga Vlaanderen (Flemish Alzheimerliga) and the Ligue Alzheimer.

Sabine Henry, President of the Ligue Alzheimer, is worried that the proposal “sends the wrong message”. The drugs in questions work for some people, she asserts - One third of people taking the drugs report that their symptoms are alleviated, while another third feels there is an actual improvement, at least in the short-term. Furthermore, Ms Henry argues that, not only should treatments continue to be reimbursed, but more focus should be put on earlier diagnosis, as the treatments could be even more effective if taken earlier in the disease course.

In a statement, the Alzheimer Liga Vlaanderen said: “It has been scientifically proven that these medicines help patients who are in the early stages of dementia. They can remain independent for longer, which means they do not have to go into a nursing home immediately.”

Medication is also not prescribed as readily as it used to be. “It is only prescribed for patients that will really benefit from it and react well to it. If we handle it that way, then the money for the reimbursement is definitely worth it,” the Alzheimerliga said.

Dr Sebastiaan Engelborghs, neurologist at the University Hospital Brussels, agrees: “These medicines combat the symptoms of Alzheimer’s disease, just as an aspirin temporarily reduces fever in the case of flu. They are not going to stop or slow down the disease, but for some patients, they can temporarily delay the disease’s progression. “Some studies even show that patients who take their medication can stay out of a nursing home for two years more than patients who do not,” he pointed out.

“Reimbursing medication is cheaper than paying for a stay in a nursing home. By stopping the reimbursement, the message to all patients and their families is that Alzheimer’s is a hopeless...
disease in which society no longer wants to invest,” Dr Engelborghs stressed.
The final vote on the proposal is planned in the week of 21 October 2019.

15 October: Spanish Government approves dementia strategy

In Spain, the Government and Autonomous Communities have approved the “Plan Nacional del Alzheimer” (National Alzheimer’s Plan) and the general conditions for the acquisition and supply of publicly produced advanced therapy drugs.
The Plan was approved during a plenary of the inter-territorial Council of the National Health System (SNS), chaired by the Minister of Health, Consumption and Social Welfare, María Luisa Carcedo.
The Plan addresses both the social and health perspectives, with a focus on early detection, to improve the diagnostic capabilities of the system and to promote dementia research.
The text establishes four objectives and principles:

- raise awareness and transformation of society to change the perception that society has of Alzheimer’s disease and dementia
- place the person at the centre of health and social care, including developing health promotion policies, improving knowledge of risk factors, as well as the most appropriate treatments, for both the public and professionals
- improve the rights, ethics and dignity of the person, improving services, supports and benefits for advance care for people in different areas
- introduce measures to promote research, innovation and knowledge.

18 October: Survey on what people value in integrated health services launched in collaboration with WHO

In collaboration with the World Health Organization (WHO), Tilburg University and Vilans have launched a European survey researching what values matter to different people in integrated health services. The web-based survey is aimed at a broad variety of stakeholders: users (representatives), professionals, managers, policymakers and researchers.
The survey is available in English and will take no more than approximately 10-15 minutes to complete. All information recorded is confidential, and names are not being included.
It is of huge importance to include the views of people with dementia in the study, as they represent a large group of integrated care service users. So if you are a person with dementia, a user representative, an informal caregiver, an advocate from an Alzheimer’s association, or a professional/researcher in this field, please help out by completing this survey. Your experiences and perspectives are very important and will be much appreciated.
The survey will run until 16 December and can be accessed via: 
http://www.vilans.nl/integratedcarestudy

21 October: English businesses lost GBP 3.2 billion last year to dementia care crisis

New research from Alzheimer’s Society (UK) has revealed that businesses in England lost GBP 3.2 billion last year, because people had to quit their jobs or change their working patterns to care for someone with dementia.
Alzheimer’s Society commissioned a report from the Centre for Economics and Business Research, with support from Legal & General, to investigate the impact on English businesses, of carers and people with dementia leaving the workforce or reducing their work hours.
Of the 355,000 people of working age caring for a loved one with dementia, more than 147,000 have had to reduce their work hours, or have had difficulty balancing work and caring.
Over 112,000 people have had to give up their jobs, with many retiring early, because of their caring commitments.
The research revealed that the cost of dementia to English businesses has increased by GBP 1.6 billion in the last four years and is set to rise to GBP 6.3 billion by 2040.
There is a noticeably disproportionate impact of care on women. Two-thirds of carers of people with dementia are women, and the loss of their skills and experience costs English businesses GBP 1.9 billion in 2019 - higher than the GBP 1.4 billion cost by men reducing hours or leaving the workforce, despite earning on average GBP 11,000 less (per annum).
This evidence helps build the case that support for carers is essential, not just for improving wellbeing for carers themselves, but also recognising the wider effects of lack of access to formal care.
Alzheimer’s Society stresses that the UK Government needs to take action urgently to Fix Dementia Care and deliver proper support for carers.
On 26 September, Cortexyme, a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders, announced that its GAIN Phase II/III trial has commenced recruitment in Europe. The study, which started enrolment in Q2 2019 in the US, is evaluating COR388 for the potential treatment of mild to moderate AD.

Previous findings suggested that the bacteria *P. gingivalis*, commonly associated with gum disease, can infect the brain and may contribute to the development of AD. COR388 is an investigational drug designed to reduce the bacterial infection and stop or slow the disease progression by deactivating the toxic proteins released by the *P. gingivalis* bacteria, called gingipains. In Phase I testing, COR388 was well-tolerated and showed positive trends in cognitive tests.

The GAIN Phase II/III study is a randomised, double-blind and placebo-controlled study assessing the efficacy, safety and tolerability of two dose levels (40 and 80mg) of COR388 oral capsules in people with mild to moderate AD. The company is aiming to recruit 573 participants in the US and Europe who will receive COR388 or placebo for 48 weeks. The primary endpoint is the mean change in the activities of daily living at week 48, measured by the Alzheimer Disease Cooperative Studies- activities of daily living (ADCS-ADL) scale. Data are expected in late 2021.

27 September: Avanir Pharmaceuticals reports Phase III top-line data for AVP-786 for agitation in people with Alzheimer’s dementia

On 27 September, Avanir Pharmaceuticals, a pharmaceutical company committed to delivering innovative central nervous system solutions, announced top-line data from its Phase III 15-AVP-786-302 study for the treatment of agitation in people with Alzheimer’s dementia.

The study enrolled 522 US and Canadian participants aged 50-90 years old with a diagnosis of probable Alzheimer’s dementia and clinically moderate to severe agitation. They were randomised to receive AVP-786 or placebo orally twice a day during 12 weeks.

The company reported that the study failed to meet its primary endpoint. Participants treated with AVP-786 did not experience a statistically significant improvement in agitation compared to participants treated with placebo, as measured by the Cohen-Mansfield Agitation Inventory (CMAI). Similarly, the study did not meet its key secondary endpoints. The most common adverse events that occurred in participants receiving AVP-786 versus placebo were falls, urinary tract infection and somnolence. No deaths were considered related to treatment.

Avanir Pharmaceuticals is conducting another Phase III clinical trial (17-AVP-786-305) with AVP-786 for the treatment of agitation in people with Alzheimer’s dementia. Approximately 400 participants will be enrolled in US, Australia and Europe.


30 September: Repairing the TOM1 pathway prevents neuroinflammation and cognitive decline in models of Alzheimer’s disease

On 30 September, Dr Alessandra Cadete Martini and colleagues published a paper in PNAS identifying a new regulator of neuroinflammation in Alzheimer’s disease, TOM1. Chronic inflammation is a feature of many age-related neurodegenerative diseases. In Alzheimer’s disease (AD), research has shown that several immune pathways are hyperactivated, causing cognitive dysfunction by prolonging inflammation. In young individuals, however, these immune pathways retain the ability to “switch off”; as a result, inflammation is swiftly limited and resolved. The TOM1 protein, which sits on the surface of recycling structures called “endosomes”, can bind to inflammatory receptors that activate immune pathways. In doing so, the cellular waste disposal machinery is activated: TOM1 pulls the inflammatory receptors into endosomes, ensuring they are broken down and eliminated. TOM1 therefore plays an important role in the resolution of inflammation in healthy individuals, helping our immune systems to “switch off” when they are no longer required. However, the role of TOM1 during the development of AD is not yet fully understood.

To address this question, Dr Cadete Martini and colleagues studied tissues and cells from people with AD as well as mouse models of disease, aiming to identify whether TOM1 could represent a therapeutic target. TOM1 was significantly reduced in brain samples from people with AD, which showed a corresponding increase in IL1R1, an inflammatory receptor. The researchers showed that this was directly linked to amyloid accumulation, as neurons treated with pathological amyloid proteins expressed more IL1R1 and less TOM1. When they disrupted TOM1 in animal models of AD, researchers observed a substantial increase in brain inflammation: microglia were less able to disperse and phagocytose harmful amyloid proteins, resulting in more amyloid plaque formation. Interestingly, the resultant cognitive decline was not observed in animals treated with a gene therapy virus that increases TOM1. Together, these results suggest that reduced TOM1 in AD promotes neuroinflammation and contributes to amyloid plaque formation.

https://www.pnas.org/content/early/2019/09/25/1914088116

2 October: Athira Pharma announces completion of Phase 1b clinical trial of NDX-1017 for Alzheimer’s disease

On 2 October, Athira Pharma announced the completion of their Phase 1b clinical trial of NDX-1017, a novel small-molecule therapeutic designed to enhance the activity of
hepatocyte growth factor (HGF). Preclinical studies of NDX-1017 showed that the drug could promote brain cell regeneration, improving cognitive function.

This announcement follows on from their presentation of interim trial results at the Alzheimer’s Association International Conference in July this year. During this presentation, Athira Pharma showed that NDX-1017 was safe and well-tolerated in 72 healthy young and elderly individuals. They also reported EEG results suggesting that NDX-1017 could cross the blood-brain-barrier, a key requirement for drugs aiming to target the brain.

In their October announcement, Athira Pharma stated that 88 young and elderly individuals with and without Alzheimer’s disease had completed their Phase 1b trial of NDX-1017. Trial results will be featured in an oral presentation at the 2019 Annual Clinical Trials on Alzheimer’s Disease (CTAD) Conference, which will take place in San Diego between 4-7 December.


**2 October: Clinical MRI study identifies differences in brain ventricle volume that predate the onset of genetic frontotemporal dementia**

On 2 October, Dr Tavares and colleagues published a paper in the Neurology journal, showing that people who go on to develop genetic frontotemporal dementia (FTD) have larger brain ventricle volumes on MRI scans when compared to relatives who are not carriers of FTD risk genes.

30% of people with genetic FTD are carriers of mutations in the MAPT, PGRN or C9orf72 genes. Previous clinical studies have shown that people with symptomatic genetic FTD (also known as “familial FTD”) present with enlargement of their brain ventricles, cavities within the brain that contain cerebrospinal fluid. Brain ventricle enlargement is visible on brain imaging scans, and clinicians often use 3D MRI scans to calculate brain ventricle volume, using this as a diagnostic tool for neurodegenerative diseases such as FTD. However, it is not yet known whether increases in brain ventricle volume can also be seen before FTD symptoms develop, when treatment is likely to have maximal benefits.

To answer this question, Dr Tavares and colleagues performed MRI scans on participants in the multi-centre, international Genetic Frontotemporal Dementia Initiative (GENFI) cohort study. These participants included presymptomatic and symptomatic FTD mutation carriers, as well as their non-carrier, unaffected relatives. Using an image analysis technique called “automated segmentation”, the researchers showed that non-carrier, healthy individuals had lower brain ventricle volumes than people who carried FTD mutations and then went on to develop symptomatic disease. The increase in brain ventricle volume in people with presymptomatic FTD could be observed from 49 years of age on average, 4 years before disease symptoms developed. Ventricular volume may therefore be a useful index of disease symptom onset in the prodromal, non-symptomatic stages of FTD.

https://n.neurology.org/content/early/2019/10/02/WNL.0000000000008386

**3 October: New report says “window of opportunity” exists in midlife, when people could make biggest difference to risk of developing neurodegenerative diseases**

A new evidence-based report, “Time matters: a call to prioritize brain health”, talks about a “window of opportunity” in midlife when individuals may be able to make the biggest difference to their risk of developing a neurodegenerative disease or of delaying its progress.

The report, published by the Oxford Health Policy Forum and launched at the European Health Forum Gastein conference on 3 October 2019, summarises published evidence and the consensus findings of an international multidisciplinary expert group, including clinicians, researchers and representatives from patient advocacy and professional groups.

The report sets out a series of consensus recommendations, including:

- improve public understanding of how to protect brain health through lifestyle measures – such as exercise and a healthy diet
- prepare for the likely increased demand for genetic testing by those wanting to understand their risk of a neurodegenerative disease
- provide access to available and effective treatments in a timely manner
- provide accessible holistic care, including prevention information, treatment options and support
- conduct research to identify accurate and cost-effective tests for disease detection and diagnosis
- develop, validate and approve tests, tools and apps for monitoring brain health.

The experts responsible for the report are now calling for a public health campaign aimed at promoting a “brain-healthy lifestyle” to reduce the risk of developing neurodegenerative brain diseases, such as Alzheimer’s disease (AD) and Parkinson’s disease (PD).
The campaign should support existing health promotion work by emphasising that “what is good for the heart is generally good for the brain,” they say.

They also urge that the campaign be underpinned by a coordinated research programme, which is aimed at developing clinical tests for identifying those at risk of developing neurodegenerative diseases - before signs and symptoms appear. Research to develop new treatments and other tests to facilitate earlier diagnosis must also continue, and health systems must prepare now for the time when such tests are available.

Jean Georges, Executive Director, Alzheimer Europe, was involved in this report.

The report can be downloaded, here: [http://bit.ly/2q7YWkm](http://bit.ly/2q7YWkm)

8 October: Study in mice reports on possible effect from drug preventing blood clots towards lowering the risk of dementia

On 8 October, researchers from Spain and the United States of America published an article on the application of a drug usually used to prevent blood clots and its effects in a mouse model of Alzheimer’s disease (AD) in the Journal of the American College of Cardiology.

The team administered the drug dabigatran etexilate, respectively a placebo in both AD mice (TgCRND8) as well as their wild-type littermates over the course of a year.

Conducting various tests over the course of the study, the team found that the AD mice who received the drug had less memory decline as well as less deposition of toxic fibrin than those AD mice who did not.

Although it is clear that a translation of these effects in relatively small groups of mice cannot be translated to humans, these results warrant further potential investigation.

Nevertheless, the authors also highlighted that there will be a need for caution when doing so, since anticoagulation drugs can also cause intracerebral haemorrhage in AD patients, which is linked to worse cognitive performance.

[http://www.onlinejacc.org/content/74/15/1910](http://www.onlinejacc.org/content/74/15/1910)

10 October: ApoE4 activates microglia in animal models of tauopathy and Alzheimer’s disease

On 10 October, Dr Yang Shi and colleagues published a paper in the Journal of Experimental Medicine showing that ApoE4 induces microglial activation in animal models of tauopathy and Alzheimer’s disease (AD), driving disease progression. This publication follows on from their 2017 Nature paper, which showed that ApoE4 exacerbates neuroinflammation and tau pathology independently of amyloid-β.

Recent studies have provided major insights into how ApoE regulates neurodegeneration. In line with clinical studies showing that ApoE4 allele is a major genetic risk factor for AD, these studies identified a direct link between ApoE4 and the levels of tau protein in the brains of people with AD. Using animal models, scientists showed that the absence of ApoE was strongly neuroprotective, preventing neurodegeneration even when pathological tau proteins were present.

Intriguingly, a marked elevation in microglial activation was observed in animals with an ApoE4 genotype, suggesting that ApoE may also play an important role in AD-associated neuroinflammation. In their current publication, Dr Shi and colleagues hoped to shine a spotlight on neuroinflammation, aiming to identify exactly how ApoE drives AD progression through its effects on microglia in the brain.

To answer this question, the researchers used mouse models of AD that had been genetically modified to produce large amounts of pathological, phosphorylated tau proteins (P301S mice). On this tauopathy background, Dr Shi and colleague added the ApoE4 gene, or removed ApoE entirely. In line with previous studies, addition of the ApoE4 gene to P301S mice accelerated the disease process in these animals, which showed much higher levels of brain atrophy than P301S mice that lacked ApoE entirely. Interestingly, when P301S/ApoE4 mice were treated with a drug that ablated microglia they were almost fully protected against neurodegeneration.

When the researchers looked more closely at the brains of these animals, they observed that the microglia within were abundant, but not activated. They also noted that the extent of microglial activation was correlated with the quantity of phosphorylated, pathological tau proteins in the brains of AD mice. This suggests that the activation status of microglia, but not their absolute number, determines their impact on neurodegeneration. Together, these results indicate that the disease-accelerating effect of ApoE4 in tauopathy models is largely due to its regulation of microglial activation.

[http://jem.rupress.org/content/early/2019/10/09/jem.20190980/](http://jem.rupress.org/content/early/2019/10/09/jem.20190980/)

11 October: Clinical study shows that misfolded amyloid beta proteins in the blood are an accurate risk marker for Alzheimer’s disease

On 11 October, Dr Hannah Stocker and colleagues published a paper in the Alzheimer’s and Dementia journal, showing that the levels of misfolded amyloid beta (Aβ) protein in the blood can accurately predict a person’s risk of developing Alzheimer’s disease (AD). During the progression of AD, Aβ proteins undergo distinct structural changes: starting off as single, ordered proteins, they become clustered, misfolded aggregates. It is these misfolded aggregates that create amyloid plaques in the brain.
kicking off the disease cascade. Recent work has shown that the amount of misfolded Aβ in the brain is correlated to misfolded Aβ in cerebrospinal fluid and blood plasma. However, studies have yet to assess the performance of Aβ misfolding as an early predictor of clinical AD, compared to more established predictors such as APOE4 status.

To address this question, Dr Stocker and colleagues turned to the ongoing community-based ESTHER cohort study. From 2000-2002, ESTHER recruited 9940 participants aged between 50-75 years, with regular clinical follow-up. Of these participants, the researchers identified 150 people with a dementia diagnosis during the 14-year follow-up, and 620 healthy controls. Using an immune-infrared sensor tool, Dr Stocker and colleagues measured the level of misfolded Aβ in blood plasma samples from these participants at baseline and over the 14-year follow-up period. In line with previous studies, APOE4 status was a good predictor of AD diagnosis: individuals with an APOE4 genotype had a 2.4-fold greater likelihood of being clinically diagnosed with AD. However, Aβ misfolding far exceeded the predictive capability of APOE4 genotype, with a 23-fold increased odds of clinical AD diagnosis even many years before the development of symptoms. Measurement of Aβ misfolding also allowed the researchers to discriminate between AD, vascular dementia and other mixed dementias. Limitations of the study included the relatively small number of participants with clinically confirmed AD; further large-scale studies are therefore required. Nevertheless, these results suggest that Aβ misfolding could be used to stratify AD risk and help clinicians distinguish between different types of dementia.


22 October: Biogen announces regulatory filing plan for Aducanumab, based on new analysis of EMERGE and ENGAGE studies

On 22 October, Biogen announced its plans to seek regulatory approval for Aducanumab, based on a new analysis of a larger dataset from its EMERGE and ENGAGE Phase III studies. These studies were discontinued in March 2019 following a futility analysis of data from 1,748 participants who had completed the 18-month study period. However, Biogen’s new analysis included data that became available after this futility analysis had been completed, bringing that participant number up to 2,066.

The new analysis revealed that the Phase III EMERGE study had met its primary endpoint, showing a significant reduction in clinical decline following administration of Aducanumab to participants with mild cognitive impairment due to AD and mild AD dementia. Aducanumab (BIIB037) is a monoclonal antibody that binds aggregated forms of amyloid-β (Aβ), which accumulates in the brain during the development of AD. The drug was designed to activate the immune system following binding to Aβ, thereby enabling clearance of these damaging protein aggregates. Participants who were sufficiently exposed to high doses of Aducanumab had reductions in brain Aβ, experiencing significant benefits on measures of cognition and function. Importantly, they also experienced an increased quality of life, with greater ability to conduct their personal finances, perform household chores and travel independently outside the home.

Biogen now plans to file a Biologics Licence Application with the US Food and Drug Administration (FDA) in early 2020, and will continue dialogue with the EU and Japanese drug authorities.


DEMENTIA IN SOCIETY

21 September: James McKillop receives 2019 Richard Taylor Advocates Award

James McKillop MBE has received the 2019 “Richard Taylor Memorial Advocates Award” – an award given out annually by the Dementia Alliance International (DAI). He was given the award personally, during the DAI’s online “Cafe Le Brain” (pictured) and then the award was officially announced, on 21 September, which is World Alzheimer’s Day.

Mr McKillop has a diagnosis of dementia and is a pioneer in the field of dementia advocacy. One of his great achievements, to date, was founding the Scottish Dementia Working Group (SDWG), of which he was also the first Chairperson. The SDWG is a national campaigning group run by people with dementia. It acts as the independent voice of people with dementia within Alzheimer Scotland.

Mr McKillop is now a member of the DAI, and continues to work locally and nationally in his native Scotland, as well as doing international advocacy work, representing the DAI.


NEW PUBLICATIONS AND RESOURCES

7 October: New online platform aims to improve autonomy of people with Alzheimer’s dementia

A new online platform, aiming to help improve the autonomy and self-reliance of people in the early stages of Alzheimer’s dementia, has been launched by the AD-AUTONOMY project. The platform makes teaching materials, online activities and real activities available to users in order to strengthen their
autonomy in nine areas - “Dimensions” - of their daily lives. For instance, the platform makes it possible to learn and put into practice several guidelines to improve postural hygiene, navigating urban surroundings and household safety.

It has been assessed by over 160 users from Spain, the United Kingdom, Slovenia, Greece and Turkey, with a high degree of acceptance and improvement of the autonomy both of people with dementia, as well as carers and healthcare professionals.

The next goal is to conduct a comparative study with which to assess the positive impact of the platform, and how the suggested strategies can improve autonomy in activities of daily living, such as shopping or managing personal finances.

The AD-AUTONOMY project partners include Türkiye Alzheimer Derneği and Spominčica – Alzheimer Slovenija, both of whom are members of Alzheimer Europe. The new platform can be accessed via:

www.adautonomy.eu/training

LIVING WITH DEMENTIA

18 October: Sean Mackell writes about his advocacy work and the importance of being open about diagnosis

I am a partner, a father, a grandfather, a brother, an uncle, a cousin and a friend. Life was good to me. I thought when I couldn’t remember things that it was just normal ageing. But in November 2018 that all changed when dementia stood up and punched me in the stomach. I didn’t see it coming. I had always been active. I walked, I debated, played golf and enjoyed the Craic and enjoyed a glass of wine now and then.

My working career was in the Irish Trade Union movement. When I retired a few years ago I had served for over 40 years. 40 years of negotiating, representing members, doing deals, supporting members and doing what was right. It was tough at times, but I found it rewarding.

I was settling into a happy retirement but a visit to the consultant knocked me for six. I was diagnosed with dementia. “You have Alzheimer’s, it’s a terminal condition and there is no cure. Do the difficult things, like making a will, sorting Power of Attorney, whilst it is still easy.” I was stunned to my core. However, I responded the only way I could. I resolved to do the very best I could for as long as I could.

Since then, I have been completely open about my condition, with our families, our neighbours and our friends. Being open has brought only good things for my partner Mary and I, people are really kind and supportive. My golf buddies now keep score so that I can concentrate on playing golf badly!

I lost no friends but gained help and support from those who knew me. So, whether it’s in the bank, the post office or the supermarket, I would encourage other people living with dementia to be open. Once you tell people, they are willing to help, allowing you to continue to be independent. If people don’t know, they can’t help and support you.

My partner Mary attended The Alzheimer Society of Ireland Family Carer Training so that she would know what helps and what hinders. Then I became involved in The Alzheimer Society, joining the Irish Dementia Working Group, which has opened up a whole new world for me.

I’ve participated in the launch of the Pre-Budget Submission – “Still Asking, Still waiting, Still Struggling” and lobbied our politicians ahead of the budget to allocate resources to support those living with dementia. We made some progress with the Irish Government funding 10 extra Dementia Advisors.

I took part in a Policy Café and have participated in a number of research studies that wanted to hear the voice of people who had been recently diagnosed with dementia.

I was recently elected on to the steering group of the Irish Dementia Working Group. They are good people and committed to try and help those of us who are living with dementia. I’m inspired by those who have been diagnosed for much
longer than I have, who are continuing to lead fulfilling lives. I’m looking forward to the Steering Group induction day and to getting stuck in to the work of being an advocate for people living with dementia.

The Alzheimer Society of Ireland invited me to undertake an examination of how dementia-inclusive Croke Park, our largest sporting stadium, is. I am glad to say that they were very helpful and are committed to supporting people like me who want to attend games. Well done, Croke Park!

On another occasion, I joined a number of others living with dementia on the stage of The Abbey Theatre for an insight into Dementia and the Arts. It was an interesting attempt to shine a light on dementia and to hear my new friends’ testimonials. It was quite a buzz to stand on the National Stage, where so many Irish actors had stood before.

Dementia will be conquered someday, as were AIDS, TB, Polio and many other illnesses. I look forward to that day. In the interim, I will do my very best to continue being healthy as best I can.

EDUCATION

15 October: Registrations are open for free University of Tasmania online course on dementia

The Wicking Dementia Research and Education Centre of the University of Tasmania (UTAS) welcomes registrations for its next Massive Open Online Course (MOOC) on “Understanding Dementia”. This is an easily accessible online course that builds upon the latest in international research on dementia. The course is run on an annual basis, is completely free and anyone can enrol. There are no entry requirements.

Access to the course itself will be open from 18 February 2020 and is scheduled to close on 1 May 2020 at 5:00pm AEST. There are 7 weeks of scheduled content.

For more information about this course and to enrol, visit: https://mooc.utas.edu.au/course/19

UTAS also runs a free annual MOOC on “Preventing Dementia”, the 2019 edition of which opened on 15 October 2019.

21 October: Jersey Alzheimer Association holds professional workshops and Dementia Friends sessions

The Jersey Alzheimer Association (JAA) holds professional workshops on a regular basis. The last series of these will be held in November 2019. Sessions include:

- Dementia Awareness
- Relationship Focused Dementia Caring
- Communication and Connection
- Looking Beyond Behaviour.

These workshops are suitable for anyone who is in a professional role and helps to support people and families affected by dementia. For more details contact Michala@jerseyalzheimers.com

The JAA also holds regular Dementia Friends training sessions. The next available sessions are 22 November and 5 December 2019. For more details contact info@jerseyalzheimers.com

JOB OPPORTUNITIES

15 October: University of Geneva seeks PostDoc PhD/Research Assistant to work at Laboratory of Neuroimaging of Aging

In a partnership with the University Hospitals of Geneva, the University of Geneva (UNIGE) is looking to recruit a full-time postdoctoral fellow/PhD/research assistant. The post is based at the Laboratory of Neuroimaging of Aging (LANVIE) in Geneva, Switzerland.

In order to strengthen the dynamic and potential of the LANVIE team, members are looking for a 100% postdoctoral fellow / PhD / research assistant as part of the AMYPAD-Diagnostic Patient Management Study (DPMS) project. The AMYPAD-DPMS project represents a new research initiative that will bring together academic and private sector partners to improve understanding of the role of beta-amyloid (β-amyloid) proteins as diagnostic and therapeutic markers of Alzheimer’s disease using positron emission tomography (PET).

The AMYPAD-DPMS consortium brings together 8 academic centres, 3 pharmaceutical companies, 2 SMEs and 1 patient organisation, spread across Europe.

The position will consist of carrying out analysis of the data of the AMYPAD-DPMS study and preparing publications and presentations referring to it. Find out more:

https://amypad.eu/news/recent-news/unige-is-recruiting-a-postdoc-phd-research-assistant/
AE CALENDAR

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<td>12-14 November</td>
<td>EPF Annual Congress. Advancing meaningful patient involvement: A path to more effective health systems</td>
<td>Ana</td>
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<tr>
<td>13 November</td>
<td>Ma volonté en fin de vie et avant – Luxembourg State (Luxembourg, Luxembourg)</td>
<td>Dianne</td>
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<td>13-14 November</td>
<td>Lausanne VI Meeting (Lausanne, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>15 November</td>
<td>EPAD Sustainability Meeting (Amsterdam, Netherlands)</td>
<td>Jean</td>
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<tr>
<td>16-18 November</td>
<td>ICCA: FYP Barcelona, Spain</td>
<td>Gwladys</td>
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<td>19-20 November</td>
<td>IBTM, Barcelona, Spain</td>
<td>Gwladys</td>
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<td>20 November</td>
<td>Patients and Consumers Working Party of European Medicines Agency (Amsterdam, Netherlands)</td>
<td>Jean</td>
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<td>25-26 November</td>
<td>PRODEMOS Consortium Meeting (Cambridge, UK)</td>
<td>Cindy and Jean</td>
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<tr>
<td>26 November</td>
<td>The role of patient’s organizations in scientific and technological research – Federación Española Parkinson</td>
<td>Ana</td>
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<tr>
<td>27-28 November</td>
<td>‘Joining the Dots’ Conference of The European Institute for Innovation through Health Data (i~HD) (Brussels, Belgium)</td>
<td>Angela</td>
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<tr>
<td>27-28 November</td>
<td>Symposium of the Joint Programme for Neurodegenerative Diseases Research (JPND) (Brussels, Belgium)</td>
<td>Jean</td>
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CONFERENCES 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>5-7 November</td>
<td>14th UK Dementia Congress, <a href="https://careinfo.org/event/uk-dementia-congress/">https://careinfo.org/event/uk-dementia-congress/</a></td>
<td>Doncaster, UK</td>
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<td>5-7 November</td>
<td>First dementia conference Krems, “Timely Detection of Dementia”, <a href="http://www.donau">www.donau</a> Uni.ac.at</td>
<td>Krems, Austria</td>
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<tr>
<td>26-29 March 2020</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://cony.comtecmed.com/">http://cony.comtecmed.com/</a></td>
<td>London, UK</td>
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<tr>
<td>20-22 October</td>
<td>30th Alzheimer Europe Conference “Building bridges”</td>
<td>Bucharest, Romania</td>
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30th Alzheimer Europe Conference
Building bridges
Bucharest, Romania
20–22 October 2020

www.alzheimer-europe.org/conferences #30AEC