I hope you all had an excellent summer break. As every year, this edition of our newsletter covers July and August. Firstly, I would like to congratulate both Chris Roberts, Vice-chairperson of the European Working Group of People with Dementia, who has received an Honorary Fellowship from Bangor University; and Luxembourgish neuroscientist Michel Goedert, who received this year’s Royal Society Medal for his Alzheimer’s disease research.

Unfortunately, on a less positive note, I am sorry to report that Novartis and Amgen stopped two Phase II/III clinical studies of CNP520 in the Alzheimer’s Prevention Initiative Generation programme. We remain optimistic, however, in the knowledge that even failed trials increase our understanding and will bring us closer to the development of better treatments. Studies are already shifting direction, and are increasingly looking beyond the amyloid hypothesis, towards inflammation and vascular causes of disease. Another theme is looking at much earlier stages in the time-course of Alzheimer’s disease/dementia. Speaking of clinical studies, we have added new trials to our Clinical Trials Watch.

From 14-18 July, I attended the Alzheimer’s Association International Conference, in Los Angeles. You can read a selection of some of the biggest AAIC stories in the AAIC Watch section on pages 17-19. During the conference, I was also invited to a meeting organised by the World Dementia Council, launching a project examining dementia-friendly initiatives worldwide.

On the European policy front, the European Commission announced the names of those who will chair the mission boards, which will receive funding from the EU’s forthcoming Horizon Europe research programme. Ursula Von der Leyen was also confirmed as the European Commission’s first ever female President; and, finally, the Work-life Balance initiative came into effect. The initiative aims to create a better balance for people with caring responsibilities. Countries now have three years to implement it. The draft strategic plan for Horizon Europe has shown brain research is being hugely undervalued. We are calling for this to be rectified. You can read more about the campaign (please support it) in the Alzheimer Europe section.

At a global level, following its meeting in Osaka, Japan, the G20 has agreed to place dementia prominently on its agenda, for the first time. This is encouraging to hear. Finally, our Annual Conference is fast-approaching and I hope to see many of you there. You can read more about some of our keynote speakers, on pages 3 and 4 of this newsletter. Online registration closes on 13 October, so make sure you book your place soon, if you have not already done so.

Jean Georges
Executive Director
1 July: Alzheimer Europe supports call for increased emphasis on brain research in Horizon Europe programme

18 major institutions from across Europe, with a shared interest in brain health and neuroscience, have launched a petition, on behalf of the scientific community, patients and carers, expressing concern about the future of this area of neuroscience research and especially research into brain diseases in Europe.

Based on the draft strategic plan for the EU’s forthcoming Horizon Europe (2021-2027) research programme, these 18 institutions, including Alzheimer Europe, agree that this area of research is hugely undervalued and deserves to be a much greater priority. The joint petition notes that we are all perplexed and seriously concerned about the decision not to choose brain health as one of the research mission areas for the first four years of the programme. Only one mission area was related to health, and this relates only to cancer. Across Europe, cancer receives approximately 15 times as much funding as dementia.

Whilst funding for the Human Brain Project is welcomed, the project is limited in scope. Additional funding must be made available to allow for study into brain development, function and decline.

It should also be noted that, if Europe does not prioritise brain research, there is a significant risk that countries such as the USA and China will make progress in the field, leaving the EU behind.

Please support the petition:
https://www.openpetition.eu/petition/online/call-for-increased-emphasis-on-brain-research-in-the-strategic-plan-for-horizon-europe

17 July: Chris Roberts awarded Honorary Fellowship at Bangor University

Alzheimer Europe was delighted to learn that Chris Roberts, Vice-chairperson of its European Working Group of People with Dementia, has been awarded an Honorary Fellowship at Bangor University (Wales, United Kingdom), for “Services to Research, Health and Social Care”. We warmly congratulate Chris on this recognition of all his hard work, both at the national and international level.

In an announcement, on its website, Bangor University describes Chris as “a pioneer and an advocate in the citizenship movement within dementia and a leading figure in the UK and in an international context, establishing a series of innovative initiatives across both the local and international communities of people living with dementia”.

The award ceremony took place at Bangor University, on 17 July 2019. Chris gave a moving response speech after receiving his title, Honorary Fellow of Bangor University:
https://www.youtube.com/watch?v=jmxMo5M08FE&feature=youtu.be
31 July: Alzheimer Europe adds new trials to its Clinical Trials Watch

Alzheimer Europe continues to develop and improve its Clinical Trials Watch (CTW), an innovative online resource providing up-to-date accessible information on clinical trials currently recruiting participants in at least one European country. The service, launched in September 2016, provides information on Phase II and III clinical trials that are investigating drugs for the prevention and treatment of dementia and/or Alzheimer’s disease.

In July 2019, Alzheimer Europe added three clinical trials to the database, which now counts eight Phase II and eleven Phase III clinical trials. The three newly-added trials are:

- LAURIET study (Phase II, Genentech)
- NorAD (Phase III, Imperial College London)
- Brexpiprazole study (Phase III, Otsuka)

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

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#29AEC - MEET THE SPEAKERS

Between the months of June and September - in the run up to our Annual Conference in October - introduces a number of our conference keynote speakers. We are pleased to introduce you to six more keynote speakers at the upcoming 29th Alzheimer Europe Conference (#29AEC), which is taking place from 23-25 October 2019, in The Hague, Netherlands.

For more information about all the keynote speakers, click here: https://www.alzheimer-europe.org/Conferences/The-Hague-2019/Keynote-speakers


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Marco Blom, Netherlands

Marco Blom graduated from the Radboud University Nijmegen, Netherlands in 1987 with an MSc in Psychogerontology. After working in a regional mental health institute for elderly people and at the National Institute of Care and Welfare, he joined Alzheimer Nederland in 1997. He worked there in several positions and was involved in setting up and implementing the Alzheimer Cafés, the development of the academic Alzheimer Centres and the start of an online platform for family caregivers. He had the opportunity to act as interim CEO from February 2017 until September 2018. Currently he is scientific director and also head of National Services.

Mr Blom is one of the speakers in Plenary 2, on 24 October.

Marjolein de Vugt, Netherlands

Marjolein de Vugt is a Professor of Psychosocial Innovations in dementia. Trained as a neuropsychologist, she works as a clinical researcher and as a clinician in the memory clinic of the Maastricht University Medical Center+ (MUMC+). She is co-director of the Alzheimer Center Limburg and is also a board member of the European network on research into early detection and timely intervention in dementia (INTERDEM). Prof. De Vugt will deliver the keynote lecture at the conference opening ceremony on 23 October.

Emma Ferguson-Coleman, United Kingdom

Dr Emma Ferguson-Coleman is a Deaf research associate within the Social Research with Deaf People (SORD) group at the University of Manchester, UK. Emma has been a researcher with Deaf sign language users with dementia and their carers for just over 9 years. Emma’s PhD explored the everyday experiences of Deaf BSL users
living with dementia with their care partners, and also explored the Deaf community’s knowledge and understanding of dementia. Dr Ferguson-Coleman is one of the speakers in Plenary 2, on 24 October.

Sebastian Köhler, Netherlands

Sebastian Köhler is an associated professor at the School for Mental Health and Neuroscience at Maastricht University and a senior researcher at the Alzheimer Centrum Limburg at Maastricht UMC+, where he leads the Neuroepidemiology research group. His work centres on risk and prevention of dementia. He is a co-Primary Investigator (co-PI) of the Maastricht Ageing Study and a management board member of The Maastricht Study. Dr Köhler is one of the speakers in Plenary 4, on 25 October.

Julie Meerveld, Netherlands

Julie Meerveld is the manager of Regional Support and Advocacy at Alzheimer Nederland. She is responsible for advocacy, the national volunteer organisation and the campaign Samen Dementievriendelijk (Together Dementia Friendly). On behalf of Alzheimer Nederland, she was the initiator of the first National Dementia Programme and the first national Dementia Care Standard. Ms Meerveld is one of the speakers in Plenary 3, on 25 October.

Mohammed Akhlak Rauf, United Kingdom (UK)

Mohammed Akhlak Rauf is the Founder & Director of Meri Yaadain CiC, a community interest company that aims to support Black Asian Minority Ethnic (BAME) people living with dementia, as well as their supporters. Mr Rauf has 20 years of experience working with BAME communities, with regard to engagement and access to information and services. He is a PhD student, and has received an MBE in recognition of his efforts. Mr Rauf is one of the speakers in Plenary 3, on 25 October.

Alzheimer Europe networking

On 2 and 3 July (Madrid, Spain), Angela, Chris and Jean attended the Scientific Coordination Board and the Consortium Meeting of the Neuronet project.
On 3 July (London, United Kingdom), Dianne and Ana attended a meeting for a project proposal.
On 4 July (London, United Kingdom), Jean attended the Review Board meeting of the European Prevention of Alzheimer’s Dementia (EPAD) project.
On 5 July (London, United Kingdom), Jean attended the GSH Health Advisory Board.
On 8 July (Luxembourg, Luxembourg), Jean met with a representative from the World Young Leaders in Dementia (WYLD).
On 8 and 9 July (The Hague, Netherlands), Gwladys and Aideen met with Alzheimer Nederland about #29AEC.
On 9 July (Basel, Switzerland), Ana attended a workshop organised by Roche.
On 11 and 12 July (Brussels, Belgium), Owen attended the Patient Access Partnership meeting on the future of healthcare in Europe.
On 12 July (Los Angeles, USA), Jean attended a meeting of the WW-Fingers on multi-domain intervention strategies for the prevention of dementia.
On 13 July (Los Angeles, USA), Jean attended a Patient Advisory Board meeting of Eisai.
From 14 to 18 July (Los Angeles, USA), Jean attended the Alzheimer’s Association International Conference (AAIC).
On 17 July (Los Angeles, USA), Jean attended a meeting of the International Alzheimer’s Disease Research Funders Consortium.
On 26 July (Paris, France), Jean attended the final project meeting of the ADDIA project.
On 28-29 August (Brussels, Belgium), Dianne and Ana attended a meeting of the European Working Group of People with Dementia (EWGPWD).
2-3 July: Neuronet Scientific Coordination Board meeting brings together project leaders from across the IMI neurodegenerative disease portfolio, encompassing EUR 260 million of funding.

On 2-3 July (Madrid, Spain), Neuronet (Efficiently Networking European Neurodegeneration Research) convened the first meeting of its Scientific Coordination Board and held a subsequent consortium meeting.

Neuronet’s high-level, overarching Scientific Coordination Board (SCB) is formed by 12 leaders of Innovative Medicines Initiative (IMI) projects in the area of neurodegeneration. The SCB 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 first day started with an introduction to the concept and overall vision of Neuronet by the project leads Carlos Díaz (SYNAPSE Research Management Partners) and Darrel Pemberton (Janssen Pharmaceutica NV).

After that, the SCB members each gave short introductions on their project goals, main results and outputs as well as identified gaps and needs, which were followed by questions and answers.

The SCB currently encompasses the following public-private projects:

<table>
<thead>
<tr>
<th>Project title</th>
<th>SCB member</th>
<th>Institution/Company</th>
<th>Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADAPTED</td>
<td>Margot Bakker</td>
<td>AbbVie Deutschland GmbH, DE</td>
<td>EUR 6.8M</td>
</tr>
<tr>
<td>AETIONOMY</td>
<td>Martin Hofmann-Apitius</td>
<td>Fraunhofer SCAI, DE</td>
<td>EUR 17.8M</td>
</tr>
<tr>
<td>AMYPAD</td>
<td>Jose Luis Molinuevo</td>
<td>Barcelonaβeta Brain Research Center, ES</td>
<td>EUR 27.3M</td>
</tr>
</tbody>
</table>

The next part of the SCB meeting focussed on open discussions that revolved around Neuronet’s current and future activities. These included potential synergies and collaborations between projects, an impact analysis to be conducted for the overall portfolio, potential members of Neuronet Working Groups on specific topics and the first concept for a knowledge base aimed at providing the project leaders as well as IMI’s Strategic Governance Group for neurodegeneration with an overall overview of the programme and insights on the projects’ highlights.

The following day was dedicated to the Neuronet consortium. The consortium meeting gave the different work packages an opportunity to provide updates on their progress and to gather input from other members of the consortium. This meeting was attended by 14 consortium members as well as Elisabetta Vaudano (representing IMI) and Giovanni Espósito (European Brain Council/EBC) who attended the meeting on behalf of a Horizon 2020-funded coordination and support action entitled EBRA (European Brain Research Area).

As part of the consortium meeting, the following five Work Packages were discussed:

- WP1: Project and impact analysis (presented by Jacoline Bouvy from NICE), with an emphasis on potential Key Performance Indicators.
- WP2: Programme integration (presented by Carlos Diaz from Synapse), which focussed on the feedback from the SCB during the previous day.
- WP3: Tools and services (presented by Nina Coll from Synapse), with an overview of the design and content of the knowledge base.
- WP4: Dissemination & Outreach (presented by Chris Bintener from Alzheimer Europe), providing insights into the draft communication strategy as well as the current
state of progress regarding the development of the expert communication group members.

- WPS: Coordination and Support Action Management & Sustainability (presented by Sandra Pla from Synapse), with an update on deliverables, budget and the planning of following meetings.

This was followed by Elisabetta Vaudano’s presentation focussed on the IMI’s expectations of Neuronet. Elisabetta highlighted some upcoming priority areas of the IMI, which included rare disease, patient engagement and advanced therapies. The consortium meeting concluded with an introduction to EBRA by Giovanni Espósito, which helped to reveal potential synergies between Neuronet and EBRA.

18 July: EPAD exhibits at AAIC 2019

Members of the European Prevention of Alzheimer’s Dementia (EPAD) project attended the Alzheimer’s Association International Conference (AAIC) held on 14-18 July. They travelled to Los Angeles (US) from across Europe for the biggest event in dementia research. This is the second year that the team exhibited the EPAD studies with its EPAD branded green and white booth in the exhibition area. They were delighted that more than 350 people stopped by at the EPAD booth to learn more about the project and discuss further topics such as the EPAD data access process, the Longitudinal Cohort Study (LCS) and the Proof of Concept (PoC) study. It was also a great opportunity to meet many current and future EPAD collaborators. EPAD also had a business suite at the exhibition area where many engaging meetings with potential interventional owners and other world experts on Alzheimer’s disease prevention took place. Altogether, the conversations they had at the booth and the business suite generated a rich exchange of ideas and they are excited that various collaborations are being considered.

At AAIC 2019, the aim of the EPAD booth was twofold. The first aim was to showcase the EPAD PoC trial platform and engage the pharmaceutical and biotechnology industry. To support this, a new high quality animated video was created to highlight the key benefits of the EPAD approach to develop drugs for Alzheimer’s disease (you can watch it here). The second aim was to show all the benefits that EPAD has to offer to the scientific community. In order to do so, the EPAD booth included an interactive screen on which attendees could browse their topics of interest including the LCS and PoC studies, the EPAD Academy, the data access process and upcoming data batches, disease modelling, the statistical study design and interviews and testimonials of many members and collaborators.

Additionally, the EPAD team had two oral presentations at AAIC on different aspects of the project. Both generated a great deal of interest from researchers outside the project:

- Associations between Multimorbidity and CSF Amyloid: Cross-Sectional Analysis of the European Prevention of Alzheimer’s Dementia (EPAD) Cohort from Lucy Stirling (UEDIN)
- Prescreening for European Prevention of Alzheimer Dementia (EPAD) Trial-Ready Cohort: Impact of AD risk factors and recruitment settings from Lisa Vermunt (VUmc).

31 July: The Neuronet Coordination and Support Action on neurodegeneration research launches its website

The Neuronet (Efficiently Networking European Neurodegeneration Research) communication team is proud to announce the launch of the official project website: http://imi-neuronet.org/

Neuronet is a three-year coordination and support action that kicked off in March 2019. The aim of Neuronet is to set up an efficient platform to boost collaboration across research projects focusing on neurodegenerative diseases, including but not limited to Alzheimer’s disease.

These projects have all been launched by the world’s biggest public-private partnership in the life sciences, the Innovative Medicines Initiative (IMI). Neuronet aims to assist in identifying gaps in research, multiply the impact of findings and enhance project visibility, whilst also facilitating connections with related initiatives in Europe and worldwide.
Alzheimer Europe will support the transition towards a federated IMI neurodegeneration research portfolio by co-leading the Neuronet communications and dissemination team. Alzheimer Europe will also lead on the development of guidelines and advice on the protection of patient privacy, as well as other tasks related to the development of tools and services for the Neuronet portfolio.

**10 August: MinD project completes design evaluation in four countries**

Now in its fourth and final year, the MinD project team is working on drawing together all the insights from this research. During this secondment, which took place in the Netherlands during July 2019, seven visiting colleagues spent two weeks, hosted by their Dutch partners, analysing and comparing findings from the design evaluations, improving parts of the designs, writing up findings for publications and preparing for the MinD conference.

At the University of Twente (UT), colleagues met to hear about and discuss the evaluation results from the Good Life Kit (GLK). Thomas van Rompay, UT, presented the findings from the Dutch evaluation conducted with partner Zorggroep Sint Marten. Rosa Almeida and Irene Gonzalez from INTRAS, Spain, presented their results, followed by Kristina Niedderer, Manchester Metropolitan University, and Jennifer Lim, University of Wolverhampton (UW), who worked on and presented the results from the evaluation in the UK. Results from the evaluations in Germany will be added in September.

The results so far show great promise for the ‘This is Me’ board game of the GLK, while the ‘Living the Life’ reflective booklet needed further development, said project coordinator Kristina Niedderer.

Alessia Macchi from Duit, Italy, Sebastian Lorenz from the Technical University Dresden, and Dew Harrison, UW, worked on the improvement of the content and a new, nature-inspired design.

The other major task of the secondment was drawing together findings in various publications for conferences, book chapters, and other, publicly accessible documents. Researchers picked up on the work from the previous secondment to revisit, improve and complete publications, such as design guidelines and policy recommendations for designers, dementia care organisations and anyone else wishing to engage in co-design and use design to improve the quality-of-life for people with dementia.

Alongside this, preparations for the international MinD conference, taking place on 19-20 September 2019, in Dresden, are coming to fruition. The full programme is now available, with three keynote speakers (design, health professions and lived experience speaker), and a variety of papers, design proposals and workshop sessions by a wide range of international presenters. Further details are available on the conference website: www.mind4dementia.eu

Last but not least, colleagues enjoyed once more the amazing “Deventer op Stelten” street theatre festival with its spectacular sights and sounds (pictured).

**26 August: MIRIADE project funded to accelerate the search for biomarkers**

The MIRIADE project has received a Marie Skłodowska-Curie Innovative Training Network grant from the European Union. Fifteen researchers in training will develop into experts in the field of biomarkers for dementia.

The diagnosis of various forms of dementia can be made more accurately with use of biomarkers. Biomarkers, in this context, are proteins in body fluids such as cerebrospinal fluid or blood. Biomarker tests must be accurate and reliable to have clinical value. MIRIADE aims to improve the workflow for the development of biomarker tests, to move biomarkers to clinical practice expeditiously. Next to diagnostic purposes, there is a great demand for good biomarkers in testing the effectiveness of new medicines.

The latest technologies in the field of biomarker research will be compared in MIRIADE, resulting in a blueprint for biomarker development for dementia. The MIRIADE consortium is spread over 12 countries (Belgium, France, Germany, Italy, Luxembourg, Netherlands, South Korea, Spain, Sweden, Switzerland, United Kingdom and United States) and includes several disciplines, including assay development, big data integration, biocomputation, process innovation, regulatory affairs, patient involvement, and more.

The fifteen researchers in training will be hosted across the consortium partners and will be involved in research, in a network-wide training programme, and public engagement activities. Moreover, they will strongly collaborate with network partners, through short-term secondments at industrial/academic partners within the consortium.

The kick-off of MIRIADE is 1 November 2019 and applications for researchers in training are open from that date. Interested candidates are welcome to get in touch before this date, via email: miriade@vumc.nl

[Donate Now! Help us make dementia a priority]
**28 August: The AMYPAD Prognostic and Natural History Study recruits from non-EPAD cohorts**

On 28 August, the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project released its tenth external newsletter and reported the important advances that have been made during the past quarter notably in the AMYPAD Prognostic Natural History Study (PNHS) aiming to follow up and understand the natural history of Alzheimer’s disease ranging from cognitively normal, through subjective cognitive decline towards mild cognitive impairment in order to define the optimal window of opportunity for secondary prevention of Alzheimer’s disease through β-amyloid PET imaging. To better understand the natural history of β-amyloid pathophysiology, AMYPAD PNHS is conducted in connection with the European Prevention of Alzheimer’s Dementia (EPAD) Longitudinal Cohort Study (LCS).

The past months have seen good progress in the AMYPAD PNHS, with the activation of new sites and the increased recruitment rate. 5 Wave 1 sites are now active and recruiting participants:
- VUmc, Amsterdam, The Netherlands
- UEDIN, Edinburgh, UK
- BBRC, Barcelona, Spain
- UNIGE, Geneva, Switzerland
- CHUT, Toulouse, France.

**EU DEVELOPMENTS**

**28 June: European Commission launches consultation on future objectives for EU-funded research and innovation**

The Commission has started to prepare the implementation of the Horizon Europe programme. The first Horizon Europe Strategic Plan (2021-2024) will identify major policy drivers, strategic policy priorities, and targeted impacts to be achieved, as well as identify missions and European Partnerships. You can have your say on future objectives for EU-funded research and innovation by participating in a consultation, launched by the Commission, on 28 June. It invites anyone with an interest in future EU research and innovation priorities to participate in the consultation, which closes on 8 September 2019.


**7 July: Latest Eurobarometer survey published by European Commission**

The European Commission has announced the names of those who will chair the mission boards for the five mission areas, which will receive specific funding as part of the next Horizon Europe research programme which will run 2021-2027. The chairs for the dedicated missions are:
- Ms Connie Hedegaard, former European Commissioner for Climate Action, for the mission on ‘Adaptation to Climate Change including Societal Transformation’. 

**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; Neuronet – grant agreement 821513.

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CHUT and UNIGE have both been activated within the last quarter. As of the end of August 2019, 454 subjects have been informed of which 220 consented. A total of 157 participants have been scanned so far. The team also received approval to include Wave-2 sites in France, UK, Sweden and Spain. The following quarter will see these sites become activated.

The consortium members have recognised the need to engage additional ongoing cohorts from which to recruit in order to achieve the goal of recruiting up to 2,000 participants. As such, considerable progress has been made in the identification and inclusion of non-EPAD cohorts as parent cohorts for the PNHS. The first non-EPAD cohort started recruiting at the VUmc in May 2019, this is called the EMIF-AD Twin cohort. As expected, this additional cohort has really helped boost recruitment. Furthermore, two other cohorts have recently been approved for inclusion: ALFA+ in BBRC and GAP in CITA (San Sebastian, Spain) became the second and third non-EPAD cohorts to join the PNHS. Additional cohorts have already been approached to assess the potential of an AMYPAD PNHS collaboration, details of these cohorts will follow in due course.

The expectation is that the recruitment rate continues to increase with the approval and activation of Wave-1, 2 sites and non-EPAD cohorts reaching approximately 500 subjects enrolled by the end of the year. Considering the recent progress, the team is confident that the AMYPAD PNHS will reach its objectives by the end of the project.
• Professor Harald zur Hausen, Nobel Prize Laureate in Physiology or Medicine, for the mission on ‘Cancer’.
• Mr Pascal Lamy, former Trade Commissioner and Director-General of the World Trade Organisation, for the mission on ‘Healthy Oceans, Seas, Coastal and Inland Waters’.
• Professor Hanna Gronkiewicz-Waltz, former Mayor of Warsaw, for the mission on ‘Climate-Neutral and Smart Cities’.
• Mr Cees Veerman, former Dutch Agriculture Minister, for the mission on ‘Soil Health and Food’.

The first deliverable of each mission board will be to propose concrete targets and timelines for each mission by the end of 2019. You can find out more about the Mission Boards, their members and their work on the European Commission’s website.

14 July: Joint call for all sponsors to publish clinical trial results in EU database

The European Commission (EC), the European Medicines Agency (EMA) and the Heads of Medicines Agencies (HMA) have co-signed a letter reminding all sponsors of clinical trials conducted in the European Union of their obligation to make summaries of results of concluded trials publicly available in the EU Clinical Trials Database (EudraCT).
The letter emphasises the importance of transparency and public access to clinical trial results, regardless of outcome, as fundamental in the protection and promotion of public health. Additionally, the letter notes that it is the responsibility of sponsors to ensure that protocol information and results of all clinical trials are submitted in EudraCT; this information is publicly available through the EU Clinical Trials Register (EU-CTR).
Since July 2014, sponsors are required to post results within one year after the end of a clinical trial (or six months for a paediatric trial). This information is also shared with the World Health Organization’s (WHO) International Clinical Trials Registry Platform (ICTRP) of which EU CTR is a primary registry. Analysis showed that in EudraCT, the reporting compliance of non-commercial sponsors (e.g. academia) was much lower than for commercial sponsors (i.e. companies), with 23.6% of results posted for non-commercial sponsors vs 77.2% for commercial sponsors. Academic sponsors or smaller companies often lack awareness or incentives to post clinical results, therefore EU authorities are taking various steps to ensure sponsors are aware of their obligations and can act on them.

The letter to stakeholders is co-signed by Anne Bucher, Director General of the EC’s DG Health and Food Safety, Guido Rasi, Executive Director of EMA, and Thomas Senderovitz, Chair of the HMA Management Group. It will be disseminated to various stakeholder groups, with a specific focus on ensuring it reaches academic sponsors.
The full letter to stakeholders can be found here: http://bit.ly/2lxAsi4

15 July: European Commission launches Support Centre for Data Sharing

The EU Commission, through its Connecting Europe Facility (CEF) funding instrument, launched a call for tender to set up a Support Centre for Data Sharing in June 2018. The objective of the Support Centre is to facilitate public and private sector data transactions, providing practical support to make these exchanges easier. The Support Centre will also monitor data sharing activity, providing public authorities with up-to-date information on data sharing transactions within the EU digital economy.

The Support Centre for Data Sharing (SCDS) went live on 15 July 2019, with a scaled-down website that provides examples of data sharing practices, news items on data sharing developments and a calendar of events related to data sharing. Users of the website are invited to give feedback on their needs with regards to technical and legal aspects of data sharing; once collated, these responses will inform the development of the respective technical and legal sections of the SCDS website.
A full version of the SCDS website will be launched in autumn 2019. The full website will include links to an API training module, a forum for exchanging knowledge and experiences within the data sharing community, and updated information on legal and technical aspects of data sharing.

16 July: European Parliament confirms Ursula von der Leyen as European Commission President

The newly elected European Parliament has voted to confirm the first female President of the European Commission, Ursula von der Leyen. Ms von der Leyen previously served as the Defence Minister in the German Federal Government.
Parliament currently comprises 747 MEPs, therefore the total number of votes required
to confirm the nomination was 374 votes. Following a secret ballot of these members, it emerged that 383 votes had been cast in favour of confirming Ms von der Leyen, with 327 against and 22 abstentions. She will take office on 1 November 2019 for a five-year term.

The Commission President-elect will now officially contact the head of state of each Member State, inviting them to propose a candidate to join the College of Commissioners.

The European Council, in agreement with the Commission President-elect, then adopts the list of candidate commissioners (one for each Member State - although the UK has indicated it will not nominate a candidate). The Commissioners-designate will then appear before parliamentary committees of their proposed portfolio, with these hearing likely to take place late September/early October.

Each committee will then draw up an evaluation of the suitability of the candidate, which will be sent to the Conference of Committee Chairs. Following discussion, these are then sent to the President of the Parliament, as well as to the Conference of Presidents to conclude the process of the hearings.

The full Commission, including the Commission President and the High Representative for Foreign Affairs and Security Policy, then needs to be approved in a single vote of consent by Parliament. If the President and Commissioners have been approved by Parliament, they are formally appointed by the European Council, acting by a qualified majority.

Hearings of the nominees in Parliament’s competent committees are scheduled to take place between 30 September and 8 October. The vote on the approval of the full College of Commissioners will then likely be held during the plenary session between 21-24 October.

The new Commission, along with the new ECB President, are due to take office on 1 November. The new European Council President will take office on 1 December.

25 July: European Commission opens Digital Europe consultation

The European Commission has launched a public consultation on the future of its new seven-year Digital Europe infrastructure plan, which aims to invest 9.2Bn EUR in supercomputing, artificial intelligence, advanced digital skills and societal uptake of new technology. To implement the plan, the Commission is aiming for the EU’s contribution of 9.2Bn EUR to be matched by participating member states.

The purpose of the Digital Europe plan is to increase the use and development of European technologies, reducing the need for use of US and Asian products and services. As part of this, there is a significant focus on strengthening Europe’s infrastructure in computing and communications. Of note within the proposals:

- 2.78Bn EUR is allocated to supercomputing and data processing infrastructure, to facilitate innovation in the healthcare sector, improve driverless car safety and accelerate the development and use of renewable energy.
- 2.5Bn EUR is to be invested in artificial intelligence-based technologies and 2Bn EUR goes to cybersecurity.
- 700M EUR is earmarked for digital skills development.
- 1.3Bn EUR is proposed to implement e-government services.


1 August: European Commission expert panel publishes document on defining value based health care

The European Commission’s Expert Panel on Effective Ways of Investing in Health, has published a document setting out a definition of value based healthcare and providing recommendations about how it should be implemented.

The paper notes that present discourse around “value” in the context of healthcare is often focused on outcomes relative to the cost of inputs, solely focused on increasing cost-effectiveness.

The expert group notes that this definition is too narrow and suggests it would be more helpful to acknowledge multiple values which underpin healthcare. Specifically, the paper outlines a definition which encapsulates:

- Appropriate care to achieve patients’ personal goals (personal value)
- Achievement of best possible outcomes with available resources (technical value)
- Equitable resource distribution across all patient groups (allocative value)
- Contribution of healthcare to social participation and connectedness (societal value).

The panel also made six recommendations as to how this approach could be embedded within healthcare systems:

- Creating greater awareness of health as an essential investment in an equal and fair European society
- Developing a long-term strategy for a step-by step value-based approach towards change of culture
- Supporting research & development of methodologies on appropriateness and unwarranted variation
- Encouraging health professionals to take responsibility and feel accountable for increasing value in healthcare
- Supporting the creation of Learning Communities, including communities of health professionals
- Supporting initiatives for patients’ engagement in shared decision-making.


2 August: Work-life Balance Directive comes into force

The Work-life Balance initiative, a key deliverable of the European Pillar of Social Rights, has come into effect across the European Union. As the measure is a Directive, countries have three years to transpose this law into national legislation and give effect to its provisions. This initiative aims to create a better balance between parents and people with caring responsibilities in relation to their working and family lives.

As well as a number of measures specifically aimed at improved parental leave, the legal measures within the Directive include specific measures for carers, including:

- Introduction of carers’ leave for workers providing personal care or support to a relative or person living in the same household, with carers being able to take up to 5 days per year.
- An extension of the existing right to request flexible working arrangements (reduced working hours, flexible working hours and flexibility in place of work) for all carers, and for parents with children up to the age of eight.

A number of non-legislative measures to complement the legislative proposal have also been published, including:

- Ensuring protection against discrimination and dismissal for parents and carers.
- Encouraging a gender-balanced use of family-related leave and flexible working arrangements.
- Making better use of European funds to improve provision of formal care services (childcare, out-of-school care and long-term care).
- Removing economic disincentives which prevent access to the labour market or working full-time.

The Communication: An initiative to support work-life balance for working parents and carers sets out the full range of legal and policy measures.

5 August: João Ferreira MEP submits written question on Alzheimer’s disease in European Parliament

João Ferreira MEP (Portugal) has submitted a written question in the European Parliament, focusing on research on Alzheimer’s disease, as well as the disbanding of the Government Expert Group on Dementia.

The first part of his question focuses on news reports related to the use of Enbrel and the data which was reported to have suggested some association between its use and a reduction in the risk of developing Alzheimer’s disease.

There are then a number of strands to the question, including:

- What (public and private) projects the EU is supporting to tackle Alzheimer’s.
- Why the Commission disbanded the Governmental Expert Group on Dementia.
- Whether the Commission intended to encourage Member States to share expertise and best practices and to adopt national strategies to tackle Alzheimer’s.


13 July: Slovenian care homes organise summer day-care for children to promote better intergenerational relationships

In the high season, a few Slovenian care homes organise summer day-care for children, aged 5-12 years. The idea was developed last year, within the home Danice Vogrinec (named “best facility for elderly care, including unit for PWD in Europe 2018” by EAN ECREAS, and part of Spominčica’s Dementia Friendly Spots network). This initiative is part of the project “Intergenerational centre Štajerska”.

Care homes provide day-care on working days from 7am to 3pm, during which time trained animators and volunteers organise thematic and interactive workshops (water games, craftwork, ice picnics, music and dance classes, among others). They also give informative tours inside the facility, so the children can learn and see how the institution operates and what working shifts look like. Children also visit urban parks and libraries.

Some of the care-home residents are also able to take part in these day-care sessions, with the children, which contributes to building better intergenerational relationships and bigger social networks for both target groups.

First impressions of the initiative are very promising, with many of the children reporting that they enjoyed listening to the stories older people told them from their younger days. The children’s parents were also positive in their feedback, saying that they knew their children were in safe hands and were having meaningful experiences, as well as having fun.
The professionals involved reported less prejudices and stereotypes around ageing, among the children taking part, attributed to the fact the children could see for themselves how the older people and that they could still have a great time together.

18 July: Alzheimer Bulgaria visits Hewlett Packard Enterprise (HPE) Bulgaria

On 18 July, volunteers from Alzheimer Bulgaria had the pleasure of visiting one of the leading international companies in Bulgaria - HPE Bulgaria. During the visit, volunteers from Alzheimer Bulgaria presented information about the causes and manifestations of various types of dementia, how it affects patients, relatives and the whole of society. They also presented some of the projects and services currently under development. The project Dementia Friends Bulgaria was presented and Alzheimer Bulgaria is proud to say that 17 new young people from HPE joined its community. Dementia Friends Bulgaria, now has 149 friends across the country. The Alzheimer Bulgaria team is thankful for the support of HPE and will be happy to participate in other similar seminars and initiatives together, to overcome the stigma related to dementia, and to create a more dementia-friendly society.

23 July: Spominčica presents “the global voice of dementia” at French conference

In June 2019, Štefanija L. Zlobec, president of Spominčica (Alzheimer Slovenia), attended the conference “Bistrot Mémoire” in Rennes, France, where she gave a presentation on “The global voice of dementia”, on behalf of Spominčica and Alzheimer’s Disease International (ADI). Her presentation outlined progress made in terms of National Dementia Strategies adopted across the globe, as well as highlighting examples of awareness-raising campaigns. Ms Zlobec also shared good practices from Slovenia. Over the past two years, a network of “Dementia Friendly Spots” (DFS) has been built. It not has 140 members and has become a recognised example of good practice on how to raise awareness at local level and how to empower residents to live well with dementia and to retain an active role in society. The DFS initiative works by informing staff in shops, banks, post offices and pharmacies, as well as policemen and other community pillars, about dementia, to empower them to better support people living with the condition. So far, Spominčica has opened DFS at the Office of the Human Rights Ombudsman, the Social Chamber of Slovenia, the Ministry for Social Affairs, and the Red Cross, as well as at various community health centres, centres for social work, administrative units and other similar locations.

One of the sessions at the Bistro Memoire conference was dedicated to minority groups with dementia. It was emphasised that minority groups have emerged as an important section of the population to be taken into consideration when debating issues around dementia.

25 July: Joël Jaouen re-elected as President of France Alzheimer

Joël Jaouen has been unanimously re-elected, for the fourth year in a row, as president of France Alzheimer. France Alzheimer is a member of Alzheimer Europe and we warmly congratulate Mr Jaouen on his re-election and look forward to continuing our collaboration with him and his colleagues. To find out more about the governance of France Alzheimer, see: https://www.francealzheimer.org/notre-gouvernance/

27 August: Alzheimer’s Society celebrates 20 years of embedding personal experience in dementia research

This year, Alzheimer’s Society (UK) is celebrating 20 years of its Research Network. Volunteers, who all have personal experience of dementia, help the Society to decide which research it funds and partner with researchers across the UK. These passionate and dedicated volunteers ensure the research the Society funds tackles the issues that could transform lives. As well as working closely with the Society, these volunteers have driven change across the UK’s research community. Alzheimer’s Society shares just a couple of their success stories:
Making big changes
In the early 2000s, 25% of people with dementia were prescribed antipsychotics. But research showed that these drugs were not effective and in fact could have harmful side effects.

Alzheimer’s Society’s Research Network volunteers worked with researchers from King’s College London to make a real change. Together, they brought this major health issue to the forefront of the political agenda. They worked with the UK Department of Health to create a best-practice guide, now widely used nationally and internationally.

Since then, there has been a 60% reduction in the prescribing of antipsychotic drugs for people with dementia.

John’s story
In research, collaboration is key. John Lanyon is a Research Network volunteer who cared for his mother. He partnered with Katrina Moore, an Alzheimer’s Society-funded PhD student.

John is the co-founder of KareInn, a company that develops technology to improve care in elderly care homes. Katrina has developed an innovative smartphone app to diagnose frontotemporal dementia at the very earliest stages, and John was able to support her brilliant research. Sharing personal experience of dementia and other skills and knowledge is invaluable to researchers, like Katrina, driving dementia research forward.

Alzheimer’s Society said:
“We’ve come a long way in 20 years, but there’s still a long way to go. We need to find a cure and make sure people with dementia get the care they need. Our Research Network will continue to support researchers across the UK and maximise the impact their research could have.

United we will transform the lives of everyone affected by dementia through research.”

Find out more about Alzheimer’s Society’s Research Network:
www.alzheimers.org.uk/research/get-involved/our-research-network-volunteers

27 August: Panhellenic Federation of Alzheimer’s Disease and Related Disorders “Bridge” project launches website

The Panhellenic Federation of Alzheimer’s Disease and Related Disorders is the coordinator of the Erasmus+ KA2 project entitled “BRIDGE” and is pleased to launch its new website platform https://projectbridge.eu/. The project aims to create serious games, treating cognitive and behavioural symptoms of dementia through various workshops, which engage younger and older people alike. Through various steps, the project will design, produce and test a number of serious games (physical, digital or “phygital”) targeted at people with dementia. By adopting a transnational approach in the project, through the cooperation of organisations and institutes at European level, the consortium will:

- Exchange knowledge and experiences from a variety of disciplines and institutions across Europe
- Build upon the efforts of local institutions to increase public awareness of dementia
- Create and promote games to improve the cognitive and behavioural symptoms of people with dementia
- Create tailored content in games, as a result of the collaborative work between healthcare professionals, members of the general public, university students, and game designers
- Contribute to the multiplier effect at European level.

During the workshops, selected young people will attend an informative training on dementia, in order to prepare them for interacting with people with dementia. After that, they will participate in the design process of the game. They will co-design and play several games in collaboration with game designers, software developers, healthcare professionals, people with dementia and careers. At the end of this creation process and during the project, at least 8 fully-working games will be developed.

The main aims of the project are:
- To increase awareness of dementia in young adults.
- To explore and showcase the possibilities of using games as tools for improving the quality of life of people with dementia
- To engage young people over the age of 15 in volunteering
- To empower generation bonds through playful intergenerational activities and game creation workshops.
- To involve professionals, volunteers and people with dementia in the creative process of suitable games.
Alzheimer Larissa Greece (ΕΕΝΑΛ) has been working for many years with people with mild cognitive impairment or dementia, encouraging them to maintain and exercise their mental skills through regular meetings. Art has been always a meaningful tool during sessions, either as a creative activity or as a means of communication, enabling trips down memory lane. On the other hand, promoting the maintenance of brain health to healthy people is always challenging, especially as people do not share the same interests, or have already chosen to follow a single hobby. A new plan was therefore implemented, using art as a medium and advertised to the general public, but also welcoming those with dementia. The pilot programme began at the start of 2019, under the direction of Dr Artemissia-Phoebe Nifli, focusing on verbal skills and socialising. So far, two groups of diverse ages and backgrounds completed the sessions, and provided evaluations about meeting personal objectives for cognitive enhancement, concentration or motivation.

Another aspect of this work is to encourage individuals to embrace their role as facilitators. There was therefore a second “field” challenge. In continuance of the fruitful collaboration with Maria Zisopoulou and the School of Art of the Municipal Gallery of Larissa- G.I. Katsigras Museum, Alzheimer Larissa invited the participants to join the active exhibition INTERCONTACT (ΔΙΕΠΑΦΗ). The visit was structured in accordance with the main theme of the exhibition, and the approach applied during the workshops. First, the artists themselves provided an interactive tour, during which they occasionally personified each other, and addressed questions, until the final disclosure of their real identity. Secondly, they discussed specific forms and colours and how Maria Zisopoulou’s black and white curves, and Dimitra Oikonomou’s colourful polygons contributed to the character of the exhibition. Finally, the artists supervised the integration of these elements in a live drawing performance, while participants moved about and networked. A third group is expected to join ΕΕΝΑΛ’s efforts during the upcoming World Alzheimer’s Month (September). Alzheimer Larissa is looking forward to their feedback.

On 28-29 June 2019, the leaders of the G20, met in Osaka, Japan, to address major global economic challenges. The G20 is an international forum for the governments and central bank governors from 19 countries and the European Union (EU). After the summit, the G20 leaders released a final declaration, point 31 of which says:

“We will promote healthy and active ageing through policy measures to address health promotion, prevention and control of communicable and non-communicable diseases, and through people-centred, multi-sectoral, community-based integrated health and long-term care over the life course in accordance with national context including demographic trends. We will implement comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers.”

It is the first time that dementia, healthy ageing and non-communicable diseases are placed prominently on the agenda of the G20, which is very encouraging.

You can read the full declaration, here:


“The Irish Government is ignoring the health crisis of our time” - This was the emotional message from Dr Helen Rochford Brennan, at the launch of The Alzheimer Society of Ireland (ASI) Pre-Budget Submission 2020 “Dementia Supports Across Ireland – Still Asking, Still Waiting, Still Struggling”, launched in July 2019.
The ASI is calling on the Irish Government to urgently fund community supports and home care for people living with dementia. The Submission details what the EUR 18.4 million national investment proposal could begin to do, to support people with dementia and their struggling families across the country.

At the launch there was the highest ever turnout of TDs (members of parliament), Senators and political representatives - 58 in total. Over 40 of these also signed a pledge to commit their support to lobby the Government for a minimum level of dementia services and supports in every county, a very encouraging start to the campaign.

The speakers included Chair of The ASI, John Clifford, CEO Pat McLoughlin and carer, journalist and advocate Teena Gates. Dr Rochford Brennan, Chair of the European Working Group of People with Dementia (EWGPWD) who was diagnosed with Alzheimer’s disease in 2012, also gave a moving presentation, emphasising the theme of the campaign. She is tired of still asking, still waiting and still struggling.

Her presentation was accompanied by a video capturing her advocacy work over the last 6 years. Dr Rochford Brennan has witnessed numerous “false dawns” as successive Budget Days have come and gone without any ring-fenced funding for dementia-specific supports and services.

All of the presentations and this video are available to view on The Alzheimer Society of Ireland’s YouTube channel.

For more information, please contact Avril Easton, Advocacy Manager, on avril.easton@alzheimer.ie

The UK Government’s social care Green Paper was announced in March 2017 and was due to set out a long-term funding solution for social care funding; however, it has been delayed six times, with no indication of when it will be published.

The analysis from the Alzheimer’s Society shows that:

- People affected by dementia have spent almost GBP 15 billion (approximately EUR 16.5 billion) of their own money on social care since March 2017, compared to less than 10 billion (approximately EUR 11 billion) spent by government.
- Since March 2017 people with dementia have spent more than one million unnecessary days in hospital beds, despite being well enough to go home, costing the NHS over GBP 340 million (approximately EUR 374 million).

Additionally, during the same period, the total number of people aged over 65 diagnosed with dementia has increased by 33,000 in England, increasing the demand for services and supports. Furthermore, people with dementia face higher costs for their care, with supports and services, on average, 15% more expensive than standard social care. The analysis estimates that people with dementia spend GBP 100,000 (EUR 110,000) on care, despite people with cancer or heart disease having their care costs covered by the NHS.

As a result, the Alzheimer’s Society is calling for a dedicated GBP 2.4 billion (EUR 2.6 billion) Dementia Fund to end the inequity in social care funding. The Dementia Fund would sit within the NHS and would cover the additional social care costs for people with dementia.


9 July: Alzheimer’s Society gathers cross-party support for action on dementia care using photo exhibition in UK parliament and calls on new government to address the issue

For too long, England’s dementia care crisis has been hidden behind closed doors, lived by people who rarely have opportunities to be heard. To draw much-needed attention to this issue, on 9 July, Alzheimer’s Society held a photo exhibition in parliament, titled “Dementia Care: The Crisis Behind Closed Doors”.

5 July: People with dementia in England have spent almost EUR 16.5 billion of their own money on care since 2017

The Alzheimer’s Society (UK) has published a new analysis indicating that people living with dementia in England have had to spend almost GBP 15 billion (EUR 16.5 billion approx.) of their own money on social care, since the UK Government first proposed reforms to the system in March 2017.
The exhibition featured 12 families affected by dementia, all of whom have struggled to access affordable, good quality care. Their stories mirror what Alzheimer’s Society hears every day, when they are contacted by people with dementia and their families struggling to navigate the social care system, and get the care they need. Too many people experience stress and anguish fighting for the appropriate support.

120 Members of Parliament (MPs) from across all the main political parties attended, and were reminded of the human cost of England’s prolonged social care crisis. Eight of the families featured in the exhibition attended the event, and spoke to MPs in more detail about their experiences. The photo exhibition was a creative way for Alzheimer’s Society to ensure that addressing the injustice faced by people living with dementia is a priority for the new government.

After walking through the exhibition, MPs were invited to sign a letter to the new Prime Minister, Boris Johnson, asking him to address the issue of dementia care by including a Dementia Fund in this year’s Spending Review. 96 MPs signed the letter, indicating that there is cross-party support for action on dementia care.

Alzheimer’s Society has now launched a public letter to the Prime Minister, echoing the call for him to take decisive action on dementia in the Spending Review this autumn. They are making sure, through work both inside and outside of parliament, that dementia care is an issue which can’t be ignored any longer.

Read more about the Alzheimer’s Society’s dementia care campaign: https://www.alzheimers.org.uk/get-involved/our-campaigns/fix-dementia-care

15 July: World Dementia Council embarks on global review of dementia friendly initiatives

For anyone interested or involved in providing services or activities for people with dementia, their main concern is for the participants. The activities need to have a positive impact for those involved and the communities they live in, and they need to be sustainable.

Proving they have an impact isn’t straightforward, and comparing activities is almost impossible, as local challenges vary considerably. However, if more dementia friendly activities are to flourish and be sustainable, their effectiveness needs to be demonstrated.

This is the aim of a new project, led by the World Dementia Council and involving the Alzheimer’s Society (UK), AARP, the Health and Global Policy Institute in Japan, Alzheimer’s Disease International and the World Health Organization (WHO). The project is seeking to understand the evidence that underpins the impact of dementia friendly initiatives (DFIs).

At the recent Alzheimer’s Association International Conference (AAIC) in Los Angeles, US, the World Dementia Council convened a meeting of global academics, civil society, local organisers, and people affected by dementia to discuss dementia friendly activities, what impact they are aiming to achieve and the challenges of evaluating success.

The challenges of defining “dementia friendliness” and how that shapes what the project aims to measure were on the agenda. Participants also talked about the need for social change such as reducing stigma. They stressed the importance of removing barriers preventing people with dementia from leading active lives. Dementia Friendly Initiatives seek to remove these barriers, to ensure access and decrease isolation.

This prompted discussions on the biggest theme of the meeting, the difference between inclusivity versus the provision of activities that are meeting a specific need of affected people. This theme of inclusion and equality ran throughout the meeting. It was agreed that inclusion is inherently good and that “friendliness” is not the goal but a pathway, or perhaps a sign post on the road to an inclusive society.

If you are involved in the development, delivery or evaluation of initiatives, and would like to contribute to this report, the World Dementia Council would love to hear from you. You can find a survey and information about how to share your views and evidence, at:

http://www.worlddementiacouncil.org/

29 August: Alzheimer Scotland calls on Scottish political parties to include commitment to deliver fair dementia care in 2021 election manifestos

Alzheimer Scotland’s “Fair Dementia Care” campaign seeks to ensure that people in Scotland with advanced dementia have equality of access to the expert health and nursing care they need which is free in line with other progressive and terminal illnesses. “It’s informed by what people living with the experience of advanced dementia and those who care for them have been telling us in the thousands of interactions we have with them”, stresses Alzheimer Scotland.

These are stories of people’s experiences of struggling with changing and increasingly complex needs; of trying and sometimes fighting to get help; of crisis; of moving between
care homes because their needs couldn’t be met; of repeated admissions to hospital or specialist dementia care; of delayed hospital discharges while funding was agreed and of family members feeling exhausted and sometimes guilty. On top of all of that; the additional anxiety and worry of the financial impact on the person and their family of social care charging. This is anxiety and worry which is often unnecessarily compounded by the complexity, lack of transparency and bureaucracy of social care charging policies. These experiences demonstrate not just the glaring inequalities faced by people with advanced dementia, their families and their carers but the devastating impact of those inequalities on their lives. This campaign is backed by people with lived experience of the inequity people with advanced dementia face.

Alzheimer Scotland is talking to all main Scottish political parties and asking them to include a commitment to deliver fair dementia care in their election manifestos for the May 2021 Scottish Elections. They also need to continue to build public support to help achieve political commitment. In order to do this, they are asking people to sign up to the campaign. Alzheimer Scotland has set a target of getting 10,000 signatures backing the campaign, which will demonstrate the public support they have. They are also asking for people to share their experiences of the inequalities people with advanced dementia are facing. Their aim is to help end this inequality, but they can only do that with have public and political support.

To sign up to the Fair Dementia Care campaign, visit www.alzscot.org/fairdementiacare or call the Helpline on 0808 808 3000 (UK) to receive a hard copy postcard to complete.

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**AAIC WATCH**

We present some highlights emerging from this year’s Alzheimer’s Association International Conference (AAIC), held from 14 to 18 July 2019 in Los Angeles, USA.

Alzheimer Europe was represented at the event by Executive Director Jean Georges.

16 July: AAIC launches press release on sex differences in AD

On 16 July, the Alzheimer’s Association launched a press release on a series of findings focussed on the sex-differences in AD that were presented during its conference.

As part of the conference presentations, researchers from the United Kingdom reported on the preliminary findings from an analysis aimed to better understand how women’s work-family demands (paid labour force participation, marriage, motherhood) may play a role in late-life memory decline. The study encompassed 6.386 women born between 1935 and 1956. It included reports of waged employment, marital and parenthood status but also results on memory performance tests that were conducted every 2 years after the participants were older than 50.

The team found that women who participated in the paid labour force between early adulthood and middle age (including mothers and non-mothers), experienced slower memory decline in late-life. They further reported that the rate of memory decline was fastest among women who did not engage in waged employment.

Another study team looked at levels of amyloid (a biomarker for AD) from 1.022 participants and analysed how well their brains metabolized glucose in regions affected by AD. In addition to this, they also evaluated their performance in verbal memory tests.

The teams’ results supported previous evidence that women outperform men in verbal memory tests when their brains show a minimal to moderate amyloid plaque deposition. However, the scientists reported that there was no difference when comparing men and women with severe amyloid deposition. The researchers also announced that they found higher levels of brain glucose metabolism in women than in men when they compared the groups who had minimal to moderate levels of amyloid. These finding led the team to the conclusion that women may better compensate early-stage AD-related brain changes than men, which in turn may contribute to women’s better verbal memory performance.

Another team drew on data from 5.522 participants to find new sex-specific genetic associations with AD and reported on 11 genes that may be relevant to the development of AD, some of which are only related to men (MCOLN3 and CHMP2B) and some of which only to females (CD1E and PTPRC).

Apart from the differences in genes, biomarkers – in this case tau - for AD may also spread differently through the brains of men and women. To learn more about these potential differences, another team of researchers involved 201 healthy participants and 161 participants with mild cognitive impairment, who received brain scans. The scientists reported that the overall tau network looked very different for men and women when they presented mild cognitive impairment.
They found that healthy women had several key brain regions that served as “hubs”, connecting different brain areas within the network. These included parahippocampus, superior parietal, insular, superior temporal. This finding led them to the speculation that the connectivity may favour an increased brain-wide tau spread in women that could in turn lead to faster cognitive decline.


16 July: Grifols presents additional results from its Phase Ib/II study in people with mild and moderate AD

On 16 July, the Spanish multinational pharmaceutical and chemical manufacturer Grifols presented additional data of its AMBAR Phase Ib/II clinical trial for the treatment of Alzheimer’s disease (AD) at the Alzheimer’s Association International Conference (AAIC) in Los Angeles.

The multicentre, randomised and controlled AMBAR study is based on the hypothesis that most of the amyloid-beta protein is bound to albumin and circulates in the plasma. The study was designed to determine whether the progression of AD could be stabilised through plasma exchange, a process that extracts plasma and replaces it with infusion of human albumin combined with intravenous immunoglobulin. The study included almost 500 people with mild and moderate AD in Spain and the US.

The data presented showed that in the primary endpoints there was a 61% statistically significant reduction in disease progression in participants with moderate AD. Additional findings showed positive change in assessments of cognitive status and daily functioning in all treated participants. A statistically significant 71% less decline in treated participants compared to those who received the placebo was observed on the CDR-Sb scale, which assessed memory, orientation, judgment, community affairs, home and hobbies and personal care. On the ADCS-CGIC scale, which assesses cognition, daily functioning and behaviour, researchers noted a significant improvement in treated participants compared with placebo. Additional results will be presented at the 12th Clinical Trials on Alzheimer’s Disease (CTAD) conference in San Diego in December 2019.


16 July: Oryzon Genomics presents initial data from ETHERAL Phase IIa trial in AD

On 16 July, the biopharmaceutical company Oryzon Genomics, which develops epigenetics-based therapeutics in oncology and neurodegenerative diseases, presented data from its ongoing Phase II clinical trial in Alzheimer’s disease (AD) at the Alzheimer’s Association International Conference (AAIC) held in Los Angeles.

ETHERAL is a Phase IIa multicentre, multinational, randomised, double-blind and placebo-controlled study evaluating the safety, tolerability and preliminary efficacy of two doses of ORY-2001 in participants with mild-moderate AD. ORY-2001 is an oral and brain penetrant drug that may reduce cognitive impairment, memory loss and neuroinflammation.

The company presented data from the first 104 recruited from the 125 European participants (49% with mild AD and 59% with moderate AD). Safety data from these first 104 participants, being treated for more than 1 month, reported that ORY-2001 is safe and well tolerated so far. Furthermore, no significant safety issues have been reported from the 36 participants who have already passed the 6-month threshold of treatment.

An initial blind analysis on the first 33 participants who have completed the first 24 weeks of treatment was presented. Although some participants show disease progression in cognition and behaviour measures, others maintain baseline values or show improvement. Similarly, encouraging changes have been detected in cerebrospinal fluid levels of S100A9, a pro-inflammatory biomarker described as an important contributor to AD pathology. The initial blind analysis showed that only 6/33 participants showed a strong increase of S100A9 levels while all the others have maintained or significant decreased values.


17 July: Eisai presents new data on BAN2401 and elenbecestat at AAIC

On 17 July, Eisai presented new data from the BAN2401 Phase II study at the Alzheimer’s Association International Conference (AAIC) in Los Angeles (US). The 18-months Phase II clinical trial is a placebo-controlled, double-blind, parallel-group and randomised study to evaluate the safety and efficacy of BAN2401, a drug targeting beta amyloid, in 856 participants with early Alzheimer’s disease (AD).

The presentation suggested that BAN2401 is associated with reduced neurodegeneration. Biomarkers of neurodegeneration showed a decrease of tau pathology after both 12- and 18-months treatment. Increased BAN2401 exposure measured by serum concentrations were also correlated with reductions of amyloid beta in the brain. All data were consistent with the previously presented findings. BAN2401 is being jointly developed by Eisai and Biogen in a Phase III study (Clarity AD) in people with early AD.

In addition, Eisai presented information about elenbecestat, an oral BACE inhibitor. A Data Safety Monitoring Board has reviewed the safety data and recommended the continuation of the ongoing MISSIONAD1 and MISSION AD2 Phase III studies investigating elenbecestat in people with early Alzheimer’s disease. Furthermore, researchers reported that
elenbecestat (50 mg) showed a significant reduction in brain amyloid load at 18 months versus the placebo group in people with mild cognitive impairment due to AD, or mild-to-moderate dementia due to AD with confirmed amyloid pathology by positron emission tomography in the Phase II study, named Study 202.


18 July: Researchers report on high prevalence of apathy in AD

On 18 July, scientists from the University of Exeter presented findings on the high presence of apathy in people living with Alzheimer’s disease (AD) at the Alzheimer’s Association International Conference.

Bringing data from 20 cohort studies together, the team was able to report on findings from 4,320 people with AD. Strikingly, 45% of the participants showed apathy and 20% had persistent apathy over time. In addition, they found that a proportion had apathy without depression, which suggests that apathy might have its own unique clinical and biological profile when compared to apathy with depression and depression only.


24 June: A case-control study reports association between anticholinergic drug exposure and dementia risk among people 55 years or older

On 24 June, researchers from the University of Nottingham in the United Kingdom published a paper in JAMA Internal Medicine analysing the link between cumulative anticholinergic drug use and the risk of developing dementia.

The study evaluated data from a medical cohort of 58,769 people with dementia and 225,574 people without dementia which took place in general practices in England from January 2004 and January 2016. They were all 55 years old or older at baseline and had a least 11 years of recorded data prior to the date of diagnosis of dementia or equivalent date in matched controls.

On 24 June, Dr. Sebastian Palmqvist and collaborators published a paper in JAMA Neurology on the testing and validation of an immunoassay for two β-amyloid peptides, using blood plasma from participants in two prospective cohort studies. Altered levels of β-amyloid peptides in cerebrospinal fluid (CSF) or on PET scans are among the official International Working Group (IWG) criteria for Alzheimer’s disease (AD), with studies showing that they can accurately diagnose AD. However, the high cost and restricted access to these two diagnostic tools limit their utility in primary care. Dr. Palmqvist and colleagues therefore aimed to test a new, fully-automated Elecsys immunoassay that measures the levels of β-amyloid peptides in blood samples.

The study was performed in two stages, initially using the immunoassay to test samples from 842 participants in the Swedish BioFINDER cohort, followed by validation using samples from 237 participants in an independent German cohort. Statistical analyses showed good diagnostic accuracies when measuring two β-amyloid peptides (Aβ40 and Aβ42) using the immunoassay platform, with a further improvement in diagnostic accuracy when APOE genotyping data was incorporated.

[https://jamanetwork.com/journals/jamaneurology/fullarticle/2736342](https://jamanetwork.com/journals/jamaneurology/fullarticle/2736342)

24 June: Enterin announces Phase I study evaluating ENT-01 for Parkinson's disease dementia

On 24 June, the pharmaceutical company Enterin, which develops novel compounds to treat Parkinson’s disease, announced the enrolment of the first research participant with Parkinson’s disease dementia (PDD) to the DEMET study.
The Phase I clinical trial is evaluating the tolerability and efficacy of repeated oral doses of ENT-01 for the treatment of PDD. ENT-01 is a synthetic derivative of squalamine, which is not absorbed into the bloodstream. The compound was recently shown to improve both motor and non-motor symptoms for the treatment of Parkinson’s disease related constipation, with the potential to modify the disease progression. The company is aiming to recruit around 30 participants over a 6-month period in the US.


1 July: SveDem study presented at the 5th European Academy of Neurology congress shows positive association between statin use and survival in people with dementia

On 1 July, Dr Bojana Petek and collaborators presented their study on statin use and all-cause mortality in Swedish Dementia Registry (SveDem) participants at the 5th European Academy of Neurology congress in Oslo.

Statins are amongst the most frequently-prescribed drug classes worldwide, acting to lower circulating cholesterol levels by inhibiting an enzyme that is crucial for cholesterol synthesis. To assess the association between statins and the risk of death and stroke in people with dementia, the researchers undertook a prospective, registry-based cohort study of 44,920 SveDem participants.

Combining the SveDem data with participant data extracted from further registries detailing medications, comorbidities, mortality and demographic characteristics, Dr Petek and collaborators identified a lower risk of all-cause mortality and stroke in people with dementia who were prescribed statins. The protective effect of statins was particularly pronounced in younger participants (<75 years), male participants and in participants with a vascular dementia diagnosis. The researchers also identified a cumulative benefit of statin exposure, with lower risk of death in participants with a longer history of statin usage.


2 July: Yan-Jiang Wang and Xian-Le Bu Receive 2019 Alzheimer Award

On 2 July, the Journal of Alzheimer’s Disease (JAD) announced that Dr Yan-Jiang Wang and Dr Xian-Le Bu, both of Daping Hospital, Third Military Medical University, Chongqing, China, are joint recipients of the 2019 Alzheimer Award.

The award is presented by the journal in recognition of a ground-breaking article that presents clear evidence that gut microbiota composition is altered in patients with Alzheimer’s disease (AD), authored by Dr Wang, Dr Bu and colleagues. The article suggests that gut microbiota participate in the disease pathogenesis, and modulation of gut microbiota might be a potential therapeutic strategy for AD.

The 2019 winning paper is “Gut Microbiota is Altered in Patients with Alzheimer’s Disease” (Zhuang et al., J Alzheimers Dis 63, 1337–1346, 2018). It is freely available to everyone to read, download, and share. Find out more, here: https://www.j-alz.com/content/yan-jiang-wang-and-xian-le-bu-receive-2019-alzheimer-award

3 July: Large retrospective cohort study identifies association between androgen deprivation therapy and Alzheimer’s disease in elderly men with prostate cancer

On 7 July, Dr Ravishankar Jayadevappa and collaborators published a paper in JAMA Network Open showing an increased risk of developing Alzheimer’s disease (AD) or dementia in elderly prostate cancer patients receiving androgen deprivation therapy.

Androgen deprivation therapy (ADT), frequently termed ‘hormone therapy’, aims to prevent hormones such as testosterone from promoting the growth and spread of prostate cancer cells. However, there is growing concern over possible associations between ADT and cognitive dysfunction, particularly in older men with prostate cancer. To investigate this association, the researchers undertook a retrospective cohort study of >154,000 people with prostate cancer in the Surveillance, Epidemiology and End Results (SEER) Medicare-linked database of the US National Cancer Institute.

Dr Jayadevappa and colleagues obtained deidentified data from men aged 66 years or older who were diagnosed with localised or advanced prostate cancer between 1996 and 2003. The cohort was followed up until 2013, with dose stratification to analyse potential associations of AD or dementia with ADT dose. Exposure to ADT was associated with an increased risk of AD or dementia, with hazard ratios of 1.14 or 1.20 for AD and dementia respectively. A dose-response relationship was observed across treatment groups, with patients receiving 8 doses or more of ADT at higher risk of AD or dementia diagnosis than those receiving fewer doses of ADT.

https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2737101

10 July: Eisai officially opens its Center for Genetics Guided Dementia Discovery in Cambridge, Massachusetts

On 10 July, Eisai announced the official opening of its Center for Genetics Guided Dementia Discovery (G2D2) in Cambridge, Massachusetts.

Research at G2D2 will focus on the brain’s immune system, aiming to discover new drug targets beyond tau and beta amyloid. Researchers at G2D2 hope to build on recent advances in human genetics, data science and precision
chemistry to develop targeted therapies for Alzheimer’s disease.

Embedded within G2D2, the Eisai Incubator for NeuroDiscovery (e-IND) aims to provide space for spin-out companies hoping to develop innovative therapeutics for neurodegenerative disease.


10 July: Researchers show how TREM2 interacts with CD33 to reduce neuroinflammation in preclinical models of AD

On 10 July, Dr Ana Griciuc and colleagues at Massachusetts General Hospital in Boston published their new research findings in Neuron, showing that TREM2 acts downstream of CD33 during the development of neuroinflammation in animal models of Alzheimer’s disease (AD).

Recent research has highlighted a prominent role for neuroinflammation (inflammation that is localised to the brain) during the development of AD. Neuroinflammation is primarily controlled by microglia, brain immune cells that adopt different – and opposing - behaviours once activated during disease development. ‘M2’ variant microglia can dampen AD-associated neuroinflammation by chewing up amyloid plaques; conversely, ‘M1’ variant microglia promote neuroinflammation, releasing factors that damage neurons and increase amyloid deposition.

TREM2 and CD33 are thought to regulate microglial decision-making, pushing microglia towards ‘protective’ M2 or ‘inflammatory’ M1 fates, respectively. However, it is not yet clear whether these two proteins have interacting effects: whether targeting pathological CD33 will affect the beneficial actions of TREM2, or vice versa. Dr Griciuc and colleagues therefore set out to evaluate TREM2 and CD33 in AD-associated neuroinflammation, using mouse models of AD in which the TREM2 and CD33 genes were knocked out individually or in combination.

Using this preclinical approach, the researchers showed that the cognitive benefits of removing CD33 in AD mice were undone when TREM2 was also knocked out. Similarly, the reduction in amyloid plaque load in AD mice lacking CD33 was reversed when TREM2 was also removed. Gene expression analysis of microglia from these mice pointed to a few culprit pathways, including inflammatory regulators such as interleukin 1β. Together, these results allowed the researchers to situate TREM2 ‘downstream’ of CD33, suggesting that therapeutic strategies targeting CD33 will only be beneficial if TREM2 is present.

https://www.cell.com/neuron/pdf/extended/50896-6273(19)30560-4

11 July: Novartis and Amgen stop two Phase II/III clinical studies of CNP520 in the Alzheimer’s Prevention Initiative Generation programme

On 11 July, the pharmaceutical companies Novartis and Amgen, along with their partner the Banner Alzheimer’s Institute, announced the decision to discontinue two Phase II/III clinical trials in the Alzheimer’s Prevention Initiative (API) Generation programme based on a planned analysis.

The trials focus on the experimental drug CNP520 that was designed to inhibit BACE1, an enzyme that plays an important role in the production of beta-amyloid. Both studies are randomised, double-blind and placebo-controlled trials investigating the efficacy and safety of the CNP520 in people at high risk of developing symptoms of Alzheimer’s disease (AD) based on their age and genetic status. The pharmaceutical companies planned to enrol more than 3.300 research participants in America, Australia and Europe.

The review of unblinded data reported that participants receiving the experimental drug worsened on some measures of cognitive function. The study sponsors concluded that the potential benefit for participants taking CNP520 did not outweigh the risks. Data will be presented at upcoming conferences.

"Beyond presenting our analyses, we will go a step further and will also share our data with the scientific community, not only to contribute to the increasing body of knowledge in Alzheimer’s research but to add value to ongoing discussions with governments, multilateral organizations, patient groups, pharmaceutical companies, and society, to ensure that we collectively address the public health challenges presented by this disease.”, said John Tsai, head of global drug development and chief medical officer at Novartis.


12 July: EIP Pharma initiates Phase II study of neflamapimod for dementia with Lewy Bodies

On 12 July, EIP Pharma Inc., which develops CNS-focused therapeutic drugs for improved patient benefit, announced the initiation of a new Phase II proof-of-concept trial evaluating neflamapimod in people with dementia with Lewy Bodies.

Neflamapimod is an oral brain-penetrant molecule that inhibits the protein kinase p38 alpha, a kinase suggested to lead to the dysfunction of synapses that causes cognitive function deficits related to several neurodegenerative diseases.

The AscenD-LB Phase II study is a multi-centre, randomised, double-blind and placebo-controlled trial evaluating the effect of neflamapimod as a treatment for the cognitive dysfunction associated with dementia with Lewy bodies. The company is aiming to recruit around 80 participants in the US and Netherlands who will receive neflamapimod or placebo with food for 16 weeks. Data are expected in the second half of 2020.

18 July: Luxembourg-born neuroscientist Michel Goedert awarded 2019 Royal Society Medal for his work on protein accumulation in AD

On 18 July, the Royal Society (UK) announced the award of its 2019 Royal Medal for Biological Sciences to Prof Michel Goedert, a neurobiology group leader at the MRC Laboratory of Molecular Biology (LMB) in Cambridge.

Prof Goedert, originally from Luxembourg, has made important discoveries on the structure and function of filament-shaped proteins that accumulate in neurodegenerative diseases such as Parkinson’s disease and AD. Two such proteins, Tau and alpha-synuclein, are now known to play central roles in the development of AD, thanks in part to Prof Goedert’s ground-breaking work.

With this award, Prof. Goedert joins an illustrious group of Royal Medal recipients, which includes Michael Faraday, Dorothy Hodgkin and Francis Crick alongside other scientific luminaries.

https://www2.mrc-lmb.cam.ac.uk/michel-goedert-awarded-the-2019-royal-medal-for-biological-sciences/

18 July: International group of experts highlights link between stroke and dementia, issuing call to action for prevention of both

On 18 July, a group of experts led by Prof Vladimir Hachinski published an article entitled ‘Preventing dementia by preventing stroke: the Berlin Manifesto’ in Alzheimer’s and Dementia. The article, consisting of a systematic literature review on stroke and dementia and a call to action, is the result of a meeting of international experts in stroke and dementia research at the October 2018 World Health Summit in Berlin.

In their article, Prof Hachinski and colleagues highlighted a growing body of evidence suggesting that prevention of stroke could also prevent some dementias. Studies show that having a stroke doubles the risk of developing dementia, and that over 90% of strokes are preventable. Moreover, stroke and dementia share many modifiable risk factors, including hypertension, heart disease and type 2 diabetes. The group of experts also drew strong parallels between the vascular dysfunction known to be an early event in the development of dementia, and the vascular pathologies that cause strokes, describing how neurovascular dysfunction can initiate a cascade of events leading to brain inflammation and neurodegeneration.

In their action plan recommendations, the group of experts call for the establishment of an International Consortium to jointly address stroke and dementia. Emphasising the importance of public-private partnerships and effective data sharing, they highlight the need for large clinical and genetic databases to accelerate the development of innovative detection technologies and interventional treatments for early-stage disease.


19 July: Article in Science shows how amyloid beta induces brain capillary constriction, amplifying vascular dysfunction in AD

On 19 July, Dr Ross Nortley and colleagues published a paper in Science showing how accumulating amyloid beta (Aβ) causes neurovascular pericytes to contract, leading to brain capillary constriction and vascular dysfunction in Alzheimer’s disease (AD).

Decreased cerebral blood flow is one of the earliest biomarkers of AD, a measure of the vascular dysfunction that underlies AD development. Recent studies on vascular dysfunction in AD have shone a spotlight on brain capillaries, blood vessels so tiny that red blood cells flow down them in single file. Despite their tiny size, brain capillaries fulfil very important functions in the brain, forming the blood-brain barrier and helping to regulate cerebral blood pressure. Narrowing of the capillaries (also known as capillary constrictions) has been observed in the brains of people with AD and is correlated with cognitive decline. In this elegant study, Dr Nortley and colleagues hypothesised that pericytes, specialised vascular cells that wrap around brain capillaries, may contribute to capillary constriction in AD.

First, the researchers used surplus brain samples from patients undergoing brain surgery to look at the function of pericytes in brain capillaries. Using advanced tissue imaging techniques, they showed that application of Aβ to live capillaries induced an acute constriction of these blood vessels. Validating these results in animal models of AD, they found that capillary constriction was particularly marked in the vicinity of pericytes, with the degree of constriction correlated to the quantity of Aβ applied. Looking for culprit molecules that might cause pericytes to contract and constrict capillaries, the researchers focused on the NADPH oxidase (NOX) family of proteins. NOX proteins are enzymes that produce free radicals such as superoxide, damaging compounds that are known to promote hypertension through their pro-contractile actions.
Using their imaging approach, Dr Nortley and colleagues discovered that Aβ actives NOX4 in pericytes, kicking off a cascade that starts with free radical generation and pericyte contraction, and culminates in capillary constriction. Crucially, blockade of NOX4 using a drug called GKT137831 reduced the capillary constriction evoked by Aβ; application of c-natriuretic peptide (a peptide that can reduce pericyte contractility) had similar effects, highlighting the central role of pericytes in AD-associated vascular dysfunction.

1 August: AZTherapies completes enrolment in ALZT-OP1 Phase II trial for early AD

On 1 August, AZTherapies, a clinical-stage biopharmaceutical company developing novel therapies to change neurodegenerative disease progression, announced that it has completed the recruitment of its COGNITE Phase III clinical trial evaluating the safety, tolerability and efficacy of ALZT-OP1 for the treatment of early Alzheimer’s disease (AD).

The COGNITE study is a global, randomised, double-blinded and placebo-controlled Phase III study designed to determine if ALZT-OP1 will slow down, arrest, or reverse cognitive and functional decline in people with early AD. The combination drug therapy ALZT-OP1 consists of the administration of two previously approved drugs, cromolyn (designated ALZT-OP1a) and ibuprofen (designated ALZT-OP1b) that have been re-engineered to suppress the brain’s neuroinflammatory response.

The company, which announced the initiation of the study in September 2015 across US, Australia and European sites, reported that approximately 1,800 people aged 55–79 were screened by cognition, function and levels of biomarkers in cerebrospinal fluid to enrol a total of 620 participants. The study completion is expected in the fourth quarter of 2020.

4 August: Eli Lilly, Apple and Evidation report their feasibility study on the use of smart devices to identify cognitive impairment

At the 25<sup>th</sup> annual conference of the Association for Computing Machinery (ACM), Eli Lilly, Apple and Evidation reported on their Real-World Evidence (RWE) feasibility study, examining the utility of consumer-grade smart devices in identifying people with cognitive impairment. RWE is derived from Real-World Data (RWD), data and information gathered in a real-world setting beyond the confines of traditional clinical trials and interventional medicine. RWD can be obtained from many different sources; for example, the RADAR-AD study on digital biomarkers for Alzheimer’s disease (AD) uses data from smartphones, wearables and home-based sensors.

In the reported study, researchers aimed to identify whether interpretable RWE could be obtained using data from an iPhone, Apple watch and Beddit sleep monitoring device. In total, 31 participants with MCI or mild AD were enrolled, along with 84 healthy individuals. The smart devices provided data on gross motor function (e.g. number of steps, walking speed), heart rate, sleep cycle and fine motor control, among other parameters.

Researchers reported that they had developed a data collection and analysis system which could effectively integrate different data streams from the devices. They identified a pattern of reduced typing speed and fewer text messages in participants with cognitive impairment. However, the researchers cautioned that these are preliminary results based on a very small number of individuals, with further studies required in order to extrapolate these observations to the wider population.

5 August: Alkahest announces top-line data from its Phase II clinical trial of GRF6019 in AD

On 5 August, Alkahest, a clinical stage biopharmaceutical company developing treatments for neurodegenerative and age-related diseases with transformative therapies, announced top-line data from its Phase II clinical trial assessing the safety and tolerability of GRF6019 infusions in people with mild-to-moderate Alzheimer’s disease (AD).

40 US participants were randomised to receive 100ml or 250ml of GRF6019, a plasma-derived product, by intravenous infusion for five consecutive days during week 1 and then for five consecutive days during week 13. The primary outcome measure included the incidence of treatment-emergent adverse effects. The company reported that the experimental drug was safe and well-tolerated in participants with mild-to-moderate AD. Secondary outcome measures included six-month change on some widely used cognitive and clinical batteries. Data showed that participants receiving GRF6019 maintained cognitive and functional status throughout the six-month period.

Alkahest is conducting another Phase II clinical trial with GRF6019 in people with severe AD. The company announced the dosing of the first participant in March 2019 and plans to enrol and randomise 20 US participants.

“These top-line results indicate a potential benefit of this plasma protein fraction in slowing the progression of cognitive
decline in patients with mild to moderate Alzheimer’s disease,” said Dr Karoly Nikolich, chief executive officer of Alkahest.


6 August: Recent statistics show dementia is primary cause of death in England and Wales

On 6 August, the Office for National Statistics published data and a report on deaths registered in England and Wales in 2018. Throughout 2018, 541,589 deaths were registered in England and Wales. Comparing to 2017, this indicates an increase of 1.6% and subsequently the highest annual number since 1999. A comment as part of the report puts the increased number into perspective, since 2011 death rates remained relatively stable when age and population size are taken into account.

The report also highlighted that while stillbirths, neonatal and infant deaths all decreased in England in 2018, deaths due to dementia and Alzheimer disease (AD) continued to increase and remained the leading cause of death, accounting for 12.8% of all deaths registered.

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bullets/deathsregistrationsummarytables/2018

20 August: Insight 46 study suggests that midlife hypertension may be linked to increased brain pathology and Alzheimer’s disease risk in older age

On 20 August, Dr Christopher Lane and colleagues published a paper in Lancet Neurology showing that hypertension in midlife (40-65 years of age) was associated with the development of brain pathology in later years. Previous studies have shown that elevated blood pressure or hypertension in middle age is linked to an increase in Alzheimer’s disease (AD) risk. However, the specific changes in the brain that occur as a result of midlife hypertension have yet to be fully investigated. To address this question, researchers turned to the neuroscience substudy of Insight 46, an ongoing longitudinal cohort study of people born within one week of each other in 1946. Insight 46 has collected detailed health information from participants at regular intervals since birth, including blood pressure measurements and measures of cognitive function.

Aiming to focus on late-life dementia risk, researchers studied a group of 502 dementia-free Insight 46 participants. Detailed MRI imaging and neuropsychological assessments were performed, evaluating brain amyloid accumulation, white matter hyperintensity (a marker of disease) and cognitive function. Decreases in brain volume and increases in white matter hyperintensity volume were observed in participants who were hypertensive in midlife – although no cognitive changes were found.

Of particular interest was the observation that midlife hypertension did not seem to affect late-life amyloid status, indicating that amyloid may not play an important role in increasing AD risk associated with early hypertension. Together, these results suggest that blood pressure management early on may help maximise brain health in later life.

https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(19)30228-5/fulltext

DEMENTIA IN SOCIETY

5 July: Europe has three of top four “Innovative Carer Practices” as identified by the International Alliance of Carer Organizations

A report by the International Alliance of Carer Organizations (IACO), supported by Embracing Carers, has recognised four leading practices, globally, that address carers’ needs. Of these four “Innovative Carer Practices”, three are in Europe and one is in Taiwan:

- In the Social Wellness category, France’s “Café des aidants” is a network of 200 carer cafés, which provide a space to exchange stories and receive support.
- In the Integration category, the United Kingdom’s “Carer Passports” initiative recognises and supports carers across the health and social care systems.
- In the Capacity category, Ireland’s “Family Carer Training” is an outcome-based carer training that builds health and social care professionals’ skills.
- In the Awareness category, Taiwan’s “respite coffee” promotes recognition and community engagement.

https://internationalcarers.org/innovative-carer-practices/

LIVING WITH DEMENTIA

6 August: Idalina Aguiar, member of the EWPWD shares her experiences at a series of awareness-raising events

Recently, I had the opportunity to actively participate in awareness-raising events about dementia for informal carers. Together with my daughter Nélida, I told the participants about my history and experience, fighting for and defending the rights of those living with dementia and carers. I also talked about the recently-approved Informal Caregiver Statute.
On 6 August, we were invited to the premises of the parish council of Caniço (in the Municipality of Santa Cruz, Madeira) to attend the closing ceremony (pictured), at which participants received their certificates. In attendance at this ceremony, were: Susana Prada, Secretary for the Environment representing the Regional Government of Madeira; Augusta Aguiar, Chair of the Board of Directors of the Social Security Institute; Filipe Sousa, Mayor of Santa Cruz; Jaime Silva, Councilman with the social department of the Chamber of Santa Cruz; Milton Teixeira, President of the parish council of Caniço and the remaining Executive of the Board. Nélida and I were also honoured, earlier in the summer, to participate actively in a number of inspirational talks organised by the municipality of Machico, Madeira. We shared our perspectives - as a person with dementia and a carer – with the public. We discussed what it means to take care of someone out of love, dedication, or just because there are no other options left (social responses), and having to provide home care. It was an excellent gathering. Special thanks to Councilwoman Mónica Vieira and social worker Sandra Nunes for this opportunity. Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina's words to English.

9 August: Chris Roberts, Vice-chair of the EWGPWD, helps monitor progress made on Dementia action plan for Wales

After being involved in producing the “Dementia action plan for Wales 2018-2022”, it was agreed that there should be a group to oversee progress, including experts by experience, people affected by dementia, as well as health professionals, service representatives and the Alzheimer’s Society Wales/Cymru. It’s now 12 months since the first meeting of the “Dementia Oversight of Implementation and Impact Group”, DOIIG (formerly the Dementia Delivery and Assurance Group, DDAG).

This group was set up to ensure that progress regarding delivery of the plan is overseen by, among others, people living with dementia and their carers and families. Progress on the plan will also be a key vehicle for demonstrating achievements and areas for improvement outlined within the Health and Care Standards for Wales.

The action plan will be reviewed at the three-year point, to see if anything needs to change or be added, so we can maintain ambitions to make Wales the first “dementia friendly country” in the world. The six key themes of the action plan are:

- Risk reduction and delaying onset
- Raising awareness and understanding
- Recognition and identification
- Assessment and diagnosis
- Living as well as possible for as long as possible
- The need for increased support.

Each of these themes can be read in the Action Plan itself, which can be consulted, here: https://gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf

To date, there have been four meeting of the DOIIG, in June 2018, October 2018, February 2019 and most recently in June 2019. For the purposes of transparency, the minutes of each meeting are being published on the Welsh Government’s website (the minutes from 2019 are pending, due to a technical issue).

There have been some tense moments where some members, including myself, have felt like we were getting nowhere, that this was all a tokenistic engagement exercise and that we were being told what was being done after the fact. We have had some very frank discussions, but I am truly pleased to say that we have all listened to each other, learned from each other, and I genuinely feel that, now, we are getting on with the job in hand with a mutual understanding of the macro view, whilst keeping an eye on the micro too.

Regarding progress made so far, I am happy to report the following:

- Number of dementia-friendly communities increased by 19. Total of 72 dementia-friendly communities now in Wales.
- First acute hospital in Wales received dementia-friendly status from Alzheimer’s Society. Ysbyty Gwynedd is only second hospital in UK to receive this status.
• Development of multi-disciplinary teams, with emphasis on involvement of allied health professionals to provide “re-enablement” approach. Crucially, these teams can provide more integrated care through activity driven by statutory and voluntary sectors.

• Examples of person-centred approach include a number of flexible and enabling respite supports, such as flexible outreach; offering respite options beyond traditional respite admission to care homes; increase in support for those in care homes or hospitals; projects that support planned discharge from hospitals.

• In addition to funding routed through integrated care fund, Welsh Government support provided to Welsh ambulance services trust (WAST), allowing for a dementia team, training and awareness for champions, and delivery of training for emergency service call-takers. WAST also involved in establishing all-Wales blue-light dementia working group to share best practices. Aim is to ensure all staff are trained to understand needs of people affected by dementia and how to provide support.

• Public Health Wales’s “1000 Lives” programme working with memory assessment services to agree standards and principles services will work towards as part of dementia pathway. Includes pre-diagnosis, assessment period, post-diagnostic support and intervention.

Chris Roberts, Vice-chair of the European Working Group of People with Dementia (EWGPWD) would like to acknowledge input from two fellow members of DOIIG, in writing this article: Jayne Goodrick (his wife and supporter) and Nigel Hullah (Chair, 3NDWG).

26 August: Idalina Aguiar welcomes EWGPWD colleague Miha Kastelic to Madeira

I was delighted, this summer, to welcome my EWGPWD colleague Miha, from the Czech Republic, to my island (Madeira). He came on vacation with his family for two weeks. My daughter and I tried to make their trip as pleasant as possible and for us, it was an unforgettable experience. It is these friendships that give meaning to life and to our struggle. These friendships remain.

Together, we visited the “Place of memories” day care centre, as well as the Alzheimer Portugal headquarters, where I am based. We did many different activities and Miha had the opportunity to enjoy some complementary therapies that we offer to those who use our centre, such as music therapy and “snoezelen room” (cognitive stimulation room). Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English.

NEW PUBLICATIONS AND RESOURCES

3 July: Scottish voluntary organisation launches learning resource for faith communities to support people with dementia

Faith in Older People (FiOP) is a voluntary organisation, based in Scotland. Its aim is to develop a stronger understanding of the spiritual dimension to the well-being of older people. The organisation works with faith communities, health and social care staff, academics and voluntary organisations. It defines spiritual care as that which “gives meaning and purpose to our lives”, and embraces nature, relationships, creativity, faith and music.

Over the past two years FiOP has been working with a development group of dementia experts, taking a person-centred approach to look at design, community connections and pastoral care. The FiOP consulted widely with faith communities to produce a learning resource called “One Step at a Time - to assist faith communities to build a more supportive environment for people with dementia and their families”. The aim of the new resource is to enable people with dementia and their carers to continue to participate in activities which matter to them, whether they remain in their own homes or are in a care setting.

The resource, which has been authored by Professor Mary Marshall, Jenny Henderson and Professor Faith Gibson, can be downloaded, here:

https://www.faithinolderpeople.org.uk/project/one-step-at-a-time/
**AE CALENDAR**

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<th>Date</th>
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<th>AE representative</th>
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<td>4-7 September</td>
<td>30AEC Famtrip Helsinki, Finland</td>
<td>Gwladys</td>
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<tr>
<td>6 September</td>
<td>VirtualBrainCloud Project Meeting (Barcelona, Spain)</td>
<td>Angela and Jean</td>
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<td>9-10 September</td>
<td>WHO European and Eastern Mediterranean Regional Workshop on addressing dementia (Malta)</td>
<td>Jean</td>
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<tr>
<td>16-19 September</td>
<td>69th session of the WHO Regional Committee for Europe (Copenhagen, Denmark)</td>
<td>Owen</td>
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<tr>
<td>17 September</td>
<td>AD/Detect/Prevent meeting (Copenhagen, Denmark)</td>
<td>Jean</td>
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<tr>
<td>17 September</td>
<td>DataSavesLives Health Data Community meeting (Brussels, Belgium)</td>
<td>Angela</td>
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<td>18-19 September</td>
<td>PARADIGM General Assembly and Patient Engagement Open Forum (Brussels, Belgium)</td>
<td>Ana, Angela and Dianne</td>
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<td>24-25 September</td>
<td>Patients and Consumer Working Party of European Medicines Agency (Amsterdam, Netherlands)</td>
<td>Jean</td>
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<td>30 September</td>
<td>Meeting with Programme Démence Prévention (Esch/Belval, Luxembourg)</td>
<td>Jean</td>
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<td>30 September</td>
<td>EU Health Programme High Level Conference (Brussels, Belgium)</td>
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**CONFERENCES 2019**

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<tr>
<td>2-3 September</td>
<td>Euro Congress on Dementia and Alzheimer's Diseases (ECDA-Rome), <a href="https://www.dementiameet.com/">https://www.dementiameet.com/</a></td>
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<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-uni.ac.at">www.donau-uni.ac.at</a></td>
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<td>26-29 March 2020</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://cony.comtecmed.com/">http://cony.comtecmed.com/</a></td>
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29th Alzheimer Europe Conference
Making valuable connections
The Hague, Netherlands
23–25 October 2019
www.alzheimer-europe.org/conferences
#29AEC