Firstly, I would like to inform our readers that Alzheimer Europe (AE) currently has two open positions, for a Project Officer and an Administrative Assistant. The deadline is 15 February. For more details, see the Job Opportunities section.

January has been an exciting month for us, with two new papers being published. The first, in the context of the PACE project, is a report with policy recommendations on the needs of older people living in long-term care facilities in Europe. AE led this work together with Age Platform. We are delighted to have been a part of the five-year PACE project, which has now come to its end. The second paper is a commentary piece published in The Lancet Neurology that highlights another set of recommendations in which we were heavily involved. The “Consent recommendations for research and international data sharing involving persons with dementia”, developed by Global Alliance for Genomics and Health Ageing and Dementia Task Team, were co-authored by our Director for Projects Dianne Gove. European Working Group of People with Dementia (EWGPWD) Chairperson Helen Rochford-Brennan and I contributed.

Further exciting news is the kick-off of the VirtualBrainCloud project. The project will develop a decision support system providing access to multi-disciplinary data for clinical practice. The result will be a cloud-based brain simulation platform to support personalised diagnostics and treatments.

On the policy front, we are pleased to report that work has officially begun on Germany’s upcoming National Dementia Strategy. Four working groups will develop the content throughout 2019. At an EU level, the European Parliament and Council have reached a provisional agreement on the Commission’s proposal for a new Directive on work-life balance, for parents and carers. The Commission first proposed the Work-life Balance Initiative in 2017 and it is a key deliverable of the European Pillar of Social Rights. The Parliament has also voted to approve the report by the Committee on Employment and Social Affairs, which would see the budget of the European Social Fund Plus (ESF+) increased by approximately 19%. The ESF+ fund contributes to social inclusion, better living conditions, health and fairer societies, among other things.

On a less positive note, Roche has just announced the disappointing news that it is stopping two of its Phase III clinical studies of crenezumab in early Alzheimer’s disease, as the drug was unlikely to meet its primary endpoint. We remain, however, optimistic in the knowledge that even failed trials increase our understanding and bring us closer to finding new treatments.

Finally, I am happy to announce that registrations for the 29th Alzheimer Europe Conference (#29AEC) will open tomorrow, as will the call for abstracts. Concessions are available for people with dementia, members and staff of Alzheimer Nederland, and students.

Jean Georges
Executive Director
ALZHEIMER EUROPE

7 January: Alzheimer Europe adds new Phase II trials to its Clinical Trials Watch

Alzheimer Europe (AE) 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 (AD). Although some trials have been removed since they are no longer recruiting participants, new trials have also been added, resulting in 18 clinical trials currently reported in the database.

AE added seven Phase II clinical trials to the service:

- Abvac40 study (Araclon Biotech S.L.)
- ACI-24-1801 study (AC Immune)
- ETHERAL study (Oryzon)
- MAPT-CS1 study (Ionis Pharmaceuticals, Inc.)
- RO7105705 study (Genentech, Inc.)
- TANGO study (Biogen)
- VALZ-Pilot study (Hugo Lovheim).

Further information about the CTW is available on:

http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch

18 January: Lancet commentary highlights recommendations developed by Global Alliance for Genomics and Health, Ageing and Dementia Task Team

The Lancet Neurology (February 2019 edition) has published a commentary by Adrian Thorogood et al. on “Openness, inclusion, and respect in dementia research”. It highlights an article entitled “Consent recommendations for research and international data sharing involving persons with dementia”, published in Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association in October 2018. The recommendations were co-authored by Dianne Gove, Director for Projects, Alzheimer Europe (AE) and contributed to by AE Executive Director Jean Georges and European Working Group of People with Dementia (EWGPWD) Chairperson Helen Rochford-Brennan.

https://bit.ly/2HDcY5T

24 January: PACE Policy Recommendations on palliative care launched in Brussels

On 24 January, in the context of the last PACE (Palliative Care for Older People in care and nursing homes in Europe) policy workshop in Brussels, a report with policy recommendations to address the needs of older people living in long-term care facilities in Europe was presented. This work has been led by Alzheimer Europe and Age Platform with input from PACE partners from the European Association for Palliative Care, Vrije Universiteit Brussel and Lancaster University. The document includes a section related to the palliative care needs of people with dementia living in long-term care facilities, which was based on input provided by AE member associations and members of the European Working Group of People with Dementia (EWGPWD) and their supporters in different consultations. Among other issues, important topics included in the recommendations are:

- to officially recognise (as stated in the WHO definition of palliative care) that people with dementia are amongst those entitled to palliative care;
- to address the stigma surrounding dementia and palliative care;
- to provide training to all personnel working in these facilities on how to provide high-quality palliative care to people with dementia and to further involve people with dementia and carers in the development, implementation and evaluation of palliative care programmes.

Alzheimer Europe would like to thank everyone involved in the different consultations for their very valuable input. The policy recommendations can be downloaded at:

http://www.eupace.eu/project-results?type=21

Sponsors of the month

Alzheimer Europe would like to express its gratitude to two new sponsors for its 2019 activities.

Read more about sponsorship opportunities here:

https://goo.gl/6KVNcE

24 January: Get ready to book your spot at #29AEC!

The 29th Alzheimer Europe Conference (#29AEC) will take place at the World Forum, The Hague, Netherlands, from 23 to 25 October 2019. If you are hoping to join us, either as a presenter or a delegate, here are some important dates to note in your calendar:

- 1 February 2019: Abstract submission starts
- 1 February 2019: Online registration starts
- 30 April 2019: Abstract submission closes
Alzheimer Europe is organising the conference in partnership with Alzheimer Nederland. Both organisations are hugely grateful to the following sponsors of the conference:
- The European Union’s Health Programme (2014-2020)
- SkyTeam (official alliance travel partner)
- Amgen (Bronze sponsor)
- Otsuka (Bronze sponsor).

To find out more about sponsoring the conference and other Alzheimer Europe activities, visit: https://bit.ly/2Rl168n

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Alzheimer Europe networking

On 16 and 17 January (Bucharest, Romania), Gwladys and Jean went on a study visit to explore venues for the 30th Alzheimer Europe Conference #30AEC.

On 17 January (Brussels, Belgium) Ana participated in a WP4 PARADIGM meeting.

On 21 January (Brussels, Belgium), Gwladys went on a site inspection of hotels around Brussels for our 2019 activities.

On 22 January (Brussels, Belgium), Jean met with EFPIA representatives for an introductory meeting and exchange on current activities and priorities.

On 23 January (Brussels, Belgium), Jean attended the meeting “Lifting the burden of neurological disorders in Europe” organised by the European Academy of Neurology (EAN) and the European Federation of Neurological Associations (EFNA).

On 24 January (Brussels, Belgium), Dianne and Ana participated in the PACE workshop “Palliative care for older people: why we all need to care, now”.

On 25 January (Berlin, Germany), Jean attended the launch meeting of the VirtualBrainCloud project.

On 30 and 31 January (London, United Kingdom), Ana and Dianne attended the launch meeting of the RADAR-AD project.

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EU PROJECTS

27 December 2018: EPAD publishes its LCS study protocol

A new paper by the European Prevention of Alzheimer’s Dementia (EPAD) initiative entitled "European Prevention of Alzheimer’s Dementia Longitudinal Cohort Study (EPAD LCS): study protocol" has been published online.

EPAD is conducting a Longitudinal Cohort Study (LCS) in alignment with an adaptive designed EPAD Proof-of-Concept (PoC) trial. This article presents the EPAD LCS study protocol including its objectives, design, methods and outcomes. The article was published in the journal BMJ Open on 27 December 2018.

http://dx.doi.org/10.1136/bmjopen-2017-021017

9 January: The ROADMAP project published a systematic literature review on important AD outcomes

On 9 January, the Outcome Definition team of the international ROADMAP project published findings from a systematic literature review exercise in the journal Alzheimer’s & Dementia: Diagnosis, Assessment & Disease Monitoring.

The review sought to find information on which outcomes could be considered important from the perspectives of people with mild cognitive impairment, people with Alzheimer’s disease (AD), their carers, but also health-professionals. As part of this exercise, partners from the team extracted statements and rankings from various studies and grouped them into overarching domains.

The domains included: clinical (memory, mental health), practical (ability to undertake activities of daily living, access to health information), and personal (desire for patient autonomy, maintenance of identity) encompassing “elicited” information for 32 outcomes of the condition.

In their conclusion, the authors underlined that, although many outcomes were referred to as being in some context important, there were some that were infrequently assessed in clinical trials. In this context, the authors noted that such infrequently assessed outcomes as preservation of the patient’s personality, or the accessibility of health services, could be potentially captured by patient-reported outcome and experience measures, which, in turn, could be used to describe and evaluate the effectiveness of treatments and quality of care.
Furthermore, they also underscored that they did not find references to outcomes that might be of importance for people with prodromal AD, nor for those who are at risk for severe AD dementia, underlining the need for additional research.

The article has been published in open access and can be read here:

https://www.dadm.alzdem.com/article/S2352-8729(18)30085-X/fulltext

15 January: EPAD turns four

15 January marked the fourth anniversary of the official launch of the European Prevention of Alzheimer’s Dementia (EPAD) initiative, in Paris. To celebrate turning four, EPAD looked back at some of its key achievements of the past 12 months.

16 January: The EPAD Academy has officially started its first activity by proposing online webinars by world-class senior researchers on current topics in Alzheimer’s disease research for EPAD young researchers.

27 February: Alzheimer Europe held a successful lunch debate entitled “Will we be able to prevent Alzheimer’s dementia?” at the European Parliament in Brussels (Belgium). The panel included a presentation by Craig Ritchie (UEDIN) who looked at what the EPAD project can offer in terms of research into prevention.

23 May: The EPAD General Assembly took place in Amsterdam under the banner “How to assure sustainability” and welcomed more than 180 attendees.

7 June: EPAD was on the news in Australia. Craig Ritchie gave a plenary lecture “Preventing Dementia: False Promise or True Progress” at the International Dementia Conference in Sydney and mentioned EPAD.

26 July: For the first time, the EPAD study was exhibited via a large EPAD booth in the exhibition area as well as hosted a satellite symposium dedicated to the EPAD Proof of Concept trial at AAIC (Chicago, US). It also took this opportunity to launch the new EPAD website and to release a new EPAD brochure.

10 August: The EPAD family of trial delivery centres grew to 20 sites with Brescia (Italy) enrolling its first research participant.

29 August: The EPAD’s Scottish team were lucky to visit the stunning University of Aberdeen campus for the inaugural EPAD Scotland conference. The event gathered almost 80 delegates including participants, site staff and the wider Scottish EPAD team.

21 September: It is a date the EPAD team will not easily forget, as the 1,000th EPAD Research Participant has joined the EPAD family by volunteering to participate in the EPAD Longitudinal Cohort Study (LCS).

October: The EPAD project was presented at various events including the IMI scientific symposium (Brussels, Belgium), CTAD (Barcelona, Spain), Alzheimer Europe Conference (Barcelona, Spain) and NHS Research Scotland Annual Conference (Perth, Scotland). The team also took the opportunity to officially release its first wave of data including the baseline data from its first 500 research participants at CTAD.

November: The EPAD team is pleased that EPAD LCS marked its best month to date for recruitment of research participants in November 2018 with 118 new research participants enrolled. They also welcomed the 39th EPAD partner to the project MSD (Merck Sharp and Dohme).

21 January: SyDAD organises workshop on “Advanced Methodology in Preclinical Alzheimer Research”

The SyDAD network arranged the workshop “Advanced Methodology in Preclinical Alzheimer Research” at the Bordeaux School of Neuroscience, running from 21 January to 2 February 2019.

SyDAD Early Stage Researchers (ESRs) are approaching the end of their PhD studies and served as instructors at the workshop, thereby spreading their expertise to a wider network of students. 22 external PhD students and post-docs from worldwide participated in the course and performed two mini-projects supervised by the ESRs. In addition, several renowned keynote lecturers were involved, including Bart de Strooper, John Hardy, Michael Heneka and SyDAD director Bengt Winblad.

SyDAD (Synaptic Dysfunction in Alzheimer’s Disease) is a European Training Network, sponsored by Horizon 2020 Marie Sklodowska Curie Actions.

www.sydad.eu

25 January: VirtualBrainCloud project holds kick-off meeting in Berlin

The representatives of the Horizon2020 funded VirtualBrainCloud project met in Berlin for its kick-off meeting. The four-year project is coordinated by Charité - Universitätsmedizin Berlin and brings together experts in computational neuroscience and systems biology. Alzheimer Europe contributes to the work packages dedicated to ethical and legal issues and to dissemination and coordination.

The VirtualBrainCloud not only integrates existing software tools, it also merges the efforts of big EU initiatives, such as
the Virtual Brain large scale simulation platform of the EU Flagship Human Brain Project. VirtualBrainCloud will develop and validate a decision support system that provides access to high quality multi-disciplinary data for clinical practice. The result will be a cloud-based brain simulation platform to support personalised diagnostics and treatments in Neurodegenerative Diseases.

The EU PRACE (Partnership for Advanced Computing in Europe) initiative, will provide the required computing infrastructure. The VirtualBrainCloud will develop robust solutions for legal and ethical matters by interacting with EU projects such as European Open Science Cloud (EOSC), ‘cloud4health’, Alzheimer Europe and ELIXIR, an organisation that manages and safeguards EU research data.

**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 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:

- **EPAD** - grant agreement 115736
- **PACE** – grant agreement 603111
- **ROADMAP** - grant agreement 116020
- **VIRTUAL BRAIN CLOUD** – grant agreement 826421

**Members of the European Alzheimer’s Alliance**

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

- **Austria**: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP).
- **Belgium**: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).
- **Bulgaria**: Andrey Kovatchev (EPP).
- **Croatia**: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).
- **Cyprus**: Costas Mavrides (S&D); Eleni Theocharous (EPP).
- **Czech Republic**: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP).
- **Denmark**: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D).
- **Estonia**: Urmas Paet (ALDE); Finland: Liisa Jaakonsaari (S&D); Anneli Jätteenmäki (ALDE); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP).
- **France**: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin (S&D).
- **Germany**: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Kostas Chrysogonis (GUE/NGL); Kostadinka Kuneva (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Eleftherios Synadinos (NI); Elissavet Vozeli (S&D).
- **Hungary**: Ádám Kiss (EPP); Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Séan Kelly (EPP); Mairéad McGuinness (EPP).
- **Italy**: Brando Benifei (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D).
- **Lithuania**: Vilija Blinkevičiute (S&D).
- **Luxembourg**: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP).
- **Malta**: Roberta Metsola (EPP); Alfred Sant (S&D).
- **Netherlands**: Gerben-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Anne Schreier-Pierik (EPP); Lambert van Nistelrooij (EPP).
- **Poland**: Elżbieta Lukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP).
- **Portugal**: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP).
- **Romania**: Cristian-Silviu Busoi, MEP (EPP); Marian-Lean Marinescu (EPP); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP).
- **Slovakia**: Miroslav Mikolášik (EPP); Ivan Stefánek (APP); Anna Záborská (EPP).
- **Spain**: Franc Bogovíč (EPP); Tanja Fajon (S&D); Alojz Peterle (S&D); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomšič (S&D); Jytte Guteland (S&D);
- **Sweden**: George Groth (S&D); Silvia Rodríguez (EPP); Ana Miranda (Greens/EFA); Patricija Šulin (EPP); Romana Tomšič (S&D); Jytte Guteland (S&D).
- **Switzerland**: Didier Burkhalter (S&D); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).

**EU DEVELOPMENTS**

7 January: JPND launches EUR 30 Million call for multinational research on personalised medicine for neurodegenerative diseases

The EU Joint Programme – Neurodegenerative Disease Research (JPND) initiative has announced a joint transnational call for multinational research on personalised medicine for neurodegenerative diseases, including Alzheimer’s and other dementias.

In partnership with the European Commission, JPND is inviting multinational research teams to submit proposals for ambitious, innovative and multidisciplinary collaborative research projects to change the trajectory of these diseases through the development of Precision Medicine approaches.

JPND has chosen to focus on the area of Precision Medicine, which relates to the targeting of specific elements responsible for pathology in a given individual at a particular point in time.
It is an emerging approach for disease prevention, diagnosis and treatment that takes into account individual variability in genes, biological/molecular characteristics together with environmental and lifestyle factors. Pre-proposals must be submitted no later than 15:00h C.E.T. on 12 March 2019. More information about this call: https://bit.ly/2MbVvXi

The EU Joint Programme on Neurodegenerative Disease Research (JPND) was established to better coordinate research efforts across countries and disciplines to more rapidly find causes, develop cures and identify better ways to care for people with neurodegenerative disease.

17 January: European Parliament votes to approve increase in European Social Fund Plus funding

The Plenary Session of the European Parliament has voted to approve the report by the Committee on Employment and Social Affairs (EMPL Committee), which would see the budget of the European Social Fund Plus (ESF+) increased by approximately 19%, compared to that initially proposed by the European Commission.

As part of the negotiations over the Multi-annual Financial Framework (MFF) for 2021-2027, the Commission had initially proposed a budget of EUR 89.6 Billion; the amendment proposed in the report increases this to EUR 106.8 Billion. Of this total, EUR 105.7 Billion would be managed jointly by the EU and Member States.

The ESF+ fund contributes to social inclusion, job opportunities, fighting poverty, education, skills and the employability of young people, as well as to better living conditions, health and fairer societies. It will merge a number of existing EU health programmes, including:

- The European Social Fund and the Youth Employment Initiative
- The Fund for European Aid to the Most Deprived
- The EU Programme for Employment and Social Innovation
- The EU Health Programme.

The Parliament will now have to negotiate the regulation with the Council and the European Commission before it can enter into force.

You can read more on the ESF+ and the amendments made by the European Parliament by following this link: https://bit.ly/2swD93Y

24 January: European Institutions reach agreement over proposals for a work-life balance Directive

The European Parliament and the Council have reached a provisional agreement on the European Commission’s proposal for a new Directive on work-life balance for parents and carers. The Commission first proposed the “Work-life Balance” Initiative in April 2017, which is a key deliverable of the European Pillar of Social Rights.

For carers, the proposals will deliver:

- The right to “carers’ leave” for workers who have caring responsibilities for relatives in need of care or support due to serious medical reasons. Carers will be able to take five working days per year. (Member States may use a different reference period, allocate leave on a case-by-case basis, and may introduce additional conditions for the exercise of this right)
- An extension of the right to flexible working arrangements.

First Vice-President Frans Timmermans, and Commissioners Marianne Thyssen and Věra Jourová welcomed the agreement with the following statement:

“The provisional agreement reached by the European Parliament, the Council and the European Commission today is good news for families in Europe. The European Pillar of Social Rights is about improving the daily lives of Europeans. Today’s provisional agreement makes this vision very concrete, giving families with working parents and carers a real choice on how to combine their work and family life. This is a huge step towards a more social Europe and shows the true spirit of the Pillar.”

Member States will now examine the provisional agreement, which still needs to be endorsed by the Council’s Permanent Representatives Committee. The formal vote in both the Council and the European Parliament will follow at a later stage. You can read more on the joint agreement here: https://bit.ly/2Ue81so

MEMBERS’ NEWS

31 December 2018: Czech Alzheimer Society introduces its project “20 answered questions about dementia”

At the end of 2018, the Czech Alzheimer Society (CALS), released 20 video shots, relating to Alzheimer’s disease (AD) and other types of dementia. The overarching title “20 Questions about Dementia” reflects frequently asked questions that CALS has answered during its 20 years of existence.

Thanks to people who are directly affected by dementia, CALS experts were able to clearly explain how to address various difficulties that accompany this diagnosis.
“I hope that our answers can bring the necessary information, support and comfort to all who are in need”, said Martina Matlova, director of CALS.

Every video also includes a useful contact at the end, so people can call a help line and ask for other support.

The videos are available on the CALS website and on its YouTube Channel, so they can be conveniently viewed at any time. An advertising spot with celebrity Czech stand-up comedian Iva Pazderkova, calls attention to the series on internet TV and YouTube.

3 January: Udruženje AiR reports on its recent iCoDem/18 conference in Bosnia and Herzegovina

iCoDem/18 – International Congress on Dementia, is now behind us! We had 28 speakers and around 500 delegates!

This three-day conference (21-23 November 2018) on dementia, promotes multidisciplinary (medical) and interprofessional (non-medical) collaboration and non-pharmacological approaches in the treatment of dementia.

Experts from different disciplines talked about causes of dementia and comorbidity, the importance of multidisciplinary collaboration for early diagnosis and recent interprofessional, non-pharmacological approaches in the treatment of dementia.

In their presentations, the experts shared their experiences and results by giving examples from a “case”. Plenary lectures were multi-disciplinary and were followed by workshops on the same topic, where participants and lecturers had open discussions and exchanged knowledge and experience.

Participants were very satisfied with non-pharmacological presentations, in which the various professionals showed therapeutic possibilities in working with people with dementia and concrete examples, again by through the means of presenting a “case”.

In the frame of iCoDem/18, we had a session where the INDEED project by Prof. Alexander Kurz was presented, followed by two workshops, led by Prof. Kurz and Prof. Pirtosek.

Participants varied in background, from students, nurses, GPs, neurologists and psychiatrists to social workers and therapists.

Impressions

Prof. A. Kurz: “With its comprehensive scope and practical focus, the iCoDem contributed to improving dementia care in Bosnia and Herzegovina and neighbouring countries, and moved forward the development of national dementia plans.”

Prof. A. Pavlovic: “Firstly, iCoDem/18 started with a session about dementia as a public-health problem, with participation from the lead persons of the health administration in BiH. Secondly, the big advantage is the multidisciplinary character of the meeting. And finally, it was great to exchange with gathered experts from the European Region, about: experience, ideas, knowledge and at the same time to collaborate with all participants!”

Prof. S. Kostic Popovic: “iCoDem/18 was also excellent in the organisational and technical aspect”

Prof. M. Boban: “iCoDem made communication possible between all stakeholders who are important for care of people with dementia!”

3 January: Turkish Alzheimer Association reports on opening of day-care centre in Istanbul

The first of our four Alzheimer’s day-care centres in Turkey, was opened in May 2011 in Istanbul, in Sisli, the local district, which is considered as the trade centre of the city and is compared to Manhattan. The operation of the Centre was jointly undertaken by Türkiye Alzheimer Derneği (Turkish Alzheimer Association) and Sisli Municipality Office. Since 2011, 101 people with dementia have used the day-care services at the Centre, with an average attendance length of 1.1 years. Countless families have also attended seminars and psychological group therapy sessions, held periodically.

After the earthquake of 1999 and the disaster that followed, first the regulations for houses, then offices and then centres like our Alzheimer’s Day Care Centre were scrutinised, and more protective measures were stipulated for buildings in order to be certified as “acceptable”. Accordingly, the building where the Day Care Centre functioned needed to be rebuilt with the newly-defined standards applied. Since a halt in services would have a big impact on people with dementia and their families, the Turkish Alzheimer Association and Sisli Municipality commissioned another building and did all the necessary modifications to convert it into a day-care centre. The meticulous work was completed on 3 January, and a joyful opening celebration took place with the centre users, their families, people from the local neighbourhood and officials of both institutions.

11 January: Alzheimer Sweden involved in Roche Sweden Alzheimer Challenge

On 11 January, Karin Westerlund, Alzheimer Sverige (Sweden) attended the: Roche Sweden Alzheimer Challenge with 60 attendees from Roche in Europe, Stockholm EIT Health Starter Lab by Karolinska Institutet’s Unit for Bioentrepreneurship and Openlab Stockholm by the Kungliga Tekniska Högskolan (the Royal Institute of Technology) and others.

The Alzheimer Challenge is also a collaborative innovation platform to host solutions for early intervention of Alzheimer’s
disease (AD) founded by the Stockholm EIT Health Starter Lab, represented by Karolinska Institutet’s Unit for Bioentrepreneurship, Openlab Stockholm and Roche. Ms Westerlund gave a presentation to the attendees, about caregiving for persons with AD and discussed the caregiving perspective, especially in the Swedish Health system. During the day, she acted as an expert at the workshop, together with creative expert and speaker Tobias Legsell. Mr Legsell also gave a presentation, to spark the innovation Geist among the teams and all attendees.

During 60 days, starting in 2018, the Alzheimer Challenge platform has been open for innovation-solutions where competing teams have used Design Thinking as method, mindset and toolset to guide the process. Selected teams met for the workshop on 11-12 January to further develop their ideas, with the aid of expert guest speakers.

The winning teams were: Braintrack Prognostic Gaming
https://alzheimerschallenge.eu/#ideaModal22
Experience Room - X-line
https://alzheimerschallenge.eu/prototype/10

Apart from getting a digital certificate in Design Thinking and winning great prizes, one team has a chance for further development together with the Challenge host, Roche. More news and updates about the Alzheimer Challenge can be found on the platform website and all material that the teams create is available here:
https://alzheimerschallenge.eu/
https://www.talarforum.se/tobias.degsell

24 January: Czech Alzheimer Society tells us about project on needs and support of family carers of older people with dementia

The project focused on the needs and support of family caregivers of elderly people with dementia in the Czech Republic. It was carried out in cooperation between Charles University, Prague and the Czech Alzheimer Society, during 2016-2018.

Preliminary results - based on interviews, focus groups, survey questionnaire, and intervention assessment - showed that the existing interventions meet the informational needs of carers (educational courses) and psychological needs (support groups and counselling). Carers, however, lacked practically-oriented and individualised interventions such as skills training and case management.

It seems that the experience of caring for spouses is different from that of adult children caring for their parents. Not surprisingly, carers’ needs in the early stages of care differ from late-stage needs, also. It was alarming, though, how much external conditions can complicate solving the crucial tasks of care. A difficult pathway to diagnose and to proper care was stark example.

The project also explored barriers that prevent relatives from participating in group interventions.

24 January: Spominčica-Alzheimer Slovenia joins project aiming to support informal carers

The other project on which Spominčica-Alzheimer Slovenia has embarked, in 2019, is S.I.N.C.A.L.A. (Supporting informal carers: a whole-family & life course approach). Through the narration method and socio-drama games, caregivers of persons with dementia can express their most common issues, share distress and develop a more positive perception of the caregiver’s role.

For S.I.N.C.A.L.A. Spominčica is preparing trainings for caregivers of persons with dementia, taking a modern approach to education, using storytelling workshops and learning through theatrical games (socio-drama). In parallel, caregivers will gain some skills, especially regarding how to overcome inconveniences they experience as dementia carers (to prevent burnout, negative emotions, vulnerability).

All developed trainings will be available through a web platform for e-learning - a Massive Open Online Course (MOOC).

Other partners in this Erasmus+ KA2 project are: MTU EEesti Omastehooldus (Estonia), Anziani e non solo (Italy), CASOSO+ (Portugal), Co-Creation Support CLG (Ireland) and the Greek Association of Alzheimer’s Disease and Related Disorders - Alzheimer Hellas (Greece).

24 January: Alzheimer’s Society-funded project develops tools designed to provide meaningful activity for people with advanced dementia

An Alzheimer’s Society-funded project has developed a set of tools designed to provide meaningful activity for people with advanced dementia, while also involving carers.

Judith Bower, internal trainer and Dementia Adviser at the Alzheimer’s Society in Lancashire, and Jane Souyave, Senior Graphic Design Lecturer at the University of Central Lancashire, had noted how often fidgeting and repetitive movements came up in conversations with carers.

They wanted to dispel the myth that fidgeting is negative or a kind of ‘disruptive behaviour’. Instead, they decided to recreate repetitive fidgeting actions such as turning, twisting, rolling, pulling and flicking movements for positive ends.

They applied, successfully, to innovation funds run by the Alzheimer’s Society and the University of Central Lancashire to help develop an intervention called Positive Connections.
Work began to design and test their ideas, and this resulted in five wooden, handheld, tactile tools that come in a handy pack called the Fidget Widget Toolkit. The tools are designed to not rely on memory or words, and not to represent a recognisable tool, such as a screwdriver or kitchen utensil. This means that people interact with them creatively, with no right or wrong way to use them.

Over a two-year period, the Fidget Widget Toolkit was tested in people’s own homes, day centres and care homes. A range of measures were used to measure its impact, including interviews and audio and video recordings.

Judith Bower and Jane Souyave found that men and women engaged with the tools equally. Families, who were supported with techniques to connect and communicate, enjoyed being involved. They particularly appreciated that these were interactions, which weren’t focused on providing personal care.

The Alzheimer’s Society has partnered with Active Minds, a supplier that develops activities for people with dementia, to produce the Fidget Widget Toolkit. It will be available through the Alzheimer’s Society online shop from late January 2019.

24 January: Alzheimer Slovenia joins project developing training to improve healthier ageing for people with Down syndrome

Spominčica-Alzheimer Slovenia started working on two new European Erasmus+ KA2 projects at the beginning of 2019. One of these projects is DS-AGEING (development of a training programme to improve healthier ageing for people with Down syndrome). Spominčica will prepare a training programme to enhance competences (behaviour, skills and knowledge) of individuals with Down syndrome after the age of 30, and also to raise awareness among professional carers and families about healthy-ageing.

Worldwide, around 6 million people have Down syndrome, a rare genetic disorder, associated with other health conditions and cognitive decline. Individuals with Down syndrome are age more rapidly, after the age of 30. Scientific studies have shown early neuropathological changes in the brains of people with Down syndrome, resulting in young-onset Alzheimer’s disease. Spominčica joined the project, because it would like to share its experience on how to cope, organise and also promote autonomy among people who have cognitive decline.

Other partners in the project are: Polibienestar (Spain), ALDO-CET (Romania), Fundación Asindown (Spain), Associação Portuguesa de Portadores de Trissomia 21 (Portugal), Društvo Downov sindrom Slovenija (Slovenia), and AUTH (Greece).

25 January: Alzheimer Bulgaria’s Dementia Friends programme has made great progress in a short time

In late 2018 (24 October), Alzheimer Bulgaria launched its Dementia Friends programme. In the short time from then to now (25 January 2019), the programme has made great progress, achieving 132 Dementia Friends (each took a 2-hour seminar about dementia).

They also have 17 Dementia Friends, each of whom undertook a 1-day training on becoming a Dementia Befriender in a nursing home for people with dementia. These 17 Dementia Friends will be visiting elderly members in two nursing homes in two Bulgarian cities- Sofia and Pleven, respectively. There are a further 6 Dementia Friends Champions, who deliver the seminars and training sessions.

Pictured: Alzheimer Bulgaria visited the Older University in Sofia and the American University in Blagoevgrad, November 2018

25 January: SDWG members use social media to share tips to avoid isolation during festive period

The Scottish Dementia Working Group (SDWG) campaigns at a local and national level, within Scotland, to increase awareness of dementia and reduce stigma. In order to do so, the group’s members engage in a variety of ways, including face-to-face meetings, consultations, events, newsletters and social media. Social media can be a particularly useful tool to raise awareness of the group, communicate with a large and diverse audience and, importantly, share the invaluable voice of lived experience in dementia.

In the run up to the festive period, SDWG members shared their personal hints and tips to maintain connections and avoid social isolation, on Twitter. SDWG members know that winter has the potential to be a particularly lonely time, as the weather can reduce the number of opportunities for people with dementia to get out and about.

Members were keen to share tips for a range of audiences and stress that we all have a responsibility to make sure no one faces dementia alone. As well as hints and tips, the Twitter
posts also shared details of the Alzheimer Scotland 24-hour helpline, to ensure that those affected by dementia have a way to access support, regardless of the issue, time post diagnosis or location.

You can find out more and keep up to date with the latest SDWG news on Twitter: @S_D_W_G

POLICY WATCH

12 December 2018: Turkey discusses scope and regulations of dementia day-care services with Ministry of Family Labour and Social Services

Türkiye Alzheimer Derneği (Turkish Alzheimer Association, TAA) organised a workshop with the theme “Day Care Services Imperative and Suitable for Persons with Alzheimer's” in collaboration with the Ministry of Family Labour and Social Services and interested NGOs and related public service institutions. The workshop took place in the day-care Centre in Konya, where one of the 14 branches of the Association functions, on 12 December 2018.

Among the many participants of the workshop, were the executive staff of associated departments of the Ministry, managers of Ankara and Konya District Health Boards, the president and board members of the TAA, representatives of NGOs like the Federation of Service Associations, the Home Care and Social Services Association, the Association of Geriatric Physiotherapists, the Association of Turkish Retirees, the Association of Musical Therapy, etc. and municipality authorities, as well as academics from Necmettin Erbakan University.

The main topic discussed was “whom should day-care centres serve and what should be the scope of the services?” After pointing out that the main aim of these centres should be to maintain the capabilities of people with dementia, and employ occupational therapy methods to help reduce aggressive behaviours and help reduce “carer burden”. It was also stated that the regulations issued in 2008 covered day-care centres for the elderly, while the one issued in 2016 apply to day-care centres for people with disabilities – meaning that people with dementia fall into a grey area between these categories, and when they are younger than 65 but still disabled due to the illness they are not within the range of any of these regulations. Thus, the conclusion was that the biggest priority of this committee remains to be defining the term “Dementia associated Disability” and designing a set of regulations describing the services that need to be offered in dementia day-care centres. The meeting adjourned with the intention of gathering in March 2019 again.

21 January: Alzheimer Scotland launches policy report on paying for care

Alzheimer Scotland has published a new policy report addressing the inequalities that people living with advanced dementia face every day under Scotland’s current social care model.

The Fair Dementia Care Commission was established by Alzheimer Scotland to consider the inequality in access to health care and the disproportionate impact of social care charges faced by people with advanced dementia, their families, and carers in Scotland. Chaired by former First Minister Henry McLeish, the commission brought together a small group of experts to work in partnership with Alzheimer Scotland, to make a series of bold recommendations to end these inequalities.

The report highlights that the complex needs associated with advanced dementia have not been fully understood or recognised as health or nursing care and therefore services have not been free at the point of delivery.

The report calls for authorities to accept and recognise that people with advanced dementia must have the equality of access to free health care on a par with people who are living with other progressive and terminal illnesses. The report also highlights the current complexity, variability and lack of transparency in social care charging policies across Scotland.

Chair of The Fair Dementia Care Commission, Henry McLeish, said: “On behalf of Alzheimer Scotland and the members of this commission I ask that the Scottish Government accept and act on the recommendations set out in this report so that we can work towards delivering fair dementia care for people with advanced dementia.”

Chief Executive of Alzheimer Scotland, Henry Simmons, said: “The findings of this report provide us with a detailed understanding of the inequalities that exist for people with advanced dementia who are living with complex health care needs. Whilst we understand that it will require significant effort and dedication to fully transform our system, we ask that the Scottish Government lead the way by accepting the definitions and recommendations in this report and commit to starting the journey towards delivering fair dementia care for those with advanced dementia in Scotland.”

The recommendations, as set out in The Fair Dementia Care Commission report, “Fair Dementia Care for People with Advanced Dementia”, include:
- The Fair Dementia Care Commission’s definition of advanced dementia is used and implemented in practice
- Advanced dementia is fully recognised for the complexities involved in the care needed as it progresses to end of life
- The Scottish Government commits to recognising that the needs of people with advanced dementia are healthcare needs and ensure equality of access to appropriate health and nursing care, which is free at the point of delivery
- The Scottish Government commits to investigating the costs of implementing appropriate and free health care for those living, and dying, with advanced dementia
- The Scottish Government, the Convention of Scottish Local Authorities (COSLA) and Integration Joint Boards commit to ending the current lack of transparency, complexity and variability in current non-residential care charging provisions across Scotland
- The recording of dementia (including advanced dementia) prevalence across all health and social care settings is urgently required to support better understanding of demand, allocation of resources and improved care and support
- All local authorities/health and social care partnerships make local charging policies accessible and readily available.

Read the full report, here: https://bit.ly/2RRLIJA

21 January: Germany launches work to develop a national dementia strategy

An event to officially commence work on the German National Dementia strategy has taken place, with stakeholders meeting to officially start their work on 21 January.

Following the announcement by Federal Minister of Family Affairs Franziska Giffey and Federal Health Minister Jens Spahn in September 2018, four working groups will develop the content of the National Dementia Strategy throughout 2019. The topics of the working groups build on the fields of action of the Alliance for People with Dementia, which was initiated in 2012 as part of the demographic strategy of the Federal Government. In addition to the ministries leading the work (Ministry for family, senior citizens, women and youth, and the Ministry for health), the German Alzheimer’s Association (DAlzG) is co-chairing the steering group. Other stakeholders involved in the work will include other ministries, federal states, civil society, scientists, service providers and social security.

Monika Kaus, Chair of DAlzG said: “People with dementia and their relatives need the support of all stakeholders in the field of dementia, even after the end of the work of the Alliance. We welcome the activities of the federal ministries to develop and implement further goals together with a National Dementia Strategy in the future as well. However, resources must be provided for this.”

The DAlzG Advisory Board “Living with Dementia”, which consists of people with dementia, was able to formulate its expectations in a workshop held in advance of the kick-off meeting. The Board suggested a number of topics for consideration, including:

- Requests for social participation
- Mobility
- Support for relatives
- The desire for assistants to help with the diagnosis.

The office of the National Dementia Strategy is based at the German Centre of Gerontology (DZA).

24 January: Alzheimer’s Society’s Dementia Connect included in England’s NHS Long Term Plan

The National Health Service (NHS) in England is getting ready for the future. January saw the publication of the new Long Term Plan, setting out the NHS’ ambition for the next ten years, backed up by GBP 20 billion (EUR 23 billion) in new funding by 2023/24. Its new service model will focus on putting more support in the community, creating new multi-disciplinary teams, to make sure people can get the support they need to stay independent in their community for as long as possible and out of hospital. Within five years, over 2.5 million more people will benefit from ‘social prescribing’, a personal health budget, and new support for managing their own health.

The Alzheimer’s Society’s own Dementia Connect service has been identified as playing a key role in supporting the plan. By 2021, one million people will be living with dementia in the UK and the Alzheimer’s Society wants to be able to reach them all with an offer of support, so no one has to face dementia alone. The Dementia Connect service includes an easy-to-access offer of support and advice over the phone, followed by face-to-face support from a Dementia Adviser for people with more complex needs.

As the Long Term Plan rolls out, the Alzheimer’s Society will work to ensure dementia isn’t left behind. The plan focuses on preventing the biggest causes of early death including heart disease, stroke, and cancer - but could go further on dementia. While the NHS has a new plan, the government is yet to announce its long-awaited Green Paper consultation on social care. The 700,000 people with dementia in England (and 850,000 in the UK) need better support, and NHS and social care policies must be developed in parallel to build a system that works for everyone.
Alzheimer’s Society Chief Executive, Jeremy Hughes said: “Dementia is the biggest challenge facing our health and care system, and the NHS Long Term Plan will help people affected by dementia get better support. However, people with dementia can’t wait for an end to the injustice in the system. We need urgent action to prioritise turning words into action. People with dementia have waited long enough for the support they need and an end to the inequity they face.”

28 January: Ireland publishes new policy position paper on dementia and loneliness

On 28 January, The Alzheimer Society of Ireland (ASI) published a new policy position paper “Dementia and Loneliness”. ASI commissioned researchers from University College Cork to carry out the research, with the aim of informing current understandings in this area. The paper reflects the experiences of loneliness for people living with dementia; how loneliness can, in part, be attributed to a lack of supports and services; and the public awareness and understanding of dementia.

In addition to a literature review, interviews were conducted with individuals over the age of 55, living at home, with a dementia diagnosis, to understand whether people living with dementia felt lonely as their lives progressed and their conditions worsened.

The report indicates that loneliness is not necessarily caused by being alone, but by being without some definite needed relationship or set of relationships or indeed the availability of local supports and services. The study particularly found that access to home-care support and public nurses enabled families to manage living life with dementia, but the difficulties of securing these supports were a source of anxiety, frustration, and loneliness.

Key recommendations from the report to alleviate loneliness for people with dementia include:

People living with dementia should be enabled to continue to engage in the meaningful social activities they enjoyed doing before their dementia diagnosis, should they wish to do so. Facilitation of this continued engagement in social activities may require support from family, formal caregivers and wider society.

Accessible and simple information to help understand dementia should be provided to the general public, service providers, health and social care professionals, and relevant volunteer/community groups. Communication tips and skills relevant to dementia need to be made available to enhance opportunities for effective engagement.

People living with dementia and their caregivers should be given an opportunity to participate in local dementia support groups. For this, these groups need to exist, and people need to be facilitated to attend and important that continued attempts are made to address the stigma associated with dementia, at a local and national level.

ASI Policy & Research Manager Dr Bernadette Rock said: “Dementia-supportive communities or other social resources are necessary to ensure people with dementia maintain social networks that foster connections and encourage people to partake in meaningful activities that preserve their sense of self-worth. The data in this study suggests that the maintenance of social connection to the wider community fosters a sense of self-worth and self-management, which in turn mitigates feelings of loneliness. It is so important for people with dementia to feel connected to their local community.”

The full report can be read here: https://bit.ly/2CQ1N4k
The Press Release can be read here: https://bit.ly/2RqnuNH

SCIENCE WATCH

4 January: Study investigates potentially inappropriate prescribing in older people with dementia

On 4 January, a group of researchers from the University of Hull (UK), published a systematic review on the identification of potentially inappropriate prescribing (PIP) in older people with dementia in the European Journal of Clinical Pharmacology.

The research group aimed to provide a first systematic view on how tools are being used to study PIP in elderly people living with dementia. This included:

- The description and summary of studies in which a published tool for the identification of PIP in people living with dementia was used
- Reporting the prevalence of PIP as well as the medications that were deemed inappropriate
- Providing an insight into the possible advantages, but also pitfalls respectively complications that may arise by the use of the tools identified.

Out of the identified 3,326 unique papers, the researchers reviewed 26 relevant articles. The group concluded that there is a varying prevalence of PIP ranging from a low of 14% to a high of 74% in older people with dementia. The most
On 7 January, researchers from Missouri, US published an assessment of racial differences in biomarkers that are used to identify Alzheimer’s disease (AD), in the Journal JAMA Neurology. Previous research on potential racial differences of biomarkers in AD yielded mixed and even conflicting results. A new study conducted in the US, aimed to shed further light on this area. Scientists enrolled 1,255 participants in a study, looking at (amongst others): reported family history of dementia; volumes of brain tissue associated with memory functioning (hippocampus); concentrations of tau and Aβ42 (proteins associated with death of brain cells and AD); a genetic risk variance - APOE e4 - for AD; and race.

In addition to other findings, the scientists reported that African Americans have lower levels of tau than non-Hispanic white participants do. The analyses also showed a significant interaction between the genetic risk factor APOE e4 and race. Although the findings are certainly interesting, the researchers also reported some limitations, such as the need to explore further potential influences, like: socioeconomic status; other diseases that occur along with AD; and further factors, which might contribute to the found differences. Nevertheless, the team underlined in their conclusion that, in light of their findings, future research on molecular biomarkers of AD should gather information on race, and statistical analyses could improve their accuracy by adjusting for it. Furthermore, since the team only looked at differences in African Americans and non-Hispanic white participants, they recommend the implementation of studies that look at the expression of biomarkers of AD across all racial and ethnic groups.

On 7 January, scientists published a range of new genetic risk factors for Alzheimer’s disease (AD) in the journal Nature Genetics. The collaborative effort was led by researchers from VU University Amsterdam (Netherlands) the University of Oslo (Norway) and the Broad Institute in Boston, MA (US). In their article, the authors report on how they brought together data from almost half a million samples (71,880 clinically diagnosed AD or AD-by-proxy as well as 383,378 controls), for a subsequent analysis. Their results suggest 29 genetic variants associated with AD (so called risk loci), thereby introducing 9 variants that were previously not linked to the disease. The scientists state that these genetic variants, which overall potentially implicate 215 potential causative genes, lead to a better understanding of the neurobiology of AD. These findings might be helpful to guide drug development in future.
9 January: Study suggests that alterations in NREM sleep is associated with early signs of AD

On 9 January, US researchers from the Washington University School of Medicine, St. Louis, reported in the journal Science Translational Medicine that alterations in non–rapid eye movement (NREM) sleep may be an early indicator of Alzheimer’s disease (AD).

Researchers analysed sleep-wake activity, cognitive performance and AD biomarkers, in 119 cognitively normal participants older than 60 years of age, from longitudinal studies of ageing at the Knight Alzheimer’s Disease Research Center at Washington University. They showed that NREM sleep slow-wave activity was negatively correlated with AD pathology in several brain areas. They found higher levels of tau accumulation and β-amyloid deposition in the brain of older adults who had less slow-wave sleep. However, several weaknesses of the study were identified, such as: the number of participants; the stages of AD pathology; and the fact that sleep alterations preceded or followed the development of AD pathology.

http://stm.scientificmag.org/content/11/474/eaau6550

9 January: Sirion and Denali announce collaboration to develop gene therapies for neurodegenerative diseases

On 9 January, the global leader in viral vector-based gene delivery technologies SIRION Biotech GmbH announced its collaboration with the biopharmaceutical company Denali Therapeutics, which develops product candidates for neurodegenerative diseases.

According to the licence and agreement, both companies will combine their platforms to create new adeno-associated virus vectors capable of allowing therapeutics to cross the blood-brain barrier - a semipermeable membrane that protects the brain - with high efficiency. These gene therapies would target neurodegenerative diseases including Alzheimer’s and Parkinson’s diseases.


14 January: Researchers suggest that blood-brain barrier breakdown is an early biomarker of human cognitive dysfunction

On 14 January, US researchers from the University of Southern California, Los Angeles reported a link between neurovascular dysfunction and human cognitive dysfunction.

161 cognitively normal adults and individuals with early cognitive dysfunction (≥ 45 years of age) were included in the published study. Results showed that people with early cognitive dysfunction develop brain capillary damage and blood–brain barrier breakdown in the hippocampus, independent of tau and amyloid biomarkers changes, which are the classic pathophysiological hallmarks of Alzheimer’s disease.

Researchers suggested that blood–brain barrier breakdown is an early biomarker of cognitive impairment and that neurovascular dysfunction may represent a factor contributing to early cognitive dysfunction.

Findings were published in the journal Nature Medicine.

https://www.nature.com/articles/s41591-018-0297-y

16 January: United Neuroscience announces results from Phase II study of UB-311 vaccine in people with AD

On 16 January, United Neuroscience, a clinical-stage biotechnology company developing active immunotherapeutics to treat and prevent brain disorders, announced top-line results of its Phase Iia trial of UB-311 vaccine in people with Alzheimer’s disease (AD).

The Phase Iia was a randomised, double blind and placebo-controlled study evaluating the safety, efficacy and immunogenicity of UB-311, the novel synthetic peptide vaccine targeting Aβ peptides, in people with AD.

UB-311 vaccine was well tolerated and the trial met the primary outcomes measures of safety and immunogenicity with a 96% response rate. Although improvements on all secondary measures – including changes in Amyloid burden, cognition, global assessment and behavioural assessment - were observed, they were not statistically significant. The company expects to present additional results at upcoming meetings such as the 14th International Conference on Alzheimer’s and Parkinson’s Diseases (Lisbon, March 2019).

https://prn.to/2FDOOpl

17 January: AgeneBio begins recruitment in phase III trial to evaluate AGB101 in MCI due to AD

On 17 January, the biopharmaceutical company AgeneBio, which develops innovative therapeutics to preserve and restore brain function, announced that it has recruited its first participant in a Phase III clinical trial evaluating AGB101 to treat amnestic Mild Cognitive Impairment (MCI) due to Alzheimer’s disease (AD). AGB101 has been developed to target the reduction of hippocampal overactivity to slow progression and delay the onset of Alzheimer’s dementia.

The Phase III trial, named “HOPE4MCI”, is a multicentre, randomised, double-blind and placebo-controlled study, evaluating the efficacy and safety of AGB101 on slowing progression of MCI due to AD. The trial will enrol 830 participants that will be randomised to receive placebo or the experimental drug (220mg) once daily for 78 weeks. Cognitive and functional efficacy will be measured by the Clinical
neurodegenerative disorders did not meet its to be safe and well tolerated. It
was decided to fund
that a higher degree of frailty was tied to a
attention" and "Trial Memory and Cognition in
ed mouse brain,
ed
addition,
diagnosis with an increasing tau and
phibrosis
In their study, giving insight into the brains' pathology after death.
study of specialis
The company completed its Phase I trial of COR388 where the
experimental drug appeared to be safe and well tolerated. It
expects to launch a Phase II/III trial this year in people with
mild to moderate AD.

http://advances.sciencemag.org/content/5/1/eaau3333

28 January: SPRINT MIND study reports on results and Alzheimer’s Association grants funding of over USD 800,000 to launch extended 2.0 study

On 28 January, the SPRINT MIND consortium published the results of its randomised controlled trial in the Journal of the American Medical Association (JAMA). The acronyms SPRINT MIND stand for “Systolic Blood Pressure Intervention” and “Trial Memory and Cognition in Decreased Hypertension”. On the same day, the Alzheimer’s Association officially announced the support of a consecutive and extended SPRINT MIND 2.0 Study. The aim of the study is to continue investigations into the impact of intensive blood pressure treatment on reducing the risk of dementia. Apart from following up previous participants, the trial will also be extended. All in all, 9,361 participants with hypertension and over the age of 50 were enrolled for the first SPRINT MIND trial. These people were then allocated to one out of two different groups with different systolic blood pressure targets (either below 120 mm HG or below 140 mm HG, which would be standard care). The researchers reported that the study did not meet its outcome to significantly achieve a lower rate of probable dementia in those with intensive blood pressure control, compared to those receiving standard care. Nevertheless, the results showed that those who received an intensive blood pressure control (target below 120 mm HG), reached a significantly reduced risk of developing mild cognitive impairment: 14.6 vs 18.3 cases per 1000 person-years. Due to these interesting findings that warrant further investigation, the Alzheimer’s Association has decided to fund the SPRINT MIND 2.0 study, which is due to begin in early 2019. The official press release is here: https://bit.ly/2HFT0wS

The results of the SPRINT MIND study can be accessed here: https://jamanetwork.com/journals/jama/fullarticle/2723256

22 January: Study investigates link between frailty and AD dementia

At the beginning of 2019, researchers from Canada and the US published a research paper on the possible link between frailty and Alzheimer’s disease (AD) dementia in the journal The Lancet Neurology. For their analysis, the team brought together data from 456 US participants, of whom 242 had been diagnosed with either possible or probable AD dementia. The study also included an evaluation of those participants’ brains that died during the study, giving insight into the brains’ pathology after death. The team found that a higher degree of frailty was tied to a higher likelihood of AD pathology along with subsequent dementia. At the same time, they also reported that people with a lower degree of frailty seemed to be better able to tolerate AD pathology.

In their conclusion, the team stated that their findings support the idea that frailty influences clinical expression of dementia and should therefore be taken into consideration during the management and treatment of older adults.

Nevertheless, the researchers also underlined that their findings bring the need to further explore how frailty and cognition change over time to better understand the relationship. They also provided insights into the limitations of their study, such as other possibly-competing risks that were not taken into account.

The article is available here: https://doi.org/10.1016/S1474-4422(18)30371-5

23 January: Study suggests a link between gum disease and AD pathogenesis

On 23 January, researchers from Cortexyme- a clinical-stage pharmaceutical company developing novel treatments for altering the course of Alzheimer’s disease (AD) and other neurodegenerative disorders - reported that periodontitis, often known as gum disease, may contribute to the development of AD. Findings were published in the journal Science Advances.

In the published study, the bacteria involved in periodontitis called gingipain was shown to be present in the brains of people with AD and to be significantly correlated with AD diagnosis with an increasing tau and ubiquitin pathology. In addition, gingipains were found to be neurotoxic in cell culture with detrimental and fragmented effects on tau. Additional tests on mouse models showed that gingipain infection led to an increased production of Aβ in the brain.

Scientists synthesised selective, brain-penetrant and small-molecules targeting gingipains namely COR286 and COR271. Using mouse models, they noted that gingipain inhibitors could reduce the load of gingipain in the mouse brain, decrease the neurodegeneration and block the Aβ production. The company completed its Phase I trial of COR388 where the experimental drug appeared to be safe and well tolerated. It expects to launch a Phase II/III trial this year in people with mild to moderate AD.

https://jamanetwork.com/journals/jama/fullarticle/2723256

Dementia Ratings Scale – Sum of Boxes (CDR-SB), Mini Mental State Exam (MMSE) and Functional Activities Questionnaire (FAQ).

The HOPE4MCI trial also includes a sub-study of specialised imaging to observe the pathology in the brains of the participants. Participants will undergo measures of neurodegeneration (structural MRI, Tau PET).
30 January: Roche halts its Phase III CREAD1 and CREAD2 studies of AD drug crenezumab

On 30 January, the Swiss multinational biotech company Roche announced that it has decided to discontinue its CREAD1 and CREAD2 Phase III studies of the investigational anti-beta-amyloid drug crenezumab in early Alzheimer’s disease (AD).

CREAD1 and 2 are multicentre, randomised, double-blind, placebo-controlled and parallel-group Phase III studies evaluating the efficacy and safety of crenezumab in 1,500 people worldwide with prodromal to mild AD. CREAD1 started in early 2016 and CREAD2 in mid-2017.

Studies will be discontinued based on the results from a pre-planned interim analysis. An independent data monitoring committee reported that crenezumab was not expected to meet its primary endpoint of change in the Clinical Dementia Rating-Sum of Boxes (CDR-SB) score. Data will be presented at upcoming conferences.

Crenezumab continues to be investigated in the Alzheimer’s Prevention Initiative (API) study. Roche will also continue its GRADUATE Phase III trial with gantenerumab and the TAURIEL Phase II trial with RG6100 for the treatment of AD.


LIVING WITH DEMENTIA

3 January: EWGPWD member Amelia Hajrić tells us about a recent conference she attended in her country

From 21-23 November 2018, I attended the iCoDem/18 International Congress on Dementia in Bosnia and Herzegovina. In the frame of iCoDem/18 - which was a very successful congress with a lot visitors and great lecturers and which brought together various professions during 4 days, including 3 full days of lectures - our support group and group of people with dementia participated in all sessions and on the last day of iCoDem/18 we held our own session.

The first day was spent organising the session "Dementia as a public challenge", where we discussed with representatives of the Ministry of Health, the Federal Agency for Control and Standardisation in the Health Sector and the Institute for Public Health.

We talked about what it means to have dementia in Bosnia and Herzegovina, about the dementia "epidemic" in society and about whether we are taking action to combat dementia. On the last day of iCoDem/18, we had lectures on stigma, carer burn-out, programmes for helping people with dementia, educational programmes, etc. The active participation of pupils and students, who had a lot of questions for our group of people with dementia, was very significant.

DEMENTIA IN SOCIETY

8 January: International trailer released for Flemish awareness-raising campaign

On 8 January the international version (in English) of a new campaign video by the Expertisecentrum Dementie Vlaanderen (Flanders Centre of Expertise on Dementia) was launched online. The Flemish version appeared the day before, officially launching a new chapter of the campaign “Forget dementia, remember the person”.

The campaign centres around the importance of focusing on what people with dementia can still do and enjoy, rather than highlighting what is no longer possible. The heart and soul of the campaign are the personal testimonies and this new video gives a sneak preview of the stories that will be shared in the coming weeks on social media (Twitter @ECDementieVI).

https://youtu.be/mAGM3zbn8KE

9 January: Music is so beneficial it should be part of all dementia care pathways, UK campaign says

The Music for Dementia 2020 campaign was launched in the UK on 9 January, with the aim of increasing public awareness and backing for music to be an integral part of all dementia care pathways.

Financial backing for this campaign comes from the Utley Foundation - a private family charitable trust, which exists to advance social causes close to the heart of the trustees. The funding will finance local and national projects, scaling them up, helping to introduce music where there is currently little or no existing provision, as well as training the workforce.

“We want everyone in the UK living with dementia to have access to the music that means most to them and for it to be accessible in the most appropriate and effective ways,” said Grace Meadows, the programme director at the Utley...
Foundation and a senior music therapist at Chelsea and Westminster Hospital, London.

“Research suggests music can help people with dementia reduce the need for medication or restraints, address agitation and help people and their families cope better with symptoms,” said UK Secretary of State for Health and Social Care, Matt Hancock. “This is the kind of good value, easy-to-use social prescription that I’m fully behind and I fully support work that helps us move to more person-centred care - a key part of the NHS’s long-term plan.”

The campaign website will share best practice and research and will have a searchable database of suitable music activities for people with dementia.

http://www.musicfordementia2020.com/

NEW PUBLICATIONS AND RESOURCES

11 January: UK publication aims to help LGBT+ people affected by dementia get better access to support and information

On 11 January, Bring Dementia Out was launched. As part of this innovation, the UK National Dementia Action Alliance (DAA) has co-produced a booklet and poster with LGBT+ people affected by dementia, the Alzheimer’s Society, and LGBT+ organisations (including Switchboard in Brighton and Hove, LGBT Foundation in Manchester, and the National LGBT Partnership). Bring Dementia Out is an innovation that aims to help LGBT+ people affected by dementia get better access to support and information in Brighton and Hove and Greater Manchester. The booklet sits alongside a series of resources, including a video, online hub and posters, to raise awareness and understanding of challenges faced by LGBT+ people affected by dementia. This is being tested out in Brighton and Hove and Greater Manchester during January and February 2019.

You can find out more and order a (free) copy of the report, here:

alzheimers.org.uk/get-involved/bring-dementia-out

17 January: Ireland publishes document to help professionals run Dementia Post-diagnostic Psycho-educational programmes

On 17 January, the National Dementia Office and the Dementia Services Information and Development Centre (DSIDC) in Ireland published a document providing guidance to help health and social care professionals to establish and run Dementia Post-diagnostic Psycho-educational programmes.

https://bit.ly/2RTZ0AD

EDUCATION

11 January: Edinburgh Centre for Dementia Prevention to host Alzheimer’s Disease Research Methodology Summer School

Following the success of a similar 2018 summer school, the University of Edinburgh Centre for Dementia Prevention will host the Alzheimer’s Disease Research Methodology Summer School 2019.

Find out more, and register for the four-day course, at: http://bit.ly/2TDmG9m

25 January: Massive online open course (MOOC) on palliative care is open for registrations

A MOOC on “Improving palliative care in care homes for older people” is open for registrations. The free course begins on 1 April 2019.

Taught by leading experts in the field - including Prof. Lieve van den Block, Prof. Katherine Froggatt, Dr Jo Hockley and Prof. Sheila Payne - this three-week course will be of interest to all staff working in care homes, (managers, physicians, clinicians, care workers, social care workers and therapy staff, among others).

The “PACE Steps to Success” programme will show you how to make six practical and organisational changes that improve care for older people, their families and staff working in, and with, care homes. You will hear from people using the programme in many European countries.


JOB OPPORTUNITIES

9 January: Applications open for PhD Studentship with Alzheimer Scotland Centre for Policy and Practice

Applications are open for a three-year-long funded PhD Studentship with the Alzheimer Scotland Centre for Policy and Practice (ASCPP) at the University of the West of Scotland in partnership with Erskine and Alzheimer Scotland.

The proposed research study will be co-developed with residents, family and staff at Erskine, academics and researchers from the ASCPP and Alzheimer Scotland. This is a participatory action research study applying the concept and method of marginal gains to meet the needs and improve quality-of-life for people with advanced dementia for meaningful, personalised activity. It aims to support human
The studentship offers an annual stipend of GBP 14,777 (EUR 16,743) per annum for three years and payment of tuition fees in full. Funding will be considered as part of a competitive round. Studentships are open to UK/EU candidates with a first degree (or equivalent) in a relevant discipline. Applications close on 8 February 2019.

Supervisory team: Dr Margaret Brown (ASCPP), Dr Rhoda Macrae (ASCPP), Dr Angela Beggan (School of Health and Life Sciences, UWS). Apply here: https://bit.ly/2HCckFX

14 January: Alzheimer Europe is looking to fill two Luxembourg-based positions

Alzheimer Europe is looking to fill the following Luxembourg-based positions:

**Project Officer (m/f) (Full-time) - On a permanent basis**

As the Project Officer, you will:

- Carry out a mapping exercise of data-sharing policies across European research projects
- Develop and update the Alzheimer Europe database on guidelines on diagnosis and treatment of dementia in Europe
- Collaborate with EU projects NEURONET and VirtualBrainCloud funded by the Innovative Medicines Initiative and Horizon2020 and contribute to data sharing and data management
- Help in the dissemination of EU funded research projects
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation’s newsletter and website.

You should have the following experience and qualities:

- Completed university education in a scientific field
- Experience in a similar position (background in data management or data sharing policies will be considered as an advantage)

**Administrative Assistant (m/f) (Part-time) - On a permanent basis**

As the Administrative Assistant, you will:

- Handle telephone calls, contacts with internal and external partners, messages and requests
- Assure efficient processing and managing of document flows
- Provide active assistance in day-to-day activities
- Perform various organisational, administrative and secretarial duties efficiently
- Keep mailing lists and databases up-to-date
- Respond to general mail requests and deal with filing
- Update the Alzheimer Europe website pages
- Support the team with the organisation of events (preparation of documents and preparations) and the Annual Conference (queries and invoices).

You should have the following experience and qualities:

- Completed secondary education and experience in a similar position (education or background in communication or secretariat will be considered as an advantage)
- A perfect knowledge of English (knowledge of French and other European languages will be a plus)
- Good writing and communication skills
- Experience of social media
- Good computer knowledge (Internet applications, Word)
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad for project meetings, scientific conferences and other networking opportunities.

For either position, please apply by sending your CV, together with a cover letter (both documents in English), by 15 February 2019 to: Alzheimer Europe, 14 rue Dicks, L-1417 Luxembourg or via E-mail to info@alzheimer-europe.org
17 January: INDUCT project seeks Marie Skłodowska-Curie early stage researcher in Amsterdam

Applications are open for an early-stage researcher (ESR) to work on the INDUCT project, based at Amsterdam VU University Medical Center (VUMC). The post is for five months.

Main tasks and responsibilities are:

- To assist in recruitment of persons with dementia and their carers
- To conduct the data collection in collaboration with the PhD student and master or bachelor students
- To process and to analyse the data
- To write scientific papers, professional publications and a factsheet
- To present the study and results at (international) scientific and public meetings
- To collaborate with other researchers in INDUCT and the department.

The successful early stage researcher would work in close collaboration with the PhD student from VUmc and Saxion University of Applied Sciences (Yvonne Kerkhof), the senior researcher (Dr Franka Meiland) and the head of the research group (Prof. Rose-Marie Dröes).

Applications close on 17 February 2019.

https://www.werkenbijvumc.nl/vacatures/early-stage-researcher-induct/

22 January: Innovative Medicines Initiative seeks Writer/Editor (M/F)

Applications are open for a short-term appointment as a Writer/Editor for the Innovative Medicines Initiative (IMI), based in Brussels.

Applications close on 18 February 2019.

To read the full vacancy notice or apply for the positions above, please visit:

https://cloud.imi.europa.eu/web/imi-vacancies

WPA Sponsored Thematic Congress
“Dementia: Psychiatric and Neurological Challenges and Perspectives”
15-18 May 2019, Ohrid, Macedonia

President of the Congress:
Helen Herrman
Organizing Committee:
Chair: Antoni Novotni
Co Chairs: Levent Kuey, Dimitar Bonevski

wpadementia2019.com
Contact Alzheimer Europe:
Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org, www.alzheimer-europe.org

Alzheimer Europe Board:
Chairperson: Iva Holmerová (Czech Republic); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: James Pearson (UK - Scotland); Honorary Treasurer: Maria do Rosário Zincke dos Reis (Portugal). Members: Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (Ireland), Stefanie Becker (Switzerland), Marco Blom (Netherlands), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Karin Westerlund (Sweden).

Alzheimer Europe Staff:
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Conference and Event Coordinator: Gwladys Guillory; Director for Projects: Dianne Gove; Project Officers: Christophe Bintener, Cindy Birch, Ana Diaz; Policy Officer: Owen Miller; Finance Officer: Stefanie Peulen; Administrative Assistant: Grazia Tomasini.

### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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</thead>
<tbody>
<tr>
<td>4-5 February</td>
<td>EPAD LCS Investigator meeting and PoC kick-off meeting (Berlin, Germany)</td>
<td>Cindy</td>
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<tr>
<td>13 February</td>
<td>Meeting with Roche (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>19-20 February</td>
<td>Programme Board of the EU Joint Action on Dementia (Edinburgh, UK)</td>
<td>Jean</td>
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<tr>
<td>25-26 February</td>
<td>Alzheimer Europe Board meeting (Brussels, Belgium)</td>
<td>AE Board and staff</td>
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<tr>
<td>26 February</td>
<td>European Parliament lunch debate “Dementia as a European research priority” (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<tr>
<td>26 February</td>
<td>Alzheimer Europe corporate round table (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<tr>
<td>27 February</td>
<td>Alzheimer Europe public affairs meetings (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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### CONFERENCES 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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</thead>
<tbody>
<tr>
<td>6-7 February</td>
<td>3rd HBP Student Conference on Interdisciplinary Brain Research, <a href="https://education.humanbrainproject.eu">https://education.humanbrainproject.eu</a></td>
<td>Ghent, Belgium</td>
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<tr>
<td>14-17 February</td>
<td>11th Panhellenic Conference on Alzheimer’s Disease and Related Disorders, <a href="http://www.alzheimer-conference.gr">http://www.alzheimer-conference.gr</a></td>
<td>Thessaloniki, Greece</td>
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<tr>
<td>20-23 March</td>
<td>13th Göttingen Meeting of the German Neuroscience Society, <a href="https://www.nwg-goettingen.de/">https://www.nwg-goettingen.de/</a></td>
<td>Göttingen, Germany</td>
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<tr>
<td>4-7 April</td>
<td>13th World Congress on Controversies in Neurology, <a href="http://www.ontecmed.com">http://www.ontecmed.com</a></td>
<td>Madrid, Spain</td>
</tr>
<tr>
<td>5-8 May</td>
<td>Understanding and Targeting Alzheimer’s disease, <a href="https://www.fens.org/Meetings/The-Brain-Conferences/Understanding-and-Targeting-Alzheimer-Disease">https://www.fens.org/Meetings/The-Brain-Conferences/Understanding-and-Targeting-Alzheimer-Disease</a></td>
<td>Copenhagen, Denmark</td>
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<tr>
<td>21-22 May</td>
<td>Alzheimer’s Society Annual Conference, <a href="https://www.alzheimers.org.uk">https://www.alzheimers.org.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>1-4 July</td>
<td>Royal College of Psychiatrists’ International Conference, <a href="https://www.rcpsych.ac.uk">https://www.rcpsych.ac.uk</a></td>
<td>London, UK</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