WELCOME

Our small, dedicated team is delighted to welcome two new colleagues - Aideen O’Brien and Angela Bradshaw. Aideen is providing administrative support to the team and Angela is collaborating on the VirtualBrainCloud and NEURONET projects.

On the subject of EU projects, the European Prevention of Alzheimer’s Dementia project (EPAD) made the headlines in the UK this month, providing comments on the potential impact Brexit will have on EU/UK research collaborations. Another project in which we have partnered, the Synaptic Dysfunction in Alzheimer Disease project (SyDAD), came to a close this month. A symposium was held at AD/PD conference in Lisbon, to mark the end of the project.

European research collaborations are so important in making forward strides in the field of dementia. We were delighted, therefore, to hear that the European Parliament has approved the framework for the next EU research programme, Horizon Europe (2021-2027).

Also at the European level, following the decision of the European Council to extend the Brexit deadline, the UK will now hold European elections, assuming it has not ratified a Withdrawal Agreement before 22 May. Our #DementiaPledge2019 campaign is already well underway, with 85 candidates supporting it so far, and we are pleased to also invite UK candidates to support the campaign.

At the national level, Spain has outlined the content of its forthcoming National Alzheimer’s Plan 2019-2023. We congratulate the Ministry of Health, as well as our Spanish member associations, Confederación española de familiares de Alzheimer y otras demencias (CEAFA) and Fundación Alzheimer España. We also applaud our colleagues at Alzheimer Suisse, who, together with 14 other major institutions in Switzerland specialising in dementia, have released a position statement underlining the importance of continuing the reimbursement of anti-dementia drugs. The decision to publish this paper was made in reaction to the French government’s highly controversial decision, in 2018, to stop reimbursement.

At the global level, billionaire philanthropist Bill Gates published a blog post on 2 April, in which he highlighted the importance of finding a workable method for diagnosing Alzheimer’s disease. He announced a new call for proposals for innovative research projects in this area.

Our colleagues at Alzheimer’s Disease International (ADI) also made a global call this month for a survey on attitudes towards dementia. The survey will run until 14 June and results will be published later this year.

Our own call for abstracts for #29AEC has been immensely successful, with a record 516 abstracts being submitted! The conference is already shaping up to be an exciting and varied event. Please register before 30 June to take advantage of our Early Bird rates.

Jean Georges
Executive Director
10-12 April: Alzheimer Europe presents report on minority ethnic groups at the North Sea Dementia Group annual meeting

The North Sea Dementia Group held its annual meeting in Stuttgart, Germany from 10 to 12 April. Several important topics were addressed, such as living well with dementia (evidence and theory), improving dementia care in differing contexts, people with dementia in the community and exploring planning, action and prevention.

On the last day of the meeting, the Robert Bosch Stiftung (RBS), which was supporting the event, organised three excursions and Brigitte Stähle from the RBS hosted a session on its dementia-related activities.

Dianne Gove, Director for Projects, Alzheimer Europe, took part in the guided tour of the Robert Bosch Hospital, which showcased the work of the department for geriatric medicine and geriatric rehabilitation. Then, on behalf of Alzheimer Europe’s expert working group on intercultural care and support, she also presented the report on intercultural care and support for people with dementia from minority ethnic groups, which is now available in English, French and German. This report received funding from the European Union’s Health Programme (2014-2020) and from the Robert Bosch Stiftung.

18 April: Roundtable discussion aims to move the continence care agenda forward

On 18 April, Alzheimer Europe took part in a policy roundtable, supported by Essity, aimed at moving the continence care agenda forward. The discussion was chaired by Cathy Smith (SpeakEasy), and Christine Marking (Marking Public Affairs) was responsible for reporting.

The group discussed what an overarching policy for the prevention and management of incontinence should look like, how to fit daily continence care into the EU-level policy climate and how to make the policy ask a reality.

The group will produce a document, which will be circulated to other organisations representing people with continence problems, for feedback and comments. Endorsements will also be sought before presenting the document to policy makers at national and European level.

Owen Miller, Policy Officer and Dianne Gove, Director for Projects, represented Alzheimer Europe at this meeting. Other organisations that participated included Eurocarers, the European Institute for Women’s Health, and Age Platform.

30 April: Alzheimer Europe Dementia Pledge campaign gathers support from across Europe

Alzheimer Europe’s #DementiaPledge2019 is well underway, with candidates in the European Parliament election being contacted by Alzheimer Europe at a European level and by member organisations at a national level.

As part of the campaign, Alzheimer Europe has asked candidates to sign up to a three-point pledge asking members to join the European Alzheimer’s Alliance (EAA), prioritise dementia across European policy areas and to become a Dementia Friend in their country.

Candidates can pledge their support on social media (Twitter and Facebook), simply stating that they support the #DementiaPledge2019. Alternatively, sign the pledge document returning it to Alzheimer Europe or to the relevant national member association, by email or in hard copy.

With the support of our members, the pledge has been translated and is available in ten languages: Croatian, English, Finnish, French, German, Italian, Luxembourgish, Portuguese, Slovenian, Spanish.

As at 30 April 2019, 85 candidates had signed up to the Pledge. Of this number, 44 incumbent MEPs have signed up, 18 of whom are new members of the European Alzheimer’s Alliance.

The Pledge campaign will run until 23 May 2019, when the first day of the European elections will take place.

1 May: Alzheimer Europe welcomes two new colleagues

Alzheimer Europe is pleased to welcome two new colleagues:

**Aideen O’Brien, Administrative Assistant**

Aideen (pictured, right) joined the team on 1 April 2019. She is working part-time, providing administrative support. Her responsibilities include: Uploading Alzheimer Europe reports and publications to the website; preparing documents and materials for meetings; taking board minutes; ensuring member associations’ details are kept up-to-date; and assistance with the Annual Conference. Aideen will also be supporting the policy and communications officers with administrative aspects of the European election campaign, as well as assisting the project team in keeping the database on guidelines for diagnosis and treatment of AD updated, and helping identify initiatives and materials related to intercultural care and support. She can be reached at aideen.obrien@alzheimer-europe.org

**Angela Bradshaw, Project Officer**

Angela (pictured, left) joined the team on 1 May 2019. She is working full-time, collaborating on VirtualBrainCloud and NEURONET - two of the EU projects supported by Alzheimer Europe. Since completing her PhD at the University of Cambridge in 2008, Ange has worked as a postdoctoral researcher, research Fellow and then Lecturer at the University of Glasgow, developing gene therapy approaches for diseases that affect the vasculature. She can be reached at angela.bradshaw@alzheimer-europe.org

1 May: Record number of abstracts submitted for 29th Alzheimer Europe Conference

The call for abstracts for the 29th Alzheimer Europe Conference (#29AEC) is now closed.

Alzheimer Europe is delighted to have received 516 abstracts this year, exceeding any of our past conferences by some margin. These will be reviewed by the Programme Committee during the month of May and all submitting authors will be informed of the Committee's decision by 31 May 2019.

All presenters need to register for the conference by the Early Bird registration deadline of 30 June 2019.

www.alzheimer-europe.org/Conferences/The-Hague-2019

Alzheimer Europe networking

On 2 April (Brussels, Belgium), Jean, Cindy and Christophe attended the Communications Event of the Innovative Medicines Initiative (IMI) where Jean showcased the communication activities of the EPAD (European Prevention of Alzheimer’s Dementia) project.

On 5 April (Luxembourg, Luxembourg), Jean met with Lenny Shallcross, the Executive Director of the World Dementia Council.

On 8 and 9 April (Oslo, Norway), Jean participated in the Work Package on timely diagnosis and post-diagnostic support of the 2nd Joint Action on Dementia.

On 10 and 11 April (Brighton, United Kingdom), Cindy and Jean attended the General Assembly Meeting of the PRODEMOS project.

On 12 April (Stuttgart, Germany), Ana attended a meeting to discuss a project proposal.

On 16 April (Rotterdam, Netherlands), Dianne attended the EPAD/AMYPAD ethics work package meeting.

On 18 April (Brussels, Belgium), Owen and Dianne attended a roundtable supported by Essity, to discuss the formulation of policy asks around continence care.

On 25 April (Manchester, United Kingdom), Jean attended the end-of-project conferences of the ESCR/NIHR Neighbourhoods and Dementia Study.
EU PROJECTS

27 March: AMYPAD project publishes its dual time window manuscript

On 27 March, researchers from the Amyloid Imaging to Prevent Alzheimer’s Disease project (AMYPAD) published an article entitled “Optimized dual-time-window protocols for quantitative [18F]flutemetamol and [18F]florbetaben PET studies” in the journal EJNMMI Research. The purpose of the study was to define optimal dual-time-window acquisition protocols for [18F]florbetaben and [18F]flutemetamol, both in terms of patient comfort and throughput, while maintaining high quantitative accuracy. These simulations were focused on early stages of the disease, given the potential value of amyloid imaging to guide interventions aimed at secondary prevention of Alzheimer’s disease dementia.

https://doi.org/10.1186/s13550-019-0499-4

31 March: SyDAD project holds a symposium at the AD/PD conference

The Synaptic Dysfunction in Alzheimer Disease project (SyDAD) is about to end. As a final event, SyDAD organised a symposium at the 14th International Conference of Alzheimer’s and Parkinson’s Diseases (AD/PD) in Lisbon, Portugal on 31 March. Three of the Early Stage Researchers (ESRs), together with five more senior SyDAD members presented their work to a packed auditorium.

The symposium, “Synaptic dysfunction in Alzheimer’s disease” ran from 9.45 to 11.45 a.m. The first part included presentations from four senior SyDAD members:

- Monica Di Luca (Italy) - “Targeting ADAM10 synaptic trafficking as therapeutic target for Alzheimer’s disease”
- Gael Barthet (France) - “Presenilin-mediated cleavage of APP regulates synaptotagmin-7 and presynaptic plasticity”
- Susanne Frykman (Sweden) - “Species and developmental difference in processing of the amyloid precursor protein”
- Eckhard Mandelkow (Germany) - “Tau in neuronal compartments: sorting, missorting, transmission, and consequences for synaptic function”

The second part was then dedicated to the ESRs who presented their work:

- Miguel Matias (Belgium) – “Dysfunction of the hippocampal circuit on a Tau seeding mice model”
- Sara Rodrigues (Germany) – “Spreading of Tau pathology in mouse models expressing pro-aggregant vs anti-aggregant Tau”
- Hazel Haytural (Sweden) – “Proteomic alterations in the molecular layer of the dentate gyrus in Alzheimer disease brain”.

Finally, Bengt Winblad (Sweden) gave a final speech on the “novel therapeutics targeting synaptic dysfunction in Alzheimer’s disease”. Juan Diego Pita Almenar (Belgium) and Christophe Muller (France) made the introductions and chaired the symposium.

To learn more about the project, please visit www.sydad.eu

2 April: The Innovative Medicines Initiative gathered its communication experts for a workshop in Brussels

On 2 April, about 70 communication experts attended the Innovative Medicines Initiatives (IMI) Projects Communication Event in Brussels, Belgium. During the meeting, a broad range of experts provided examples of good communication and best practice. Fruitful discussions followed.

Presentations addressed topics such as:

- IMI communication channels available to IMI projects;
- European Commission and Publications Office channels available to projects;
- Current and future trends in communications.

In addition to these presentations, three IMI projects were invited to introduce their communication strategies, while giving the delegates some examples of how and why they engage with different audiences.

The day concluded with workshops on topics revolving around questions such as how to motivate individual partners to engage in communication activities, but also on how to deal with criticism.

https://www.imi.europa.eu/news-events/events/imi-projects-communication-event
2 April: RADAR-AD project launches its website

The RADAR-AD (Remote Assessment of Disease and Relapse – Alzheimer’s Disease) project is proud to announce the official launch of its website www.radar-ad.org.

RADAR-AD aims to radically improve the assessment of Alzheimer’s disease (AD) and the care for people with AD, by exploring how mobile technologies, such as smart phones, wearables and home-based sensors, can be used to measure disability progression associated with AD.

7 April: EPAD project commentary on Brexit makes front page news

On 7 April, the European Prevention of Alzheimer’s Dementia project (EPAD) featured on the front page of UK newspaper The Sunday Post, which is based in Scotland. EPAD co-coordinator Professor Craig Ritchie and EPAD study participant Eileen Penman provided their comments on the potential impact Brexit would have on EU/UK research collaborations and projects such as EPAD. Both Prof. Ritchie and Ms Penman highlighted the importance of EU-wide collaboration and shared their concerns about the future standing of Scotland in research, when outside the EU.

“While funding for the present project is secure, what happens as we move forward with our research findings?” “Normally, we would be very excited about following on with the results of our research and using that as a platform to the development of treatment.

“But we can’t be excited because of the uncertainty of future EU funding and continued collaboration”, said Prof. Ritchie. Eileen Penman said she took “great pride” in participating in the EPAD programme:

“When I heard we were to leave the EU, it was a devastating moment and I don’t think people carefully considered what would happen to all these vitally important research programmes.”

The article can be read here. The story was also covered on the television channel STV on its main news bulletins (watch broadcast here).

10 April: PRODEMOS project holds its general assembly meeting in Brighton

On 10-11 April, the PRODEMOS - Prevention of Dementia using Mobile Phone Applications - project held its general assembly meeting in Brighton, UK, hosted by the University of Sussex (UoS).

The meeting commenced with Harm van Marwijk, UoS welcoming around 20 participants. Then, Edo Richard, Academic Medical Centre Amsterdam (AMC) introduced the meeting and gave an overview of the project. Nicola Coley, Institut national de la santé et de la recherche médicale (INSERM) presented the systematic reviews conducted within work package 2 (strategies for dementia prevention). Activities within the work stream for work package 3 (crossing cultural barriers) were reported, including the preliminary results interviews conducted in The Netherlands, The UK and China. Bram van de Groep, Vital Health Software showed a demo of what the mHealth platform will approximately look like, including goal setting and population management possibilities. The day was brought to a close by Anders Wimo, Karolinska Institutet, who presented the health economics of dementia prevention.

The second day of the meeting was dedicated to the preparation of the trial including the recruitment strategies, procedures and measurements in Sussex, Cambridge and Beijing. Then, a very fruitful session took place on the trial practicalities and challenges. This was followed by discussions on the trial pilot in Sussex and Beijing. Linda Barnes, University of Cambridge, delivered a presentation on the dissemination work and highlighted that the PRODEMOS consortium has already carried out some impressive dissemination activities. Before the wrap-up session, Marieke P. Hovenaar-Blom, AMC gave an update on the coordination and management of the project.

Jean Georges, Executive Director and Cindy Birck, Project Officer, attended the general assembly meeting on behalf of Alzheimer Europe (AE). AE is partner in the project and is involved in the coordination and management, crossing cultural barriers and dissemination and communication work packages of this project.
16 April: Members of combined EPAD-AMYPAD projects ethics work package meet in Rotterdam

The ethics working group of the Amyloid Imaging to Prevent Alzheimer’s Disease project (AMYPAD) and the European Prevention of Alzheimer’s Dementia project (EPAD) met in Rotterdam, Netherlands, on 16 April to discuss ongoing and future work on both projects. The group discussed various issues, including: the role of the Participant Panel; plans for the EPAD general assembly in Geneva, Switzerland, in May 2019; possible work after the IMI funded period; and the final report on ethics for AMYPAD.

17 April: AMYPAD project launches its Prognostic and Natural History Study in Barcelona, Edinburgh and Toulouse

The Amyloid Imaging to Prevent Alzheimer’s Disease project (AMYPAD) has made great progress during the first quarter of 2019, and major milestones were achieved for the Prognostic and Natural History Study (PNHS).

Following the great news of the first recruitment in Amsterdam at the VU University Medical Center (VUmc) in May 2018, three more sites received approvals and were activated:
- Barcelonaβeta Brain Research Center, Barcelona, Spain
- University of Edinburgh, Edinburgh, UK
- Centre Hospitalier Universitaire de Toulouse, Toulouse, France.

The four sites are now actively enrolling participants in the AMYPAD PNHS across four European countries. The PNHS team has already contacted 126 participants, of whom 55 have already consented.

A fifth site, at the University of Geneva, Switzerland has received all approvals and will be activated shortly. Other wave 1 sites are already lined up for approvals and the expectation is that they will all be actively recruiting before the end of the second quarter in 2019.

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 Initiative2 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
- PRODEMOS - grant agreement 779238
- RADAR-AD - grant agreement 806999

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 144, 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); Monika Vana (Greens/EFA). 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 (S&D); Jana Žitnanská (ECR). Cyprus: Costas Mavrides (S&D); Eleftherios Simos (S&D); Sylvia Chrysochou (S&D); Sylvie Guillaume (S&D); Angelika Niebler (EPP); Terry Reintke (Greens/EFA); Udo Voigt (NI). Czech Republic: Olga Sehnalová (S&D); Pavel Švoboda (EPP); Pavel Ťelíčka (ALDE); Tomáš Zdeckovský (EPP). Denmark: Margrethe Auken (Greens/EFA); Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). Estonia: Urmas Paet (ALDE). Finland: Lassi Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natři (S&D); Merja Kylönen (GUE/NGL); Sirpa Pietikäinen (EPP). France: Dominique Bilde (ENF); Brando Benifei (S&D); Cyril Rivière (EPP); Cyril Rivière (EFDD); Dominique Bilde (S&D); Dominique Bilde (EFDD); Dominique Bilde (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyriki (EPP). Germany: Stefan Gehrdt (EPP); Angelika Niebler (EPP); Terry Reintke (Greens/EFA); Udo Voigt (NI); Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Stelios Kougolou (GUE/NGL); Kostadinika Kuneva (GUE/NGL); Kyriks Miulidis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyriki (EPP); Eleftherios Synadinos (NI); Elisavet Vozemberg (EPP); Angelika Niebler (EPP); Terry Reintke (Greens/EFA); Udo Voigt (NI). Greece: Costas Chrysochou (GUE/NGL); Manolis Kefalogiannis (EPP); Stelios Kougolou (GUE/NGL); Kostadinika Kuneva (GUE/NGL); Kyriks Miulidis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyriki (EPP); Eleftherios Synadinos (NI); Elisavet Vozemberg-Veridon (EPP). Hungary: Ádám Kós (EPP); Ireland: Lynn Boylan (GUE/NGL); Matt Cathy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ’Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Gilles Pargneaux (S&D); Isabelle Thomas (S&D); Germany: Stefan Gehrdt (EPP); Angelika Niebler (EPP); Terry Reintke (Greens/EFA); Udo Voigt (NI). Ireland: Lynn Boylan (GUE/NGL); Matt Cathy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ’Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ní Riada (GUE/NGL); sí: Isabella Adinolfi (EFDD); Brando Benifei (S&D); Nicola Caputo (S&D); Elena Gentile (S&D); Stefano Maulo (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (Patrizia Toia (S&D); Damiano Zoffoli (S&D). Lithuania: Vilija Blinkyviciute (S&D). Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Viviane Reding (EPP). Malta: Roberta Metsola (EPP); Alfred Sant (S&D); Netherlands: Gerben-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP); Lambert van Nistelrooij (EPP). Poland: Elżbieta Łukacijewska (EPP); Kolodko (EPP); Mieczysław Kodeń (EPP); Paweł Adamowicz (S&D); Marek respiratory (EPP); Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); José Inácio Faria (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). Romania: Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP); Daciana Octavianu (S&D); Claudepi Ciprian Târnescu (S&D); Renate Weber (EPP). Slovakia: Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Anna Záborská (ECR). Slovenia: Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP). Spain: Iñigo Bilbao Barandica (ALDE); Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ana Miranda (Greens/EFA); Jordi Solé (EPP). Switzerland: Costas Mavrides (S&D); Eleni Theocharous (EPP).
EU DEVELOPMENTS

10 April: Mental Health Europe publishes assessment on the European Disability Strategy 2010-2020

Mental Health Europe (MHE) has published its assessment of the European Disability Strategy 2010-2020, specifically giving consideration to the rights of persons with psychosocial disabilities.

The evaluation concludes that the strategy has not always led to ambitious policies, nor to the rights of persons with psychosocial disabilities to be fully implemented in all EU actions.

As such, MHE calls on the European Commission to renew its commitment to the promotion and protection of rights of persons with disabilities, including those with psychosocial disabilities, by adopting a comprehensive post-2020 European Disability Strategy that continues to support and engage organisations of and for persons with disabilities, and which includes:

- Comprehensive objectives with clear benchmarks and indicators
- An adequate budget allocated for the implementation of the Strategy
- An adequate and well-resourced monitoring mechanism
- Disability focal points in all relevant Directorates of the European Commission and relevant EU institutions and agencies
- An interinstitutional coordination mechanism
- A plan for the ratification of the Optional Protocol to the UNCRPD.


15 April: European Federation of Neurological Associations launches Brain Life Goals grants

The European Federation of Neurological Associations (EFNA), as part of its #BrainLifeGoals campaign, is offering grants of EUR 2,500 to European-based organisations to raise awareness and improve understanding of neurological disorders.

Grant applications must be submitted by 14 June 2019. You can access more information about the grants, the full list of application criteria and the application form here:

http://www.efna.net/BLGrants/

24 April: European Parliament endorses future science and technology programmes

In the final plenary session of the current term, Members of the European Parliament (MEPs) have approved the framework for future science and technology programmes, including the next research programme of the European Union, Horizon Europe (2021-2027).

The outline agreement on Horizon Europe, which was agreed in principle March 2019 in and has now been signed off by both the Council and Parliament, provides clarity for significant portions of the research programme including the five “mission” areas, which will include cancer and plastics, as well as further details on eight industry partnership areas.

This vote allows the Commission to start laying the groundwork for these programmes to begin in January 2021, however, the budget for the programmes have not been set and will be negotiated by MEPs elected during the elections in May 2019. There remains significant distance between the European Commission’s proposed €94.1 billion for Horizon Europe and the €120 billion for which the Parliament has previously voted.

The framework does not include details of how the programmes will work in practice, such as participation rules for non-EU countries, including the UK after Brexit. These will be defined as part of the budget negotiations as part on Multi-Annual Financial Framework (MFF). The deadline for the conclusion of these discussions has been delayed until October. The full text of the agreement can be found here:

24 April: UK candidates to stand in European Parliament elections following Brexit extension

The UK is likely to field candidates in the forthcoming European Parliament elections following an extension to the date of the UK’s exit from the European Union.

Following the decision of the European Council on 11 April 2019, the UK has until 31 October 2019 to leave the European Union. As part of this, if the UK has not ratified the Withdrawal Agreement by 22 May, it must hold elections for the European Parliament. If it does not do so, the UK will leave the EU, without a deal, on 1 June 2019.

Whilst the UK Government continues to attempt to break the current impasse within the UK Parliament, political parties in have started the process of selecting and publicly declaring their candidates for the elections.

In the event that it does take part in the election, due to be held on 23 May in the UK, the number of Members of the European Parliament (MEPs) elected will remain at 751 (not 705 as had been previously proposed), until such time as the UK leaves the EU, at which point, redistribution of some of UK’s seats may take place. As such, Alzheimer Europe is looking for candidates from the UK to support its #DementiaPledge2019 campaign, which already has two UK supporters, at the time of writing.

MEMBERS’ NEWS

30 March: Alzheimer Sweden attends annual event in Stockholm celebrating the life of AC/DC guitarist Malcolm Young

On 30 March 2019, Karin Westerlund represented Alzheimer Sweden at an annual event held by Swedish fan-club ACDC Machine, at the Generator Hotel in Stockholm.

The night was a celebration of legendary AC/DC guitarist Malcolm Young, who sadly passed away with Alzheimer’s disease (AD) at the young age of 64, in 2017. Malcolm Young founded AC/DC with his brother Angus, in 1973 and 30 years later, in 2003, the band was inducted into the Rock and Roll Hall of Fame.

Ms Westerlund (pictured, with members of ACDC Machine), who is also a Board member of Alzheimer Europe, was invited as a guest speaker. She gave a short presentation about the ongoing work of Alzheimer Europe and joined the gathering for the evening thereafter.

The programme included a series of rock-performances, including one from American artist Nikki Hill, and an auction was held to raise funds to help people living with AD.

Approximately SEK 10,000 (around EUR 1,000) was donated to support the work of Alzheimer Sweden. This is the third donation the association has received from ACDC Machine.

Read more about ACDC Machine here (in Swedish):
https://www.acdcmachine.com/tillsammans-mot-alzheimers/

31 March: Several dementia-related events take place around Greece during the month of March

March was a busy month for regional branches of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders - Alzheimer Larissa and the Greek Association of Alzheimer’s Disease and Relative Disorders (of) Chalkida.

During Brain Awareness Week (BAW) 2019, from 11 to 17 March, Alzheimer Larissa took the opportunity to educate the public about brain function and brain health. The President of Alzheimer Larissa, Eleni Kamboura-Nifli organised a series of activities, together with scientific advisor neuroscientist Artemissia-Phoebe Nifli. These were organised under the banner “Brain function-An experiential approach”.

On 11 March, Greece observes the “Clean Monday” holiday and on this day, volunteers took residents at the Municipal Larissa care home on an outing. They spent the morning competing in events with children in a nearby field and flying kites (pictured).

On 12 March, a visit to Sxoli Karavana took place, where students learned the basics about brain structure and function. Together with the Municipal Gallery of Larissa- G.I. Katsigras Museum, Alzheimer Larissa organised a special activity for advanced students at the Junior School of Art, to facilitate communication of sensory experiences.

On 14 March, a workshop was held during a coffee break, to show how social interaction shapes experience, and that exercising the brain does not necessary involve the pursuit of solitary activities, such as crosswords or reading.
BAW activities concluded on 28 March, at a remote city location, in agreement with the Deputy Mayor handling Social Policy Affairs, showing a mutual interest in dissemination in the area of brain health. Dr Ioanna Papathanassiou, Assistant Professor of Community Psychiatric Nursing, University of Thessaly, discussed the changes normal ageing as well as diseases may have on the brain, and described the signs of physical and mental fatigue or exhaustion, as well as discussing coping strategies, drawing particular attention to quality of sleep. The feedback received was positive and Alzheimer Larissa plans to organise more such workshops in the future.

On 26 March, the Greek Association of Alzheimer’s Disease and Relative Disorders (of) Chalkida, invited primary school pupils and teachers to participate in an excursion, together with a group of older people (pictured).

Organised by the “St. Irene” day-care centre, the excursion used a tourist train, stopping at a number of sights. The idea was to help bridge the generation gap and minimise the stigma and prejudice around dementia. Day-care centre staff initiated conversations relating to old and new information about each sight and some of the older people described how the sight used to be or how it has changed over the years. Pupils asked questions and also spoke about the sight as it is used now. At the end of the trip, the pupils were given copies of the book “Why Grandma doesn’t remember my name” by Alzheimer Athens, which explains dementia to children.

1 April: Alzheimer Croatia signs agreement to create the country’s first dementia friendly retirement home

At the beginning of April, in the dementia friendly municipal City of Zagreb, Croatia, the Retirement Home Maksimir signed an agreement with Alzheimer Croatia to begin a transformation, to become a ‘dementia friendly’ social institution. This retirement home, owned by the City of Zagreb, is one of largest in Croatia and has a newly built dementia department. As part of the programme to further adapt to the needs of residents with dementia, the Home will ensure further training for their professional staff, as well as cognitive ability testing of all residents, in case they need them for clinical examination. The goals of the Home also include the development of Dementia Information Points within their municipality, and counselling support for relatives of their residents with dementia.

This first developmental experience, with the Retirement Home Maksimir, will lead to further developments under the banner of the Croatian Dementia Friends Initiative.

13 April: Alzheimer Hellas organises event “In step with dementia”

On 13 April 2019, Alzheimer Hellas held the scientific meeting “In step with dementia” in Thessaloniki, for families of people with dementia. The programme included an informative speech, experiential workshops for caregivers and intergenerational interventions, where all family members participated: people with dementia, caregivers and grandchildren. Through experiential workshops with art and theatrical play tools, interactive techniques and alternative stimuli, such as service dogs and the use of fairy tales, participants were able to experience feelings, interact with other caregivers, family members, and discover new ways to manage care and fulfil their role.

16 April: Ministry of Science of Montenegro funds research on Alzheimer’s disease and cancer

On 16 April, the Faculty of Medicine in Podgorica hosted the kick-off meeting for the project "New methods for risk stratification for the progression of cancer and Alzheimer's disease in patients in Montenegro - DEMONSTRATE". The meeting was led by the Dean of the Faculty of Medicine, professor Miodrag Radunović, MD, PhD. Team members from the Institute of Biomembranes, Bioenergetics and Molecular Biotechnology from Italy and the Clinical Center of Montenegro, as well as external experts from the Faculty of Science and Mathematics of the University of Montenegro, University of Donja Gorica, and from the Non-governmental Organisation Futura attended the event.

The project is based on interdisciplinary collaboration between scientists and doctors from Montenegro and Italy, with the
The goal of studying the use of new methods for the stratification of patients with colorectal adenocarcinoma and Alzheimer’s disease, according to the risk for progression of these diseases. This will improve algorithms used for the assignment of appropriate therapeutic modalities. The outcome of this project may also improve quality of life, survival rate and decrease complications caused by these diseases. This project was inspired by growing scientific evidence showing that these two chronic diseases usually do not occur together in the same individual - in people with cancer, the incidence of Alzheimer’s disease is very low, and vice versa. These specific patterns of co-morbidity profile suggest that the common cell signalling pathways are deregulated in the opposite direction in these two diseases, but the exact underlying mechanism at the molecular level is still unclear. The project is funded by the Ministry of Science of Montenegro.

https://www.demonstrate.ucg.ac.me/

16 April: New UK Dementia Research Institute Care and Technology Centre opens

The new Care Research & Technology Centre at Imperial College London joins six national biomedical science centres that collectively make up the UK Dementia Research Institute (UK DRI).

This ground-breaking GBP 20 million (EUR 23.2 million) research centre will develop new technologies to create dementia-friendly “Healthy Homes” and provide insights into how dementia develops.

The UK DRI aims to transform the way that dementia is diagnosed and treated, to bring us closer to the day we have a cure. The UK DRI is the UK’s biggest investment in dementia research to date, representing GBP 250 million (EUR 290 million) from founding partners the Alzheimer’s Society, the Medical Research Council and Alzheimer’s Research UK.

The Alzheimer’s Society is delighted to see this new element of the UK DRI come to life with scientists, engineers, doctors and researchers working closely with people affected by dementia. Together, they will harness technology like artificial intelligence, robotics and wearable sensors and bring it all together into dementia friendly Healthy Homes. All of this will help people with dementia to live safely and healthily at home for longer.

Fiona Carragher, Chief Policy and Research Officer at the Alzheimer’s Society said “Developing dementia shouldn’t have to mean losing your independence and your choice to live in your own home, but we know there can be problems - from the 74-year-old who kept leaving the gas on, to the woman whose urine infection went undetected so long she ended up spending 12 weeks in hospital - and we want to find a solution.”

The UK DRI Care Research and Technology Centre aims to develop technology that can pick up early signs so that people get the help they need before problems hit a crisis. One fifth of Hospital admissions for people with dementia in the UK are due to entirely preventable causes such as falls and infections. Professor David Sharp, Neurologist at Imperial College London and Director of the new centre said: “The new technologies will allow us to intervene at an early stage. What’s more we’ll be able to improve our understanding of dementia onset and progression.” For more information visit: https://www.alzheimers.org.uk/blog/5-new-technologies-could-help-people-dementia-live-home-longer

25 April: Dementia Friends programme successfully launched in Greece

The Greek Dementia Friends Programme was presented during the 11th Panhellenic Conference on Alzheimer’s Disease & 3rd Mediterranean Conference on Neurodegenerative Diseases, which took place earlier this year. At the launch, Daniela Fernandez Gomora and Sanna Laaksonen presented Dementia Friends in England and Wales and the Global Dementia Friends Network, in English, after which a Dementia Friends Session was delivered by Tsatali Marianna. During the programme’s implementation, participants learned the five key messages through structured activities and had the opportunity to ask questions and share their personal experiences regarding dementia, as well as proposing future actions to help make dementia a national priority.

An example from Greek mythology was also presented: The Odyssey, which may well be the first ever literary description...
of dementia. Homer’s epic poem mainly focuses on Odysseus, king of Ithaca, and his journey home after the fall of Troy. It takes him ten years to reach Ithaca after the ten-year Trojan War. In his absence, it is assumed he has died, and his wife Penelope and son Telemachus deal with a group of unruly suitors, the Mnesteres or Proci, who compete for Penelope’s hand in marriage. One of the characters in the story is Laertes, Odysseus’ father, whom, it is thought from descriptions of him in the text, had dementia. Much like Odysseus’ journey back to Ithaca, the road towards the end-goal of curing dementia is long and hard, but as the poet Konstantinos Kavafis says in his poem, Ithaca, it is important to focus on the journey, not just the destination.

In general, delegates were very interested in becoming Dementia Friends. Specifically, after the session, the first 50 Greek Dementia Friends received their badges. Additionally, a representative of the Greek association for deaf people requested to deliver an informative session for deaf people.

After these initial steps, the Dementia Friends programme will be spread throughout Greece via the Panhellenic Federation of Alzheimer’s Disease website and newsletter.

28 April: Thousands of runners take a stand against dementia for the Dementia Revolution at 2019 Virgin Money London Marathon

On 28 April, over 1,500 runners took to the streets of London to participate in the iconic 2019 Virgin Money London Marathon, in aid of the ‘Dementia Revolution’ campaign. The Dementia Revolution is a ground-breaking partnership from Alzheimer’s Society and Alzheimer’s Research UK, as the official Charity of the Year for the Virgin Money London Marathon. The two charities have united together for the year-long campaign to raise awareness of dementia and that through research one day we can beat it and raise GBP 3.5 million (approx. EUR 4 million) to fund the vital dementia research of the UK Dementia Research Institute (UK DRI).

A record-breaking number of Dementia Revolution runners, known as Revolutionaries, travelled from all across the UK and even as far as Australia to be on the start line of the 26.2-mile (42 kms) course. Runners were aged from 18 to almost 80, many of whom were affected by dementia in some way, including carers for relatives, scientists working at the UKDRI, and two runners living with dementia themselves. Other notable participants were ‘Barbara’s Revolutionaries’ (actors from British television programme EastEnders running for screen icon Dame Barbara Windsor, who was diagnosed with Alzheimer’s disease in 2014), as well as Guinness Book of World Record attempts, including a man dressed as famous London landmark Big Ben.

Race day had a fantastic atmosphere that served as a very fitting finale to the year-long partnership. Hundreds of enthusiastic volunteers in blue and purple Dementia Revolution colours supported the Revolutionaries at cheer points along the course, uniting together with the runners to make a very public stand against dementia and raise vital funds for dementia research.

To find out more about the Dementia Revolution visit: www.dementiarevolution.org

29 April: Federazione Alzheimer Italia publishes the guide "Dementia: words matter"

Listening, welcoming, understanding, involving people with dementia. This is what a dementia friendly community does. It is a network of socially conscious citizens committed to making their city - with its spaces, its initiatives, its social relations - fully accessible, including for people with dementia and their families, without excluding or stigmatising them.

How can such a complex action be put into practice? As a starting point, Federazione Alzheimer Italia (FAI) proposes the use of appropriate language, which, it says, demonstrates our intention to respect people with dementia.

"Dementia: words matter" is a new guide, published by FAI, for use in creating Dementia Friendly Communities and also for those who want to commit themselves to choosing their words carefully when talking about dementia and people living with dementia. It highlights the need for dementia-friendliness to begin with the use of appropriate, inclusive and non-stigmatising language, which is not offensive to people affected by dementia.

Some examples of non-stigmatising language suggested by the new guide are:

- The terms "dementia" or "Alzheimer’s disease and other forms of dementia" are preferred, as they describe what dementia actually is: not a single and specific disease, but a set of symptoms caused by a brain disease. In fact, there are many forms of dementia, each with their own causes. Inaccurate terms are to be avoided, such as the outdated "senile dementia", used when it was mistakenly thought that memory loss or other cognitive problems were part of normal ageing and not specific brain pathologies.
"Person with dementia", "person living with dementia", "person diagnosed with dementia" are terms that maintain the dignity of the individual, without any judgement about their condition, and are preferred over the use of "victim" and "patient" - terms which forget the person and focus solely on the condition.

Highly derogatory terms such as "demented" risk putting the condition of dementia before the person and cause serious offense.

Avoid using the term "burden", or other similar terms when referring to the impact of dementia on a person or on society. These make broad assumptions and forget that each person - whether a person with dementia, a family member, or a carer – experiences the condition differently.

Similarly, when talking about the impact that dementia has in everyday life, which is different from person to person, it is important to be factual rather than labelling it as "painful" or "hopeless". Terms like "life-changing" or “disabling” are accurate and avoid making assumptions about individual experiences and painting a pessimistic and fearful picture.

The position statement, published on 6 April 2019, recalls current knowledge and hopes in the field of dementia and AD care and treatment. The authors ask that, in the wake of the 2014-2019 National Dementia Strategy, all those concerned continue to be entitled to an accurate diagnosis and reimbursement for anti-dementia drugs, by the compulsory health care insurance.

The position statement emphasises that dementia progresses with age and requires a combined approach, of drugs as well as non-pharmacological interventions, in order to improve or stabilise cognitive symptoms.

The institutions also state that early diagnosis and treatment of dementia improves people's autonomy and prolongs the possibility of care at home, and stress the need for more training for health professionals, as well as the importance of educating the general public further, about dementia. They emphasise that scientists and the media must take responsibility in this area.

The position statement and the list of signatories (FR) can be found here: https://bit.ly/2PxyBER

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19 April: Spain outlines content of forthcoming National Alzheimer’s Plan 2019-2023

The Spanish Minister of Health, Consumption and Social Welfare, María Luisa Carcedo, has outlined the priority areas for the country's National Alzheimer’s Plan 2019-2023. In a press release, the Minister sets out some of the measures within the forthcoming strategy, which aims to improve diagnosis of the condition and support people with dementia and their carers.

The plan aims to reduce the impact of the disease, promoting the ability of the person with dementia to continue to live within their own environment, implementing the necessary social and health responses and improving knowledge regarding the needs of people with dementia and their families.

As part of this, early detection is a key area of focus, including improvements in the diagnostic capabilities of the system, as well as establishing the promotion of research on the origin, diagnosis and treatment of the disease. In addition, there are proposals to develop information and awareness programmes for health professionals, specifically around signs and symptoms of the disease.

In relation to economic and social impact, the plan will include measures to support family caregivers through protection systems, such as social security, employment or housing. Included within this are measures such as the training of primary care professionals to detect overload and stress situations of family caregivers.

The plan further considers the need to involve all stakeholders and society in the response to the challenges posed by

6 April: Prominent dementia institutions in Switzerland underline the importance of continuing to reimburse anti-dementia drugs

Fifteen major institutions specialising in the treatment and research of dementia and Alzheimer’s disease (AD) in Switzerland have released a position statement, underlining the importance of continuing the reimbursement of anti-dementia drugs. The decision to publish this paper was made in reaction to the French government’s decision, last year, to stop reimbursing anti-dementia drugs, and to ensuing doubts among a section of the population in Switzerland.

The position statement, published on 6 April 2019, recalls current knowledge and hopes in the field of dementia and AD care and treatment. The authors ask that, in the wake of the 2014-2019 National Dementia Strategy, all those concerned continue to be entitled to an accurate diagnosis and reimbursement for anti-dementia drugs, by the compulsory health care insurance.

The position statement emphasises that dementia progresses with age and requires a combined approach, of drugs as well as non-pharmacological interventions, in order to improve or stabilise cognitive symptoms.
The study showed that almost 600 people over 75 years of age with normal cognitive abilities and mild cognitive impairment participated in the home-based assessment study. The assessment methods used were:

- Mail-in questionnaires with live telephone interviews
- Automated telephone calls with an interactive voice recognition
- Internet-based computer technology, using a kiosk interface installed at the participants’ homes.

The research team reported that all three methods were feasible (ability to recruit, screen, enrol and retain participants). Dropout rates were low and similar across technologies, but participants who had kiosk tools installed in their homes were more likely to drop out earlier.

Staff resources (number of staff and time spent per participant) were significantly higher for the kiosk group. At the end of the study, all in-home instruments distinguished groups with cognitive conversion and cognitively stable groups. Internet-based assessments were less efficient, compared with testing by live assessors.

https://doi.org/10.1016/j.jalz.2019.01.007

On 29 March: researchers from Boston University School of Public Health published a study investigating rare genetic variants associated with Alzheimer’s disease (AD) risk in the journal JAMA Network Open.

Scientists performed a genetic association study of more than 5,600 participants with AD and 4,500 controls from data generated by the Alzheimer’s Disease Sequencing Project (ADSP). They analysed rare genetic variants that were present in people with AD but not in the control group. A total of 24 genetic variants from 19 genes were reported.

The scientists highlighted two rare genetic variants that might be associated with AD and other types of dementia. They are located in the NOTCH3 gene and the TREM2 gene. According to the researchers, the NOTCH3 variant has not previously been described in AD. Mutations in this gene have been associated with cerebral autosomal-dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL), a disorder marked by severe headaches in young adulthood followed by strokes and dementia later in life. Mutations in the TREM2 gene have been described in AD in previous studies.

In the published study, authors noted that different genetic variants were described in the same gene and suggested that mutations in the same gene can result in different types of dementia.

https://doi.org/10.1001/jamanetworkopen.2019.1350

11 March: Researchers report results from study evaluating home-based assessment in Alzheimer’s disease prevention

On 11 March, a team led by researchers from the Alzheimer’s Disease Cooperative Study (ADCS) at the University of California in San Diego reported results from a clinical trial evaluating different home-based methods for monitoring and measuring cognitive function. Findings were published in the journal Alzheimer’s & Dementia.

The four-year study is a randomised clinical trial evaluating three methods of performing home-based assessments for Alzheimer’s disease (AD) prevention. Almost 600 people over 75 years old with normal cognitive abilities and mild cognitive impairment participated in the home-based assessment study.

The assessment methods used were:

- Mail-in questionnaires with live telephone interviews
- Automated telephone calls with an interactive voice recognition
- Internet-based computer technology, using a kiosk interface installed at the participants’ homes.

The plan establishes four lines of action:

- Research on the determinants of the disease
- Development of health promotion policies, as well as progress in early diagnosis and selection of appropriate treatments
- Improvement in services, supports and benefits
- Raising awareness and improving societal attitudes in relation to dementia.


The Ministry of Health, Consumption and Social Welfare is in the process of finalising the document, although no timescale for publication has been announced. The full statement can be found here:


The research team reported that all three methods were feasible (ability to recruit, screen, enrol and retain participants). Dropout rates were low and similar across technologies, but participants who had kiosk tools installed in their homes were more likely to drop out earlier.

Staff resources (number of staff and time spent per participant) were significantly higher for the kiosk group. At the end of the study, all in-home instruments distinguished groups with cognitive conversion and cognitively stable groups. Internet-based assessments were less efficient, compared with testing by live assessors.

https://doi.org/10.1016/j.jalz.2019.01.007

29 March: Researchers suggest rare genetic variants associated with Alzheimer’s disease
29 March: United Neuroscience presents results from Phase IIa study of UB-311 in Alzheimer’s disease

On 29 March, United Neuroscience, a clinical-stage biotechnology company developing active immunotherapeutics to treat and prevent brain disorders, presented results from the Phase IIa study of UB-311 in Alzheimer’s disease (AD), at the 14th International Conference on Alzheimer’s and Parkinson’s Diseases (AD/PD) and related neurological disorders in Lisbon, Portugal.

The Phase IIa trial was a randomised, double-blind, placebo-controlled, parallel-group and multicentre study to evaluate the safety, tolerability, immunogenicity and efficacy of two doses of UB-311 in people with mild AD. UB-311 is a novel synthetic peptide vaccine targeting beta-amyloid.

43 participants from 60 to 90 years old with mild AD dementia (CDR 0.5 or 1, MMSE 20-26) were enrolled in the study. All participants, save 2, completed final assessments at week 78.

The vaccine candidate was found to be safe and well-tolerated. Participants in this trial are now eligible to join a long-term extension study that will continue to evaluate the safety and efficacy of UB-311 for 108 weeks.


2 April: Bill Gates announces new call for proposals for innovative Alzheimer’s disease diagnosis research projects

On 2 April, billionaire philanthropist Bill Gates, co-founder of Microsoft, published a blog post, in which he lays out the importance of finding “a reliable, affordable, and easy-to-use” method for diagnosing Alzheimer’s disease (AD).

This is important, he states, so that clinical trials to find new treatments can enrol participants at an earlier stage in the disease process and in the most non-invasive, inexpensive way possible.

Currently, the best diagnostic tools are brain scans and lumbar punctures (aka spinal taps), neither of which are optimal.

Aside from a possible diagnostic blood test, which he declares could potentially “start being used to recruit patients into Alzheimer’s drug trials within the next year or two”, Mr Gates mentions other interesting research currently being done into changes in speech and writing patterns as possible ways to diagnose AD.

In his blog post, Mr Gates also announces the launch of a new research initiative from the Diagnostics Accelerator programme at the Alzheimer’s Drug Discovery Foundation and encourages researchers with novel ideas in this area to apply. The Diagnostics Accelerator aims to fast-track technologies that could provide new ways to detect Alzheimer’s disease (AD). Together with other highly influential billionaires in the philanthropic arena - including Amazon CEO Jeff Bezos and his wife MacKenzie Bezos - Mr Gates has donated generously to the programme. He has also donated generously to the UK-based Dementia Discovery Fund - a private fund working to diversify the clinical pipeline and identify new targets for treatment.

His interest in this area of research was sparked by his father’s Alzheimer’s diagnosis, he said in early 2018. You can read the full blog post, “The unexpected way we might one day diagnose Alzheimer’s”, and find details about the new call for proposals, here:

https://www.gatesnotes.com/Health/The-unexpected-way-we-might-one-day-diagnose-Alzheimers

2 April: IDEAS study publishes results on effect of amyloid PET imaging to improve clinical management in dementia

On 2 April, scientists from the Imaging Dementia-Evidence for Amyloid Scanning (IDEAS) study published an article on a brain imaging technique to identify amyloid plaques (clumped proteins that are involved in the death of brain cells) and its implications for clinical management. The study was published in the journal JAMA and involved both people with Mild Cognitive Impairment (MCI) and people with dementia (in whom the cause of the syndrome were uncertain).

This large-scale multicentre study involved 11,409 participants, who underwent brain scans using amyloid positron emission tomography (PET scans). The scans were performed in order to clarify the cause of cognitive impairment (etiology) and subsequently inform patient management (Alzheimer’s disease drug therapy, other drug therapy; or counselling about safety and future planning).

Out of the 11,409 participants who completed the study procedures, the scans showed positive amyloid PET results for 3,871 people with a form of MCI and 3,154 with dementia. Overall, the brain scans led to changes in the etiologic diagnosis in 4,061 cases (change from Alzheimer’s disease to non-Alzheimer’s disease in 2,860 cases as well as change from non-Alzheimer’s disease to Alzheimer’s disease in 1,201 cases).

The researchers then analysed whether the subsequent adaptation of care management (due to the corrected diagnosis) occurred in a clinically meaningful proportion of participants (change in at least 30% of the participants). These analyses were administered separately for the subgroup of people with MCI and for the subgroup of people with dementia.

The results showed that the change occurred in a much larger number of participants than anticipated. The authors reported
that the composite clinical management changed in 60.2% of the participants with MCI and in 63.5% of the participants with dementia, underlining the value of PET imaging to improve clinical management.

https://jamanetwork.com/journals/jama/article-abstract/2729371

2 April: Scientists assess correspondence between eye scan results and cognitive impairment

On 2 April, researchers from the US published a study looking at whether decreased blood flow in the eyes, which had been observed in previous studies of people with Alzheimer’s disease (AD), is also present in people with early AD and people with amnestic Mild Cognitive Impairment (aMCI) - a form in which memory problems are dominant. The research was issued in the journal PLOS ONE.

For their study the team involved 32 participants out of which 16 were either affected by aMCI or early AD and 16 people without cognitive or memory related problems.

In addition to the measurement of blood flow, the scientists also performed tests on blood vessel density, as well as the thickness of the nerve fibre layer (back of the eye), amongst others.

The scan results were then compared, between the two groups. In addition, the researchers also checked whether the measures taken from the eyes correlated with cognitive performance (assessed with a pen-and-paper test).

Their results showed that the two groups differed in two measures, in the parafoveal superficial capillary plexus as well as in an index on blood flow. In addition to this, the researchers also reported that they found a correlation between the pen-and-paper test performance and the vessel density (in the parafoveal superficial capillary plexus) as well as the density of vascular layers (capillary vessel length density of the radial peripapillary capillary).

These findings led them to the conclusion that the imaging technique they used - entitled optical coherence tomography angiography (OCTA) - might be helpful to identify individuals with early cognitive impairment in future, rendering this technique an interesting area for further research.

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0214685

3 April: Amylyx Pharmaceuticals announces first recruitments to recently expanded Phase II trial for Alzheimer’s disease drug candidate

On 3 April, Amylyx Pharmaceuticals, a clinical-stage pharmaceutical company developing a novel therapeutic for Amyotrophic Lateral Sclerosis, Alzheimer’s disease (AD) and other neurodegenerative diseases, announced that it has dosed its first participants in a recently expanded Phase II clinical trial evaluating AMX0035 in AD. The announcement was made in collaboration with the Alzheimer’s Association (US), the Alzheimer’s Drug Discovery Foundation and the Cure Alzheimer’s Fund.

The 24-week clinical trial PEGASUS is a randomised, double-blind, multi-site, and placebo-controlled Phase II study evaluating the safety, tolerability and neurobiological effects of AMX0035 in people with late mild cognitive impairment (MCI) or early dementia due to AD. AMX0035 is a combination of existing compounds designed to prevent neuroinflammation and nerve cell death.

The Cure Alzheimer’s Fund, a non-profit dedicated to funding the most promising research to prevent, slow or reverse AD, has provided additional funding to expand the PEGASUS trial that has doubled its planned enrolment to 100 US participants between 55 and 89 years old, who will receive either AMX0035 or a placebo. Study results are expected in 2020.

https://apnews.com/Business%20Wire/8ca2377a428c42e1a887af99a7a4a80f

7 April: Study aims to stop gum disease bacteria from traveling into the brain and releasing toxins possibly involved in Alzheimer’s disease

On 7 April, Jan Potempa, head of the department of microbiology at Jagiellonian University in Krakow, Poland, presented recent research on how bacteria involved in gum disease (Porphyromonas gingivalis) might be stopped from moving from the mouth to the brain, where they might release toxins potentially linked to the developments of Alzheimer’s disease (AD). The presentation was held during the annual meeting of the American Association of Anatomists in Orlando, Florida, US.

Porphyromonas gingivalis (P. gingivalis) is involved in periodontitis, a serious form of gum disease. These toxins the bacteria release might also be connected to rheumatoid arthritis and aspiration pneumonia.

Recent findings from human post-mortem brain samples already underlined that there might be a connection between these toxin-releasing bacteria and AD, which showed that P. gingivalis was more commonly found in the brains of people who died with AD than in those who did not. Other studies revealed that this could be due to the bacteria’s ability to travel from the mouth to the brain.

Prof. Potempa, presented a current phase I clinical trial for AD that aims at inhibiting so called “gingipains”, in the hope that blocking these enzymes, important to P. gingivalis bacteria,
can render them unable to travel to the brain and subsequently contribute to the development of AD.


10 April: Researchers analyse blood samples to predict disease progression in early-onset AD

Earlier this year, a large group of scientists published findings on a new potential marker of disease progression for people with early-onset Alzheimer’s disease (AD), in the journal Nature Medicine.

Previous research showed that a blood test for the protein neurofilament light chain (NFL) might be a useful marker of disease progression in different diseases of the brain. Since research on AD is focusing more and more on accurate ways to predict disease progression, the team looked at the potential in using this relatively novel technique in AD as well.

The researchers included samples from 405 people, who participated in the Dominantly Inherited Alzheimer Network study (DIAN). This study involved people who carry one of the gene mutations (Presenilin1, Presenilin2 or APP) that are known to cause dominantly inherited AD, which is also referred to as familial Alzheimer’s disease.

Looking at different factors, the scientists found that on one hand the levels of NFL in the fluid of the spinal cord (using 187 samples) and the serum in the blood (using 405 samples) corresponded to each other. This is especially interesting, since many patients and research participants consider the extraction of spinal cord fluid much more unpleasant than the collection of blood. Furthermore, results showed that NFL levels in people with familial AD are elevated in stages before symptoms appear.

Further analyses following up on the same participants (196) showed that the rate of NFL in the serum also peaked in those who developed symptoms over time and that this came along with ‘cortical thinning’, a thinning of the brain’s outer layer (monitored with a brain imaging technique).

The team also reported that they were able to predict the rate of cortical thinning as well as changes in thinking performance (assessed with a pen-and-paper test) based on the measured NFL rate in the serum.

Based on these results, the researchers concluded that measuring NFL dynamics in the serum might be useful as a clinical biomarker, although noting that further research is needed to determine whether these results can also be translated to other forms of AD, such as sporadic AD.

https://www.nature.com/articles/s41591-018-0304-3

11 April: Researchers publish findings of halted Phase III AD drug trial on verubecestat

On 11 April, investigators responsible for the verubecestat trial in prodromal Alzheimer’s disease (AD) published its findings in The New England Journal of Medicine.

The publication of the trial’s results follows the announcement of the discontinuation of the Phase III APECS study during the Clinical Trials on Alzheimer’s Disease (CTAD) conference in February 2019. The APECS trial was a randomised, placebo-controlled, parallel-group, double-blind Phase III clinical trial evaluating the efficacy and safety of verubecestat in people with prodromal AD - an early phase of AD in which people have memory problems as well as positive biomarkers for the disease, but remain independent.

Verubecestat belongs to a group of AD drugs called BACE inhibitors, which block the production of the beta-secretase enzyme involved in the formation of toxic amyloid proteins.

The trial enrolled 1,454 participants, who either received a daily dose of 12 mg (485 participants), 40 mg (484 participants), or a placebo (485 participants).

All in all, 704 participants had enrolled in the post-test after participation during two years. In these participants, results from the administered pen-and-paper test suggested a worse outcome in those taking verubecestat than in participants who took the placebo. Furthermore, the investigators reported that adverse events were also more common in the verubecestat group compared to those who took the placebo. Participants who enrolled later were withdrawn from the study due to its termination.


15 April: Trials start for short iPad test to detect early signs of dementia

A new dementia test is currently being rolled out in the UK, aiming to detect early signs of dementia in just five minutes.

The National Health Service (NHS) has teamed up with London-based medical tech firm Cognetivity Ltd to develop the quick, simple test. Trial participants are shown different images using an iPad, while researchers measure their responses.

The new test was designed to serve as a single diagnostic for early dementia detection. It makes use of artificial intelligence (AI) to gauge brain function.

Participants will be shown 100 different photographs, some containing animals. Each image will appear on the screen for a brief moment only and researchers will then ask participants to identify whether the photo they have just seen depicted an animal or not. They will then identify differences in how fast the participants were able to answer and how accurate those
answers were. They will use the data to detect potential signs of dementia. If trial results prove positive, the diagnostic tool could be rolled out UK-wide by next year.

DEMENTIA IN SOCIETY

15 April: Alzheimer’s Disease International launches global dementia attitudes survey

Alzheimer’s Disease International (ADI) has launched a global survey examining attitudes and beliefs about dementia. The organisation has commissioned the London School of Economics (LSE) to conduct the survey, which is aimed at a broad range of stakeholders including people with dementia, their caregivers, healthcare professionals and the general public from across the world, including rural and urban communities.

The survey is available both online and offline in multiple languages and takes approximately 10-15 minutes to complete. All information from the survey will be kept confidential and data will be anonymised.

The results from the survey will be published in the World Alzheimer Report 2019, which will be published later in the year. The survey will run until 14 June 2019.

https://www.alz.co.uk/research/world-report-2019

LIVING WITH DEMENTIA

9-19 March: Tomaž Gržinič, member of the European Working Group of People with Dementia, celebrates his love of sailing

Living with dementia is definitely not easy, but it is bearable. If you are lucky and are surrounded with a loving family and friends, dementia is not a reason to quit your passions. Between 9 and 19 March 2019, I had a life-changing experience: I spent a 10-day holiday on a remote island in Guadeloupe – an island group in the Caribbean.

A crew of 7 best friends celebrated 20 years of friendship and a love of sailing together. We decided to capture this special moment with an epic journey, far away from home. Sailing has been a way of life for me since I was a young man. Every year, my companions and I are off sailing to tropical paradises.

Over the past two decades I have visited eight different countries in this way: Croatia, Greece, Montenegro, Turkey, The Virgin Islands, Spain, France, and Italy.

As my supporter, Alenka Virant often asks me where I find the courage to travel overseas and I always answer the same way: When you have friends, you feel safe, comfortable and more confident. I am only afraid sometimes that I might get lost in city centre crowd, but my considerate friends are just around the corner. When I bought souvenirs, they waited for me. One of my friends also did me a favour – he put a red hat on his head and led the way.

Sailing with my friends is so relaxing and timeless. We work as a team: One is a chef, one is a captain, one is a fisherman and another is a photographer. Each one of us has a specific task to do. Most of the time I am a right-hand man to everyone.

We caught two big fish: a tuna and a barracuda, which we prepared for dinner. As you can see in the picture, I had the chance to sail a catamaran - under the supervision of a professional captain, of course. This picture shows that even person with dementia sometimes can do amazing things. You might need support, but you can still do it.

During this sailing vacation, I joked that “a person with dementia can be a captain, as long as there are no other sailboats approaching” and that “sailing a boat is even better than driving a car, because you always go in the right direction and there is no chance you will drive over a cliff.” This trip was undoubtedly a precious experience. We also made a short video about it. So, my take-home message is: “If you have a plan, you should go for it!”
24 April: Idalina Aguiar celebrates Statute of Informal Caregiver being passed in Madeira

I live on the island of Madeira, Portugal, which has an Autonomous Regional Government. In an unprecedented act in Portugal, the proposal by the Regional Government on the Statute of the Informal Caregiver in the Autonomous Region of Madeira has been unanimously approved. I am proud that my region is a pioneer, at the national level, in recognising this social function. This is a real milestone for carers fighting for their rights, and it marks the beginning of a new stage, giving hope to hundreds of carers in Madeira.

My daughter Nélida and I were invited to be involved in discussions as part of a joint action between Alzheimer Portugal and ANCI (National Association of Informal Caregivers). We are immensely proud of being a part of this work.

At the national level, discussions are still underway, but I hope that in the coming months, progress will be made for all of Portugal’s informal carers.

Idalina is a member of the European Working Group of People with Dementia (EWGPWD) and is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English.

http://bit.ly/2UPmVP1

25 April: Carol Hargreaves, member of the European Working Group of People with Dementia, likes to keep busy

I must admit I have not had the best few weeks, but thank goodness I am feeling better. I know I have to adjust with this illness and staying busy is one of the things that helps. I was asked to meet a lovely lady as part of our buddy system, to help her settle in. I feel she will be great for the group (Scottish Dementia Working Group – SDWG). Others have done the same for new group members in the past and it is something we are proud to do. More members make us stronger.

This week, I have been asked to do an interview with some new staff. I feel this is a privilege as it shows that people with this illness can be strong and make very serious decisions.

I am also really looking forward to visiting the Emerald Isle (Ireland) to work with Helen. I will be travelling with Wendy from Dundee, which I know will be great, as I know she will be a great companion.

NEW PUBLICATIONS AND RESOURCES

20 April: Croatian book showcasing 10 years of poster presentations shows increasing interest in dementia among medical professionals

A unique book has been published in Croatia, “The book of posters of professionals from University Psychiatric Hospital Vrapče: 2007-2016” (Knjiga posreta stručnjaka Klinike za psihijatriju Vrapče: 2007-2016). It presents all poster presentations during 10 years, by medical professionals at Hospital Vrapče and their external collaborators. It is edited by Prof. Ninoslav Mimica, and Prof. Vlado Jukić. This 1,143-page hardback book, in encyclopaedic format, is richly illustrated and delivers as many as 530 posters, divided into 10 chapters. Each poster has two pages dedicated to it, with one page being the poster in A4 format and the page opposite detailing all relevant information. The publishers are Medicinska naklada and Klinika za psihijatriju Vrapče from Zagreb, Croatia.

It is interesting to note that the largest chapter, containing 115 posters, is in the field of neurocognitive disorders.

Contributors include psychiatrists, neurologists, neuroscientists, psychologists, social workers, nurses, social pedagogues, internists, family doctors, medical students and volunteers. Compared with a previous book covering 1978-2006, it is clear there has been a significant increase in interest in the area of Alzheimer’s and other dementias. There has also been an increased interest in participating in professional conferences.

The book is also available on DVD, making it easier to search for authors and conferences.
### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>3 May</td>
<td>Meeting with Alzheimer Nederland (Amersfoort, Netherlands)</td>
<td>Jean</td>
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<tr>
<td>3 May</td>
<td>Meeting of Alzheimer Europe Working Group on the ethics of dementia research (Amsterdam, Netherlands)</td>
<td>Dianne and Jean</td>
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<tr>
<td>6 May</td>
<td>European Commission Scientific Panel for Health (SPH) forum on health research (Brussels, Belgium)</td>
<td>Owen</td>
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<tr>
<td>6-10 May</td>
<td>MinD project study visit (Luxembourg)</td>
<td>Dianne and Ana</td>
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<tr>
<td>8-11 May</td>
<td>M&amp;I Forum (Monchique, Portugal)</td>
<td>Gwylads</td>
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<tr>
<td>15-17 May</td>
<td>EPAD project General Assembly (Geneva, Switzerland)</td>
<td>Jean, Cindy and Dianne</td>
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<tr>
<td>20 May</td>
<td>EuropaBio - Patient Engagement Meeting (Brussels, Belgium)</td>
<td>Owen</td>
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<tr>
<td>30 May</td>
<td>AMYPAD ExCom Meeting (London, United Kingdom)</td>
<td>Jean</td>
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### CONFERENCES 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>5-8 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="http://www.alzheimers.org.uk/conference">www.alzheimers.org.uk/conference</a></td>
<td>London, UK</td>
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<tr>
<td>8-9 June</td>
<td>International Forum on Women’s Brain and Mental Health: the gateway to Precision Medicine, <a href="http://www.forum-wbp.com">http://www.forum-wbp.com</a></td>
<td>Zurich, Switzerland</td>
</tr>
<tr>
<td>1-4 July</td>
<td>Royal College of Psychiatrists’ International Conference, <a href="http://www.rcpsych.ac.uk">https://www.rcpsych.ac.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>5-7 November</td>
<td>14th UK Dementia Congress, <a href="https://careinfo.org/event/uk-dementia-congress/">https://careinfo.org/event/uk-dementia-congress/</a></td>
<td>Doncaster, UK</td>
</tr>
</tbody>
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29th Alzheimer Europe Conference
Making valuable connections
The Hague, Netherlands
23–25 October 2019
www.alzheimer-europe.org/conferences  #29AEC