WELCOME

I am pleased to announce that our Dementia Pledge campaign has been a success, gathering 230 signatures from MEP candidates. We are now cross-checking the list of pledgees with elected MEPs, and will announce the new European Alzheimer’s Alliance shortly. It will officially be reformed for the 2019-2024 term once new MEPs are inducted, in July. I would like to personally thank our national member associations, who worked tirelessly to gather support in their countries; the members of the European Working Group of People with Dementia, who helped us drum up support via social media; and of course the 230 signatories!

At national level, we have good news from Iceland, where the process of creating a national dementia strategy looks to be well and truly underway. Dementia specialist Dr Jón Snædal, nominated by the Minister for Health to author the strategy, has met with representatives from our member Alzheimer Iceland to ask for their input. Read more in the Policy section. In other good news from Iceland, a dementia working group has just been formed. You can read more in the Members section.

In Denmark, a target of 100,000 “demensven” (dementia friends), was set when the programme was launched by Alzheimerforeningen (Alzheimer Denmark) in 2016. The target has been reached, this month. We congratulate them on their achievement and hope the success of the programme will bring the change they want to see in their communities.

At global level, the World Health Organization (WHO) is continuing to do everything possible to ensure its Global Action Plan on dementia is implemented and with this in mind, is seeking peer reviewers to ensure its new knowledge exchange platform meets quality and good practice criteria. The WHO has also just published guidelines on dementia and dementia risk. You can read more on both stories in the Policy section and Publications section respectively.

On the EU project front, the ROADMAP project launched its new data cube tool; the MOPEAD project published an article in the journal Alzheimer’s & Dementia; the EPAD project held its General Assembly in Geneva; the MinD project had its fourth and final visit to Luxembourg, where we were delighted to host them, together with the University of Luxembourg; and the new DISTINCT project is currently seeking 15 Early Stage Researchers (ESRs), with applications closing mid-June.

Finally, I am excited to announce that the 516 abstracts submitted for the 29th Alzheimer Europe Conference (#29AEC) have been reviewed by the Scientific Committee and all applicants are currently being contacted. Early Bird registration ends on 30 June and all presenters (oral and poster) must register before that deadline.

Jean Georges
Executive Director
27 May: #DementiaPledge2019 campaign draws to a successful close

Following the European Parliament elections between 23-26 May, Alzheimer Europe’s #DementiaPledge2019 campaign has drawn to a close.

With 230 candidates signed up to the pledge, Alzheimer Europe broke its record of 219 candidates signed up in the 2014 election.

We would like to say a huge thank you to all of the associations who supported the campaign, contacted candidates and played an integral part in making the campaign such a success.

Additionally, we would like to thank the European Working Group of People with Dementia (EWGPWD) for their contributions to the campaign, helping us send strong messages to candidates that dementia needs to be a priority during the next term of the parliament.

In the coming weeks we will write to elected candidates, asking them to follow up on their commitment, as well as asking members to make contact to establish a closer connection between MEPs and national Alzheimer’s organisations, which is one of the things candidates signed up to in the Pledge.

Alzheimer Europe will also work during the summer to re-establish the European Alzheimer’s Alliance, as well as working with other civil society organisations to identify members supportive to social, health and research matters, and engage with members who signed the pledge to encourage them to help push dementia as a priority area in future EU work.

At the close of the campaign, here is the breakdown of pledgees by country (the countries in bold are the top five):

- Austria 1; Belgium 4; Bulgaria 0; Croatia 3; Cyprus 1; Czech Republic 4; Denmark 2; Estonia 0; Finland 12; France 85; Germany 9; Greece 1; Hungary 4; Ireland 25; Italy 4; Latvia 1; Lithuania 0; Luxembourg 19; Malta 0; Netherlands 1; Poland 0; Portugal 6; Romania 3; Slovakia 1; Slovenia 32; Spain 6; Sweden 1; and United Kingdom 5.

The Parliament will meet for the first time in plenary in July 2019 to induct the newly elected MEPs, during which time the members will elect their President.

On 28 May, quarterly science and technology publication SciTech Europa published an interview with Alzheimer Europe, in which Policy Officer Owen Miller discusses the state of play for dementia policy across Europe.

Overall, the picture is a mixed one. At a national level, there has been considerable progress made, in terms of the number of countries with a dementia strategy (or an equivalent neurodegenerative strategy) in place. A lack of dedicated funding in certain cases, however, means that practical implementation can fall far short of the theory.

At the European level, the Horizon 2020 research programme has been very positive for projects tackling many aspects of dementia, including those in which Alzheimer Europe is/has been a partner. The second Joint Action on Dementia, funded through the EU’s Health Programme, has enabled countries to collaborate and exchange knowledge, information and best-practices. On the downside, however, we are beginning to see EU policy shift away from disease-specific policies towards broader ‘catch-all’ health approaches. Whilst understanding that addressing areas of commonality between disease areas could have its benefits, there is a risk that doing so will mean EU Commissioner, subject to confirmation by the European Parliament, followed by the selection of the Council of Commissioners for different areas of work. The official end of the term of the Juncker Commission is October 2019.

For a detailed breakdown of the MEPs elected in each country, more information is available on the European Parliament website:

https://election-results.eu/
some of the unique challenges and experiences of people living with dementia are overlooked.

You can read the full SciTech Europa interview, here:

https://www.scitecheuropa.eu/alzheimers-disease/95280/

Alzheimer Europe’s Dementia in Europe Yearbook 2018 provides a comparison of dementia strategies across Europe. You can download it or purchase a hard copy of it, via:

https://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks

31 May: Alzheimer Europe finalises abstract selection for #29AEC

Alzheimer Europe would like to thank everyone who submitted abstracts for its 29th Annual Conference (#29AEC) in The Hague from 23 to 25 October 2019. The Scientific Committee has reviewed a record 516 submitted abstracts and has approved 140 oral presentations and an additional 260 poster presentations.

Notifications are currently being sent out to all applicants. Selected presenters for poster and oral presentations must register by 30 June, when Early Bird registration closes.

Alzheimer Europe networking

On 2 May (Amersfoort, Netherlands), Jean met with Alzheimer Nederland for the preparations of the 29th Alzheimer Europe Conference.

On 3 May (Amsterdam, Netherlands), Dianne and Jean attended the first meeting of the working group on the ethics of the participation of people with dementia in research.

On 6 May (Brussels, Belgium), Owen attended the European Commission’s Scientific Panel for Health forum, discussing the future health research in Europe.

From 6 to 17 May (Belval, Luxembourg), Dianne, Ana, Chris, Cindy and Owen attended the 4th MinD study secondment hosted by Alzheimer Europe and the University of Luxembourg.

From 8 to 11 May (Monchique, Portugal), Gwladys attended an edition of the M&I Forums.

On 13 May (London, United Kingdom), Dianne and Ana attended the DISTINCT kick-off meeting.

From 15 to 17 May (Geneva, Switzerland), Cindy, Dianne and Jean attended the General Assembly of the EPAD (European Prevention of Alzheimer’s Dementia) project.


On 30 May (London, United Kingdom), Jean attended the Executive Committee meeting of the AMYPAD (Amyloid Imaging to prevent Alzheimer’s disease) project.

EU PROJECTS

3 May: The RADAR-AD project introduces itself

The RADAR-AD project has sent out a press release, titled “New Research Consortium Aims to Measure Progression of Alzheimer’s Disease Through Use of Digital Technologies”. The project, which launched in January 2019, used the release to introduce itself to the research community and wider dementia community. Here is the main thrust of the release:

A new international consortium of academic and industrial leaders in the field of Alzheimer’s disease (AD) is pleased to announce the launch of “RADAR-AD” (Remote Assessment of Disease And Relapse - Alzheimer’s Disease). The collaborative research programme aims to develop technologies that remotely identify and measure “digital biomarkers” to assess the progression of early AD. RADAR-AD is a three-and-a-half-year public-private partnership, sponsored by the Innovative Medicines Initiative (IMI), and led by King’s College London and Janssen Pharmaceutica N.V.

The RADAR-AD consortium kicked off the project in London on 30-31 January, with team members discussing the work at hand and how the project will move forward. Consortium partners shared their insights and how best to utilise everyone’s expertise across the entire project.
The ultimate goal of RADAR-AD is the development and validation of technology-enabled, quantitative and sensitive measures of functional decline in people with early stage AD. To achieve this, the consortium will select, and if needed, modify, the most relevant available devices that can sensitively measure early and clinically meaningful functional decline in people with AD. This will be done in close collaboration with patient organisations and regulators.

To be successful in the relatively short project period, RADAR-AD will build on the experience and assets developed in the RADAR-CNS project, such as the RADAR-base platform. The selected devices will be validated in a cross-sectional multicentre observational clinical study of 220 individuals across the AD spectrum. The close association with RADAR-CNS and ample experience with, and availability of, large-scale clinical data will allow RADAR-AD to leverage experience already gained from that consortium. The project will run from January 2019 to July 2022.

Read the full Press Release here:

6 May: Public-Private consortium publishes the first interactive overview of available outcomes in European data sources for AD research

On 6 May, the ROADMAP consortium, a public-private partnership launched by the Innovative Medicines Initiative, opened access to its data cube tool.

The data cube is an interactive tool with which interested people can get an overview of the different outcomes that are available in various data sources such as clinical trials, Electronic Health Records and cohorts.

Although it offers a variety of functions, the cube is easy to use, offering insights on the importance of various outcomes from the point of view of people with dementia, carers but also health professionals along different stages of the disease.

This tool is the result of two years of collaboration and combines efforts from different working groups who each contributed to different aspects of the data cube. These include workshops with people with dementia, a public survey on the importance of outcomes, literature reviews, collaboration with data custodians from the various data sets and much more.

Dr Jacoline Bouvy, Senior Scientific Adviser, National Institute for Health and Care Excellence (NICE), explains: “The Data Cube is an important outcome of the ROADMAP project as it provides a much needed, overarching picture of priority outcomes, across the disease stages, and whether data is available. It helps to identify gaps in the evidence and provides a useful tool for regulatory and Health Technology Assessment purposes.”

7 May: The Innovative Medicines Initiative funded MOPEAD project publishes project introduction

On 7 May, the MOPEAD project published its project introduction in Alzheimer’s and Dementia: The Journal of the Alzheimer’s Association.

This 33-month project aims to deliver a step-change in Alzheimer’s disease patient engagement strategies and a paradigm shift from late-stage diagnosis to early-stage diagnosis. Multiple regional project sites have been established to identify and test models of efficient early identification of mild Alzheimer’s disease dementia and prodromal Alzheimer’s disease patients. The paper provides a comprehensive overview of the rationale behind the project and introduces the four patient engagement models that are being tested in five countries (Germany, Netherlands, Slovenia, Spain and Sweden) including assessment based on Alzheimer’s disease citizen science (online), Open House Initiatives, Primary care and diabetologists’ offices.

You can read the article release here: https://www.alzheimersanddementia.com/article/S1552-5260(19)30072-X/fulltext

8 May: EMIF project publishes new research article on AD biomarkers

On 8 May, Dr Cristina Legido-Quigley and collaborators on the European Medical Information Framework (EMIF) project published a paper in the Alzheimer’s and Dementia journal, identifying primary fatty acid amides (PFAMs) as potential biomarkers for amyloid beta (Aβ) in people with Alzheimer’s disease (AD).

Identifying people during the very early, preclinical stages of AD is extremely challenging, as the more definitive diagnostic tests (such as measuring Aβ in cerebrospinal fluid) are highly invasive. One of the research goals of EMIF was therefore to find biomarkers of preclinical AD, which could be measured less invasively from blood plasma samples of people at risk of developing AD.
In this study, Dr Legido-Quigley and co-authors screened blood plasma samples from 593 EMIF participants with normal cognition, mild cognitive impairment and AD. They identified a panel of metabolites (small molecules produced during metabolic processes), which were altered in the blood of participants with elevated Aβ. Interestingly, this metabolite panel included PFAMs thought to be synthesised in the brain, such as oleamide, an endocannabinoid. More detailed analyses showed that altered PFAM levels were associated with certain cognitive symptoms of AD, such as lower attention levels and short-term memory problems.


13 May: DISTINCT project kicks off in London

The kick-off meeting of the EU-funded Marie Curie DISTINCT project (Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology) took place on 13 May, in London. The project focuses on improving the usability of technology in dementia care, by evaluating its effectiveness and implementation issues in relation to social health.

A total of 15 Early Stage Researchers (ESRs) will be hosted across the network and will work in research, a network-wide training programme, public engagement activities and collaboration with network partners, through short-term secondments in European industrial/academic partner laboratories.

DISTINCT comprises 13 world-leading research organisations across 8 European countries and 9 partners. Many members of the DISTINCT team are researchers in INTERDEM (a pan-European network of researchers collaborating in research on and dissemination of Early, Timely and Quality Psychosocial Interventions in Dementia).

Alzheimer Europe and its European Working Group of People with Dementia will be involved in this project. Director for Projects Dianne Gove and Project Officer Ana Diaz represented Alzheimer Europe at the kick-off meeting.

For further information about DISTINCT and the 15 ESR opportunities please visit: https://www.dementiadistinct.com/

Please note that application closing dates for all ESR positions are in mid-June. Prospective candidates are welcome to get in touch with supervisors directly, if they are interested in specific projects.

15 May: The EPAD project holds its General Assembly meeting in Geneva

This year, the European Prevention of Alzheimer’s Dementia (EPAD) General Assembly meeting was held in Geneva (Switzerland) from 15 to 17 May. The meeting brought together delegates from across many different countries who work on the EPAD project to discuss progress, latest developments and future plans.

The General Assembly meeting commenced with Giovanni Frisoni, Serge Van der Geyten and Craig Ritchie welcoming almost 200 attendees. They reflected the evolution of EPAD and introduced the agenda for the coming days. Craig Ritchie then briefly explained the EPAD flow and its crucial components. The EPAD proof-of-concept (PoC) platform has been developed to speed up the development of effective, safe medicines which slow down or prevent the development of Alzheimer’s dementia. Craig stated that the recruitment into the EPAD PoC is exclusively from the EPAD Longitudinal Cohort Study. It was interesting to hear that the EPAD PoC team is being directly approached by many potential Intervention Owners.

There was an exciting announcement that EPAD will formally request IMI to grant a no-cost 6-month extension to the project. 2019 is going to be a year of transition for EPAD as the consortium members are looking forward to the post-IMI period, named EPAD 2.0. The next session was then dedicated to the EPAD sustainability Work Package. The team behind WP7 has made significant progress with the aim to help create a sustainable EPAD platform for the prevention of Alzheimer’s dementia. Different scenarios and approaches for the project’s future were shared and punctuated by lively discussions.

The second day was full with a variety of talks from Work Package leads and members. Project outcomes and updates on the current activities were presented. The EPAD family of Trial Delivery Centres is growing with currently 23 sites open of which 21 sites are already enrolling across 7 European
countries and more than 1,600 research participants screened. Over the next weeks and months additional sites will be opened. Then, the potential PoC appendices and the progress towards the first PoC Trial were reported. All vendors have been selected and the necessary processes are in place. The contract negotiations and appendix drafting are ongoing and the team is aiming for a start next year with the inclusion of the first candidate for the PoC in Q2 2020. The afternoon session focused around workshops, giving everyone the opportunity to attend parallel sessions of interest. These breakout sessions on amyloid disclosure, online registries, sample management and data access were hugely valuable. One of the highlights was the presentation of the EPAD Research Access Process, designed to give academic researchers and institutions from all over the world a way of accessing the data, samples and imaging data collected during the EPAD LCS. The first wave of data (v500.0) is now available for EPAD researchers only until November when access will be opened to the entire research community. There was also a meeting of the Participant Panel which was attended by participants from the Netherlands, the United Kingdom, France and Spain.

The third and final day of the meeting hosted an interactive session where all delegates had the opportunity to ask questions to the EPAD leadership. Engaging discussions were held on the PoC platform, EPAD data and sustainability. Finally, the EPAD Consortium gathered for an EPAD Academy session where six EPAD young researchers presented their respective work. The EPAD fellows’ talks were an engaging end to an overall great General Assembly meeting. The event was then brought to a close by Craig Ritchie and Serge Van der Geyten, Executive Director Jean Georges, Director for Projects Dianne Gove and Project Officer Cindy Birck attended the meeting.

17 May: MinD project had a packed schedule during its fourth and final visit to Luxembourg

The fourth and final scheduled secondment to Luxembourg took place during May. The Luxembourg secondments have often been about taking stock, writing and planning. This meeting followed on in that vein. During an extended fortnight, 13 people participated, including five colleagues from Alzheimer Europe (Ana, Dianne, Cindy, Chris and Owen).

Two people from the group, Vjera Holthoff and Rosa Almeida, gave presentations to public meetings organised by the InfoZenter Demenz (Luxembourg). Both were well attended and well received.

One major task was completing the MinD Dementia Design Guidelines, relevant for a designer readership and anyone intending to hold co-production workshops.

Alongside this, the meetings were used to draft a set of policy recommendations. Owen Miller, Alzheimer Europe’s Policy Officer joined the meeting, during this section of the programme, to discuss writing policy guidelines. These are still being circulated within the project team, for comment and later consultation. The intended audiences are policymakers, educators, designers, design regulators and voluntary organisations concerned with older people’s issues and dementia.

Half of the group were working on publication of the phase 1 data collection and on more recent data from the evaluation of the Good Life Kit. There was a presentation by Vjera Holthoff and Rosa Almeida about the baseline findings from interviews with people with dementia. The four themes identified from the data were quite positive; for example, about feeling empowered and reporting how people adapted to life after a diagnosis of dementia.

Preparations for the international MinD conference (19-20 September 2019, in Dresden, Germany) are also in progress. The full programme is now available and includes three keynote speakers (design, health professions and lived experience speaker), as well as a variety of papers, design proposals and workshop sessions, delivered by a wide range of international presenters. Further details are available on the conference website: www.mind4dementia.eu

The MinD project is grateful to hosts at the University of Luxembourg and Alzheimer Europe. They were particularly impressed with the excellent facilities for working in, as well as the catering and commented on how beautiful and green Luxembourg is, in springtime.

21 May: Journal of Alzheimer’s Disease publishes mini-forum on IMI PharmaCog and its findings on the role of biomarkers to help track disease progression in AD

On 21 May, the international Journal of Alzheimer’s Disease issued a mini-forum revolving around three publications by the Innovative Medicines Initiative’s PharmaCog project.

The PharmaCog project started in 2010 and had a duration of 5 years. Although finished, it keeps on producing results. These findings focus on the study of the usefulness of different biomarkers to help understand how Alzheimer’s disease will progress in people at the early stages, namely those who have mild cognitive impairments and memory problems but still manage their activities of daily living.

Alzheimer Europe has been an active partner in this project and references to the results can be found on our website: https://www.alzheimer-europe.org/Research/PharmaCog/Publications#fragment8
EU project acknowledgement

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

- **EMIF** – grant agreement 115372
- **EPAD** - grant agreement 115736
- **MOPEAD** - grant agreement 115985
- **PHARMACOG** – grant agreement 115009
- **ROADMAP** - grant agreement 116020
- **RADAR-AD** - grant agreement 806999

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

Currently, the total number of MEPs in the Alliance stands at 161, representing 28 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 Europe’s Alliance:

- **Austria**: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Angelika Mlinar (ALDE); Paul Rübig (EPP); Monika Vana (Greens/EFA).
- **Belgium**: Mark Desmesmaeker (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 (EKR).
- **Cyprus**: Costas Mavrides (S&D); Eleftheriou Charouzas (ALDE).
- **Czech Republic**: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Pavel Telička (ALDE);
- **Denmark**: Margrethe Auken (Greens/EFA); Ole Christensen (S&D);
- **Estonia**: Urmas Paet (ALDE);
- **Finland**: Heidi Hautala (Greens/EFA);
- **France**: Isabelle Thomas (S&D);
- **Germany**: Stefan Gehroll (EPP);
- **Greece**: Angeliki Nielber (EPP);
- **Hungary**: Tamás Deutsch (EPP); Ádám Kósa (EPP);
- **Ireland**: Lynn Boylan (GUE/NGL);
- **Italy**: Teresa Grifoni (GUE/NGL);
- **Lithuania**: Věra Jourová (S&D);
- **Luxembourg**: Georges Bach (EPP); Frank Engel (EPP);
- **Malta**: Roberta Metsola (S&D);
- **Netherlands**: Gerben-Jan Gerbrandy (ALDE);
- **Portugal**: Carlos Coelho (EPP);
- **Romania**: Cristian Silviu Busoi (MEP);
- **Slovakia**: Andrejs Mamikins (S&D);
- **Slovenia**: Krstina Kuzman (S&D);
- **Spain**: Iñigo Urkullu (EPP);
- **Sweden**: Anna Kinberg Barkhult (S&D);
- **Switzerland**: Jean-Pierre Audy (NI);
- **United Kingdom**: Robert Good (EPP);
- **United States**: Patrice Kom (S&D);
- **Uruguay**: Silvia Garcia (EPP);
- **Venezuela**: Jorge Rodríguez (ALDE);
- **Vietnam**: Tran Hoai Anh (S&D);
- **Yemen**: Ahmed Al-Mutawakel (S&D).

**EU DEVELOPMENTS**

**13-17 May: The European Public Health Association to mark European Public Health Week**

The European Public Health Association (EUPHA) coordinated a series of events and awareness raising activities, as part of its inaugural European Public Health Week, which ran from 13-17 May 2019. The focus of the week was “celebrating healthy populations”, with the aim of raising awareness across a range of topics within the field of public health. Each of the five days had a different focus and messaging:

- **Monday 13 May** – "Becoming, being and remaining physically active". This day focused on subjects including activity-friendly environments, preventative health benefits of being physically active and rehabilitation.
- **Tuesday 14 May** – “Healthy environments”. The messaging on this day was focused on issues around public health.
health communities and environments, air pollution and urban health.

- Wednesday 15 May – “Care 4 care”. Topics covered on this day included self-management of chronic diseases, primary healthcare, health services research, the role of informal caregivers and access to healthcare.

- Thursday 16 May – “Sustainable and healthy diets”. The focus of this day was primarily on healthy diets, food safety laws and sustainable agriculture.

- Friday 17 May – “Youth mental health”. This day was used to promote messages around mental health services, online and offline balance, and social relationships.

More information can be found here:
https://eupha.org/European_Public_Health_WEEK_2019

13 May: European Commission opens recruitment for research advisory board

The European Commission has issued a call for applications to join the advisory boards of the new research “missions” which will be established as part of the new Horizon Europe research programme.

There is a single call for all for five boards (one for each “mission area”, as recently agreed between the European Commission, Council and Parliament), however, applicants can indicate their preferred area.

Each board will have 15 members and will advise the Commission on the design and management of the missions, setting the specific goals they should achieved.

While the boards will design the missions, their role is advisory in that the plans must be approved by a programme committee of national representatives and formally adopted by the Commission.

The Horizon Europe legislation says board members need to be “high level individuals” and hopes to have a broad range of people represented on the boards, including former public figures, people from international agencies, civil society organisations and non-governmental organisations.

You can read the European Commission’s call for applications here:

15 May: European Commission appoints new president of the European Research Council

The European Commission has appointed Mauro Ferrari, an expert in the field of nanotechnology in medicine, will be the new president of the European Research Council (ERC). He will replace the current president, Jean-Pierre Bourguignon, on 1 January 2020.

The president chairs the ERC’s “Scientific Council” which sets the scientific priorities of the organisation, which in turn guides how it allocates its research funding.

Specifically, the ERC’s Scientific Council has 22 members, including the president, which sets the Council’s overall direction, whilst day-to-day business of handling grant applications and other matters is matters is handled by the ERC’s Executive Agency, run by the Commission.

Mauro Ferrari will lead the ERC throughout the period of the transition from the Horizon 2020 research programme, to its successor, Horizon Europe (which will run from 2021-2027). In this time, the ERC’s budget will increase from EUR 13.1 billion in Horizon 2020 to a proposed EUR 16.6 billion.

The term of the ERC President will run for at least four years, until 31 December 2023, and can be renewed once for an additional two years, until the end of 2025.

29 May: Results of the European Parliament elections are announced

Following the elections between 23 and 26 May, 751 MEPs from across 28 European countries have been elected to the European Parliament.

Based on a combination of confirmed results and projections, the European Parliament website, as at midday on 29 May 2019, estimated that the breakdown of MEPs by parliamentary grouping would be as follows:
The Parliament will meet for the first time in plenary in July 2019 to induct the newly elected MEPs, during which time the members will elect their President.

The next step in the process will be for a candidate (likely to be the EPP Spitzkandidat Manfred Weber) to be put forward as EU Commissioner, subject to confirmation by the European Parliament, followed by the selection of the Council of Commissioners for different areas of work. The official end of the term of the Juncker Commission is October 2019.

Alzheimer Europe will now work to re-establish the European Alzheimer’s Alliance (EAA), work with other civic society and patient organisations to identify members supportive to social, health and research matters, and engage with members who signed the pledge to encourage them to help push dementia as a priority area in future EU work.

For detailed breakdown about the MEPs elected in your country, more information is available on the European Parliament website:

https://election-results.eu/

MEMBERS’ NEWS

29 April: NGO Futura Montenegro announces new dementia care project

A new project, “Care for older people with dementia”, has been approved in Montenegro, NGO Futura announced on 29 April 2019. More specifically, the association says it has employed, in cooperation with the Employment Service of Montenegro, five nurse-caregivers, who will work and help in the care of persons with dementia and support them in their day-to-day needs at home, during four months.

2 May: Ireland’s Minister for Health attends 25th Anniversary Alzheimer’s Tea Day event

After a successful call out on social media, Minister for Health Simon Harris TD attended The Alzheimer Society of Ireland’s National Tea Party to mark the 25th Anniversary of Alzheimer’s Tea Day, at the charity’s Orchard Day Care Centre in Blackrock, Co Dublin on 2 May 2019. Alzheimer’s Tea Day is the charity’s largest fundraising campaign.

Minister Harris met with CEO of The Alzheimer Society of Ireland (ASI) Pat McLoughlin, Chair of the Irish Dementia Working Group Ronan Smith, ASI staff, volunteers and supporters, as well as clients of The Orchard Day Care Centre, as he vowed to support the organisation in its “vital work”, at this celebratory event.

Also, during a speech, the Minister highlighted the importance of raising awareness of dementia to help families around the country and agreed to a further meeting with Mr McLoughlin and a delegation from the charity in Leinster House, Dublin later in May, to discuss dementia care in Ireland.

The Minister added:

“I am really pleased to be here to mark Alzheimer’s Tea Day. So many families in the country have been affected by this illness and it is really important we do everything we can to bring awareness to this illness and help The Alzheimer Society of Ireland continue to do the vital work they do.”

Pictured: Minister Simon Harris (right) and The ASI CEO Pat McLoughlin (left)
3 May: France Alzheimer video gives insight into its post-diagnosis support programme for people with dementia

In March this year, Alzheimer Europe published an article about its member, France Alzheimer’s new post-diagnosis support programme for people with dementia. A new video, released by France Alzheimer on 3 May, suggests that the programme is meeting its main objective, to improve the quality of life for people with dementia and their caregivers and especially to enable the newly-diagnosed person to be proactive in dealing with what they are going through, by helping them to process the situation. Some of the participants are filmed (consensually) in discussions about what they find helpful in the meetings they attend and about some of the difficulties they experience, which they feel are lessened by sharing them with others and hearing how they have dealt with similar situations.

You can view the video (French, with English subtitles), here:
https://youtu.be/QWFqKU64iVM

4 May: Denmark celebrates reaching target of 100,000 dementia friends

On 4 May, the Danish Alzheimer association, Alzheimerforeningen announced that its Demensven (dementia friends) campaign had reached its target of 100,000 dementia friends across the country. This target was chosen because there are approximately 100,000 people with dementia in Denmark.

Alzheimerforeningen released a video (in Danish) celebrating this milestone:
https://www.youtube.com/watch?time_continue=5&v=z6euKFfvJuI

Since the Demensven campaign was launched in 2016, coinciding with the association’s 25th anniversary, the concept has taken many forms. Denmark now has a number of dementia-friendly supermarkets, pharmacies, bus companies, sports associations, cultural places, kindergartens and even a dementia-friendly bodega. In total, more than 450 local partnerships have emerged around the country.

The concept of “dementia friends” was born in Japan, where a campaign to create a dementia-friendly society began in 2004. Since then, the idea has spread, and today there are more than 16 million dementia friends spread across 45 countries.

The next goal in Denmark is to reach 500,000 Dementia friends - one for every person affected by dementia, whether living with dementia themselves or as a family member of someone who is.

7 May: Alzheimer Croatia looks back on 20 years of progress

On 7 May, Alzheimer Croatia celebrated its 20th anniversary, at an event in the Palace Dverce - a property of the City of Zagreb used for gala banquets and other representative purposes. This was an opportunity to showcase the society’s work, including, for example, continuous counselling for people with dementia and their family members, available in person or through the national SOS helpline.

Since its foundation on 7 May 1999, Alzheimer Croatia has released various educational materials, delivered public lectures and has marked World Alzheimer’s Day in a variety of ways. In 2006, Alzheimer Croatia became a full member of Alzheimer’s Disease International (ADI) and in 2009 it became a member of Alzheimer Europe. The society began to branch out, at that time, and intensified its activities. Self-help groups were formed, regular attendance at international conferences began, and co-operation with the University of Zagreb also began, so that students in the areas of social work, psychology, educational rehabilitation and medicine could gain practical experience of working with people with dementia.

It has been especially important that, thanks to the influence of Alzheimer Croatia, new regulations have been passed, meaning dementia is no longer considered a mental illness. Since then, Croatian retirement homes have been able to accommodate people with dementia.

Since 2013, the society has been increasing its activity in the area of public awareness-raising. Alzheimer’s Cafés, Memory Walks and other actions to help recognise the early signs of
dementia have been initiated, and during the European election campaigns for 2014 and 2019, Croatian MEPs and MEP candidates have been encouraged to sign Alzheimer Europe’s Dementia Pledge. In 2014, Alzheimer Croatia, together with the Croatian Medical Association for Alzheimer’s Disease, announced the proposal of a Croatian strategy to fight Alzheimer’s disease (AD), which was presented to the Croatian Ministry of Health and former Croatian President Ivo Josipović. The increasing prevalence of AD and other dementias has also led to a growing need for other associations to engage in the fight against dementia, and many of these have become affiliates of Alzheimer Croatia.

In 2015, the society began to hold annual educational conferences on AD, focusing primarily on care and nursing practices, which will have an international character, as of 2019.

By the end of 2016, Alzheimer Croatia had started collaborating with Slovenian partners, to implement a European cross-border project, aiming to develop a training programme for the first ever dementia specialist nurses in Southeast Europe, and to make a strong contribution to the creation of the first Croatian recommendations for design of the dementia departments in retirement homes. In that same year, Alzheimer Croatia joined the international Dementia Friends initiative, and the following year, the capital of Zagreb began its efforts to become a Dementia friendly community. The City of Umag followed suit, shortly after.

More recently, Alzheimer Croatia has co-operated in the development of the first university textbook on AD and other dementias, the first national research on dementia attitudes in Croatia, and the development of dementia-friendly retirement homes.

These 20th Anniversary celebrations were also an opportunity for numerous delegates from Croatian ministries, the City of Zagreb and others to thank Alzheimer Croatia for its prominent, long-standing volunteer work, with a special mention for the society’s founder and Vice-president, Mira Dajić.

21 May: Alzheimer Iceland has a new Board

At the start of May, Alzheimer Iceland held its annual meeting. During the meeting, the new Board was confirmed. The existing Board members were re-elected and two new members also joined. The priority of the new Board is to open an Alzheimer centre in Iceland, within 5 years, where they will bring together knowledge and services for people with dementia.

24 May: Larissa branch of Panhellenic Federation ensures people with dementia are included in Easter celebrations

One of the regional branches of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders, Alzheimer Larissa Greece, was pleased, in April, to be approaching Easter in the company of the residents of the local Municipal Elderly Care Home.

Traditionally, Easter is preceded by an extended period of feasting, while people are engaged in religious activities. During the final week, people are getting busy to prepare for Easter festivities, especially the Easter feast. Unfortunately, due to health and safety reasons, residents are not easily able to follow the tradition, and it is quite common for them to feel excluded and isolated. Alzheimer Larissa Greece decided, therefore, to introduce several activities to help the care home residents embrace the spirit of the feast days.

Eleni Kamboura-Nifli and Nafsika Kiritsi started with a narrative of the Easter story. Every week, residents were welcome to add their memories, complete quizzes and practice rituals. They were also encouraged to do crafting. These classes are always open to all residents, but normally, there are only a few who decide to stay. The staff were pleasantly surprised that more and more seemed to be motivated to participate in these session, which reached the highest record of participation, as well as the record number of men participating. The participants made twine Easter eggs - which they kept to decorate their rooms - and were given help adorning Paschal candles.

They were also enthusiastic about communicating their wishes to the public, through the medium of drawing, or by recording personal messages. Artemissia-Phoebe Nifli did some editing, to bring the drawing and messaging together, and then Alzheimer Larissa Greece sent the result out via e-mail, as the association’s official Easter greeting card. The greetings card was also shared on the association’s Instagram account.

25 May: Alzheimer Iceland introduces its newly-formed working group of people with dementia

Earlier this year (January 2019), the Icelandic working group of people with dementia (IWGPWD) held its first meeting. The idea of having such a working group had previously been discussed within Alzheimer Iceland, in recent years, but finding participants had been unsuccessful.

Things started to move forward at the 28th Alzheimer Europe Conference (#28AEC), in October 2018, in Barcelona, Iceland had a representative with dementia, for the first time - a step that reflects the changing views on dementia and the abilities of people with dementia in Iceland. This representative was able to gain some insight into the work of the European Working Group of People with Dementia (EWGPWD) and immediately wanted to do something similar at home. He is
Stefán Hrafnkelsson (pictured, with the current Chairperson Ellý Katrín Guðmundsdóttir and Vice-chairperson Jónas Jónasson).

So far, there are six people with dementia involved, together with their spouses. The group has already met five times and is working on setting clear goals and ambitions. Already there has been interest from, and coverage in, the media. Members have also been invited to participate in research at the University of Reykjavík, and have received requests to guest lecture at the University of Iceland in autumn 2019, on the course “Dementia: an introduction for professionals”, which is taught at a graduate level. Furthermore, the group is taking active part in planning the Annual Conference hosted by Alzheimer Iceland on 21 September, to commemorate World Alzheimer’s Day. A few members of the group are also planning on attending the 29th Alzheimer Europe Conference (#29AEC) in The Hague this October, to make valuable connections. Everyone included has high hopes for the group and looks forward to continuing working towards a more dementia-inclusive community in Iceland.

“This is the first time that we manage to do this and now the group counts 12 people (6 couples). We are looking forward to working with them and we know how important their opinion is regarding needs and hopes. In the end, we will do better in our work”, said Árni Sverrisson, Chairman of Alzheimer Iceland.

For the past couple of years, the World Health Organization (WHO) has been developing the Global Dementia Observatory (GDO), a data and knowledge exchange platform, in consultation with international stakeholders and country focal points. The GDO aims to support countries in strengthening policies, service planning and health and social care systems for dementia. The GDO data portal, in particular, functions as the monitoring mechanism for the global action plan on the public health response to dementia 2017-2025. Key dementia indicators assist countries in measuring progress towards reaching national and global targets across the seven action areas of the global dementia action plan. As of March 2019, over 80 countries either have submitted their GDO data or are in the process of collecting GDO data. As a next step, the WHO would like to expand the GDO knowledge exchange platform, which contains key resources to support the implementation of the global dementia action plan and enhance countries’ response to dementia. The
knowledge exchange platform will provide a space for all relevant stakeholders to share resources (e.g. good policy, guidelines and practice examples for dementia) to facilitate mutual learning and promote the exchange of good practices in the area of dementia. Resources are submitted by users of the platform and will be mapped to at least one of the strategic action areas of the global dementia action plan. Automated filters will further allow users to search for country-, region- or language-specific resources, narrow down their searches by types of resources (e.g. policies, trainings, tools, practice examples) or explore settings and target audiences on which the resources focus.

A comprehensive peer-review process consisting of experts by experience (i.e. people living with dementia or their families/friends) and experts by profession will ensure that submitted resources meet developed quality and good practice criteria.

To support the peer-review process, the WHO is inviting people to consider joining this growing network of GDO peer reviewers, using the following registration link: https://extranet.who.int/dataform/456967?lang=en

If you have any questions or concerns please contact Dr Michal Herz herzm@who.int or send an email to whodementia@who.int

15 May: Swedish minister announces additional funding for dementia measures

The Swedish Minister for Health and Social Affairs, Lena Hallengren, has provided detail funding for additional measures related to dementia.

Ms Hallengren highlighted that with an increased number of people living with dementia there was a need to increase the understanding of dementia to build a society better able to support people with dementia. As such, she outlined a total of SEK 15 million (EUR 1.4 million) being invested into increasing the knowledge of care staff for older people.

The announcement focuses on raising the knowledge and skills of staff working in the care of older people. Specifically, four areas are in receipt of funding:

- The National Board of Health and Welfare receives SEK 4 million (EUR 370,000) to develop a guide for day-to-day activities for people with dementia, to counteract isolation and to stimulate activity.
- The Swedish Dementia Center is granted SEK 6 million (EUR 560,000) to develop a new website, to develop a new basic web education (Dementia ABC 2.0) and develop the training model Starred, which would result in participating units having 80% of their staff trained in dementia.
- The Behavioural and psychological symptoms of dementia (BPSD) register receives SEK 2.5 million to update the register and implement training initiatives. Among other things, a special training material will be produced and disseminated throughout the country.
- The Swedish Dementia Register is granted SEK 2.5 million (230,000) to make the registry more user-friendly and implement a new module to follow up home care and care efforts for people with dementia, creating a nationwide tool for equal and best treatment for dementia.

15 May: Swiss National Dementia Strategy has not yet met its objectives

The Swiss National Dementia Strategy on the federal and cantonal level expires this year. An evaluation has shown that, although important fundamentals have been elaborated, the care situation and quality of life of the 600,000 persons affected - people with dementia and their relatives - have not yet significantly improved.


24 May: Iceland’s Minister of Health assigns responsibility for national strategy to dementia specialist Dr Jón Snædal

Iceland has been waiting, for some time now (since May 2017, when Parliament agreed to start the process), for its Minister of Health to announce the establishment of a working group to lay out a national dementia strategy.

Earlier this year, in February, the Minister decided, instead, to give the assignment to one individual, a doctor named Jón Snædal. Dr Snædal has been the main doctor when it comes to dementia for the last 30-40 years in Iceland.

Alzheimer Iceland has since met with the doctor, to give its input, right from the start of the process. Another meeting is planned, when Dr Snædal has finished the first draft. The plan is for this to happen in June 2019.

“Because of this development, we are optimistic that we will see the first issue of a strategy for people with dementia in Iceland later this year”, said Árni Sverrisson, Chairman of Alzheimer Iceland.

Another positive development, in Iceland, is the establishment of an Icelandic working group of people with (early stage) dementia (see the “Members’ news” section for more information on the group).
On 1 May, researchers from the Broad Institute of MIT and Harvard published a landmark study in Nature, in which they profiled genetic changes in individual brain cells from people with Alzheimer’s disease (AD).

Obtaining postmortem brain samples from participants enrolled in ROSMAP, a longitudinal cohort study of ageing and dementia, co-senior authors Li-Huei Tsai and Manolis Kellis performed single-cell RNA sequencing (scRNA-seq) analysis. scRNA-seq is a powerful high-resolution technique that is used to specifically profile gene expression levels in single cells, revealing changes that low-resolution ‘bulk’ sequencing techniques are unable to detect. This is of particular importance in AD, where the contribution of different brain cell types to disease development is not yet fully understood. The research team reasoned that scRNA-seq would allow them to precisely map gene expression changes that occur during AD development, providing new clues on the role of specific brain cells in this complex disease.

To perform this mapping exercise, they applied the scRNA-seq technique to over 80,000 single cells taken from prefrontal cortex samples of 24 male and female ROSMAP participants at different stages of AD development, comparing them to samples from an equivalent number of gender-matched healthy controls. scRNA-seq was able to discriminate between, and genetically profile an array of brain cell types, from neurons to astrocytes, microglia to oligodendrocytes and beyond. Interestingly, the researchers showed that many cell-specific gene expression changes occurred in early AD, unmasking molecular pathways that had previously been obscured when using low-resolution sequencing techniques. Underlining the value of scRNA-seq, some of these gene expression changes were correlated with clinical markers of AD severity, such as cognitive impairment and amyloid plaque burden. The most surprising finding, according to the researchers, was that cells from women with AD showed much more pronounced changes in gene expression – in some cases, in the opposite direction to cells from men with AD. Moving forwards, the research team will focus on validating these findings on a larger scale, with additional experimental follow-up studies.

On 6 May: Alector announces the recruitment of the first participant in Phase Ib trial of AL002 for AD

On 6 May: Alector, a biotechnology company developing immuno-neurology therapies to treat neurodegenerative diseases, announced the dosing of the first participant with Alzheimer’s disease (AD) in its Phase Ib trial of AL002, a monoclonal antibody that enhances the activity of TREM2.

The Phase Ib trial named INVOKE is a multi-centre, randomised, double-blind and placebo-controlled study evaluating the safety, tolerability and pharmacokinetics of multiple doses of AL002 in people with mild to moderate AD and healthy adults. It will measure target specific biomarkers in both plasma and cerebrospinal fluid.

6 May: Researchers link cognitive decline in Parkinson’s disease with genetic variants of AD

On 6 May, researchers presented preliminary findings on a possible link between established Alzheimer’s disease (AD) related genetic variants and cognitive decline in Parkinson’s disease. The presentation was held during the Annual Meeting of the American Academy of Neurology in Philadelphia, Pennsylvania.

Although there is still a big knowledge gap about how and why certain genetic factors might trigger the development of dementia over the life course, researchers have invested a great deal of work to identify genetic variants that correlate with the probability to develop AD. Engagement with “at higher risk” individuals is especially important for researchers who work on the development of treatments as well as those who would like to get a better understanding of the disease course in the early stages, before any symptoms occur.

The new results now showed that some of these variants might also be of value for Parkinson’s research. The investigators analysed 151 people with Parkinson’s disease without dementia and found that genetic variants that contribute to the risk to develop AD dementia (single nucleotide polymorphisms at susceptibility loci CR1, BIN1, CLU, and PICALM) were also connected to the risk of cognitive decline in people with Parkinson’s disease.

The team underlined that these are preliminary findings, which would need to be assessed in long-term studies to see if they can be replicated. Nevertheless, further research seems to be warranted.


7 May: Actinogen Medical announces results from its Phase II clinical trial XanADu in AD

On 7 May, the Australian biotechnology company Actinogen Medical developing innovative treatments for Alzheimer’s disease (AD) and the cognitive impairment associated with neurodegenerative diseases, announced results from its Phase II clinical trial XanADu of Xanamem, which is a drug candidate targeting excess brain cortisol.

The Phase II trial is a double-blind, randomised and placebo-controlled study investigating the safety, tolerability and efficacy of Xanamem (10 mg daily) in people with mild dementia due to AD. XanADu started recruitment in 2017 and enrolled 186 participants across Australia, UK and USA.

Initial data showed that a 10 mg daily dose of Xanamem is safe and can inhibit cortisol production. However, the experimental drug had not demonstrated efficacy in improving cognition. The primary and secondary endpoint measures failed to demonstrate statistical differences between Xanamem (10 mg) and placebo. The company pursues studies which are evaluating Xanamem at higher doses (20 and 30 mg). Results are expected by end of June.


7 May: Merck presents positive Phase III data of suvorexant for the treatment of insomnia in AD

On 7 May, Merck, a leading global biopharmaceutical company known as MSD outside of the US and Canada, presented positive results of its Phase III trial evaluating suvorexant for insomnia in people with mild to moderate Alzheimer’s disease (AD) dementia at the 2019 American Academy of Neurology Annual Meeting in Philadelphia (US). Suvorexant is currently approved in the US for the treatment of insomnia characterised by difficulties with sleep onset and sleep maintenance.

The Phase III study is a randomised and placebo-controlled clinical trial investigating the safety and efficacy of suvorexant for the treatment of insomnia in people with mild to moderate AD. It included 136 participants who received suvorexant 10 mg and 141 participants who received placebo. Of the patients treated with suvorexant, 77% increased their dose from 10 mg to 20 mg after the second week of the trial.

The company reported that the trial met both its primary and secondary efficacy endpoints. For the primary endpoint, treatment with suvorexant over four weeks led to an improved mean total sleep time by 28.2 minutes versus placebo. For the secondary efficacy endpoint measurement, an improvement in wake after persistent sleep onset (WASO) was observed in the suvorexant group compared with placebo (15.7 minutes improvement for the drug). During the study, adverse events were observed in 22.5% of participants receiving suvorexant compared to 16.1% of those receiving placebo.


7 May: Study suggests that spatial navigation ability may help identify people at high genetic risk of developing AD

On 7 May, researchers reported that assessment of navigational behaviour measured by a virtual computer game may help identify people who are at high genetic risk of developing Alzheimer’s disease (AD). The study was published
in the journal Proceedings of the National Academy of Sciences of the United States of America.

Sea Hero Quest app is a spatial navigation video game dedicated to helping global research into dementia. In Sea Hero Quest, players have to navigate and control a virtual boat.

Scientists analysed data from over 27,000 players between 50 to 75 years old in the United Kingdom to create a global benchmark to know how people navigated the game. They also analysed results of 60 participants who had undergone genetic testing. Then, they compared how people with the APOE4 gene (most common genetic risk factor for AD) navigated the game compared to people without this gene. In the published study, researchers showed that people who are genetically at risk of developing AD can be reliably distinguished from those who are at low-risk using spatial navigation. People with a high genetic risk, the ApoE4 carriers, performed worse on spatial navigation tasks.

On 8 May, Prof. Simon Lovestone and colleagues reported that the JAK-STAT signalling pathway, which is known to promote inflammatory conditions such as Crohn’s disease and psoriasis, may also be involved in the development of Alzheimer’s disease (AD).

Recent technological advances in next-generation sequencing (NGS) have yielded vast quantities of genetic data, transforming the scientific landscape. Using high-performance computers, researchers can now study genetic data from thousands of people with different health conditions, identifying novel genes that may contribute to the development of disease. The starting point for this study, published in Cells, was to probe a large catalogue of genome sequencing data (the NHGRI-EBI GWAS database) for susceptibility genes shared between people with AD and people with other conditions such as Crohn’s disease, psoriasis and lupus. They identified a potential association between these groups when analysing genes in the JAK-STAT signalling pathway, reinforced by real-world clinical data from the US National Hospital Discharge Survey.

To check whether the JAK-STAT signalling pathway is involved in AD, the researchers then analysed RNA-seq data from >200 people with AD and a similar number of healthy individuals. This type of NGS data counts how many RNA copies of a specific gene is present, allowing researchers to accurately measure the expression levels of thousands of genes in parallel. Interestingly, these analyses revealed altered levels of JAK-STAT gene expression in people with AD. These observations were reinforced by experiments performed in cell and animal models of AD, which showed increased JAK-STAT gene expression after exposure of cells and animals to amyloid Beta, the main component of amyloid plaques found in the brains of people with AD.

8 May: Researchers studying large genetic datasets identify JAK-STAT signalling as a potential target for AD therapy

On 8 May, the American Food and Drug Administration provided the biotech company Optina Diagnostics with the esteemed breakthrough device designation for a new Retinal Imaging Platform designation for a Retinal Imaging Platform that aspires to aid in the diagnosis of Alzheimer’s disease (AD).

There is a rising interest in the identification of people at early or even preclinical stages of dementia. Recent findings have underpinned the potential value of eye scans to support diagnosis of AD and dementia. The motivation for this focus is intensified because researchers seek to administer drugs that may slow or halt progression of toxic build-ups in the brains of people affected before their brains are negatively affected. In this context, efficient and successful identification of people at early stages of the disease course is seen as co-dependent with the successful development of still lacking treatments.

The Optina Diagnostics platform uses Artificial Intelligence on eye scans that are captured with the Metabolic Hyperspectral Retinal Camera and the Cerebral Amyloid Predictor Retina Scan. The press release can be read here:

https://prn.to/2Z0eLpg

10 May: Jülich completes Phase I trial for its AD drug PRI-002

On 10 May, the German Forschungszentrum Jülich centre, one of the largest interdisciplinary research centres in Europe, announced the successful completion of the Phase I trial investigating the drug candidate PRI-002 for the treatment of Alzheimer’s disease (AD).
The Phase I trial was a randomised, double-blind and placebo-controlled single ascending-dose study evaluating the safety and tolerability of PRI-002 in healthy volunteers. PRI-002 is a peptide developed to directly destroy the toxic oligomers without the involvement of the immune system. Findings showed that PRI-002 was well tolerated in healthy participants after administering the experimental drug daily for four weeks. These results allow a further development of the drug candidate. Researchers are now planning to show the drug's efficacy in Phase II trial.


11 May: UK researchers investigate the experiences of adolescents and their attitudes towards people with dementia

On 11 May, a UK-based research team published an article on the investigation of the experiences of adolescents and their perceptions of dementia in the journal “Aging & Mental Health”.

The researchers provided questionnaires in four schools (across Sussex, England) assessing the attitudes of a group of 901 students (13-18 years old).

The team noted in its publication that overall there was a tendency to have neutral or positive attitudes towards dementia and that females reported more positive attitudes compared to males (although not significant).

Furthermore, the article underlined that many adolescents indicated that they had little to no knowledge or direct experience of dementia. Most of them who had any exposure to the subject of dementia would have gained their knowledge from adverts, such as billboards and leaflets while over half of the respondents (596) indicated that they had never learnt about dementia in school. Interestingly, about a third (287) of the respondents also indicated that they would like to learn more about dementia.

https://doi.org/10.1080/13607863.2019.1613343

LIVING WITH DEMENTIA

15 May: Petri Lampinen, member of the European Working Group of People with Dementia, takes part in a video to help spread awareness

I was pleasantly surprised, when I was contacted by the Alzheimer’s Society. They told me about a joint international project between them, Dementia Alliance International and the 3 Nations Dementia Working Group. I had previously heard about this project, which was looking for some active dementia speakers around the globe and I accepted the task gladly. It is great to be involved in this international project. I feel that my active work has been noticed and I am on the right track, having been asked to be a speaker on many occasions. Although, at first I pondered this request for a while, because my English pronunciation is a bit bad. They told me I could speak in my own mother tongue, that is, in Finnish. The video would have subtitles in English, so my bad pronunciation would be understood.

The day of filming was very nice and the cameramen were professional and easy to work with. The filming was done at the local office of the memory association (Muistiliitto – The Alzheimer Society of Finland).

I got very good help from the association’s employees and the fact I had already been involved in some filming before made it easier to do this one. I was able to be relaxed and wasn’t nervous about the interview. I felt I could also talk about how I became an active speaker.

After the interview, I remembered something that took place a few years ago. In the early days of my condition, I searched for a lot of information about dementia on YouTube. Especially information about living with dementia and the changes it brings to many things. Through watching videos, I noticed the importance of sharing things and that is why I do this work with pleasure. It is good that we share information with each other, around the globe. The same problems, such as stigma, affect our lives in many ways. When speaking at meetings, in the media, and at various events, we can change the perceptions of living with dementia. By being brave, I have overcome many obstacles, when doing this work. The feeling after making a speech is unique, when you notice its impact on the audience. Inclusion is sharing things that concern us all. It is great that there are active players around the world. This is how we spread awareness, together.
23 May: Idalina Aguiar, member of the European Working Group of People with Dementia, finds music therapy beneficial

As someone living with a diagnosis of Alzheimer’s, I believe in the importance of complementarity between pharmacological and non-pharmacological therapies.

A complementary and fundamental therapy in the treatment of many pathologies is music therapy, which I have been attending regularly, since 2012. I am a staunch advocate of music therapy, because I have seen it do wonderful things for people and it is one of the tools I use most.

Music therapy is a therapeutic intervention, which allows people to express themselves verbally and/or nonverbally. It is a person-centred therapeutic process that allows us to adjust therapeutic intervention to the specific interests, needs and goals of each individual. Music therapy can be applied in diverse populations, from pre-school children to older people, with the objective of optimising their quality of life and improving their physical, emotional, cognitive and social well-being.

I would like people to rethink the importance of the complementarity of treatments, to integrate them and to recognise their importance.

Last year, at the 28th Alzheimer Europe Conference, my daughter Nélida and I presented a poster on this topic. We were pleasantly surprised to win 2nd prize in the conference poster competition. We donated our prize money to the day centre, which I attend. The money has been earmarked especially to allow other centre-users to enjoy music therapy sessions, with a certified music therapist.

For at least the next 6 months, the "Garouta do Calhau" day centre is guaranteed a music therapist (who also has other skills). They join a fantastic team of professionals who have done everything possible to make it a National Reference Center, in responding to the needs of people with dementia.

NEW PUBLICATIONS AND RESOURCES

9 May: Agnes Houston publishes new book on sensory changes associated with dementia

Agnes Houston MBE, a former member of the European Working Group of People with Dementia (EWGPWD) and member of the Scottish Dementia Working Group, has published a new book, “Talking Sense: Living with sensory changes and dementia”.

The book, published by HammondCare, was launched on 9 May, at the inaugural International Conference on Palliative Dementia Care (ICPDC) in Belfast, Northern Ireland (UK).

Ms Houston was diagnosed with younger onset dementia in 2006. She found that there was little support for continued independence, and even less awareness of the common experience of sensory change.

“It was as if I had been given a diagnosis, was assessed cognitively, medication monitored and left to my own devices,” she said. “Instead, I chose to go on a quest for knowledge to understand what was happening to me. Surely, I was not the only one having these sensory changes?”

Since her diagnosis, Ms Houston has been on a quest for knowledge, both for herself and for others in a similar situation. She shares her knowledge and experience in this new book, which is available as a free download, via:


14 May: Report on the state of play in clinical trial research on Alzheimer’s disease is published

On 14 May, the Biotechnology Innovation Organisation (BIO) - the largest trade organisation in the world that represents the biotechnology industry - released a new report, “The State of Innovation in Highly Prevalent Chronic Diseases Volume IV: Alzheimer’s Disease Therapeutics”. This report is the fourth in a series on the innovation landscape of highly
prevalent, chronic diseases. This volume takes an in-depth look at the state of innovation for therapeutics in Alzheimer’s disease (AD).

The analysis, which aims to assess the depth and breadth of innovation to meet the needs of people with AD, also features historical clinical success rates, failed mechanistic strategies, as well as trends in venture financing and investment into new clinical trials.

Download it here: http://go.bio.org/rs/490-EHZ-999/images/BIO_HPCD4_ALZHEIMERS.pdf

15 May: World Health Organization (WHO) publishes dementia prevention guidelines

The World Health Organization (WHO) has published new guidelines highlighting some of the ways in which individuals can reduce their risk of developing dementia. The document specifically draws attention to areas such as regular exercise, smoking, harmful use of alcohol, controlling body weight, healthy diets, and maintenance of healthy blood pressure, cholesterol and blood sugar levels.

The guidelines have two key intended objectives:
To provide evidence-based recommendations on lifestyle behaviours and interventions to delay or prevent cognitive decline and dementia in the general population.
To provide evidence-based recommendations on management of specific physical and mental health conditions, to delay or prevent cognitive decline and dementia.

This work aligns with the prevention strand of the WHO’s “Global action plan for the public health response to dementia (2017-2025)”, which addresses a number of key areas around dementia; diagnosis, treatment and care; supporting carers of people with dementia; and research and innovation.

An updated factsheet on dementia, providing high-level information on diagnosis, treatment, human rights and epidemiology, has also been published.

The full report on the dementia guidelines can be read here: https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf?ua=1

The updated factsheet on dementia can be read here: https://www.who.int/news-room/fact-sheets/detail/dementia

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Alzheimer Europe Board:
Chairperson: Iva Holmerová (Czech Republic); Vice-Chairperson: Charles Scerri (Malta); Honorary Secretary: James Pearson (UK - Scotland); Honorary Treasurer: Maria do Rósario Zincke dos Reis (Portugal). Members: 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).

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# AE CALENDAR

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<td>4-5 June</td>
<td>Guideline meeting of EAN (European Academy of Neurology) (Vienna, Austria)</td>
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<td>12 June</td>
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<td>25-27 June</td>
<td>EWGPWD meeting (Brussels, Belgium)</td>
<td>Dianne and Ana</td>
</tr>
</tbody>
</table>

## CONFERENCES 2019

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<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="https://www.rcpsych.ac.uk">https://www.rcpsych.ac.uk</a></td>
<td>London, UK</td>
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<tr>
<td>2-3 September</td>
<td>Euro Congress on Dementia and Alzheimer’s Diseases (ECDA-Rome), <a href="https://www.dementiameet.com/">https://www.dementiameet.com/</a></td>
<td>Rome, Italy</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>
<tr>
<td>26-29 March 2020</td>
<td>14th World Congress on Controversies in Neurology (CONy), <a href="http://cony.comtecdn.com/">http://cony.comtecdn.com/</a></td>
<td>London, UK</td>
</tr>
</tbody>
</table>
29th Alzheimer Europe Conference
Making valuable connections
The Hague, Netherlands
23–25 October 2019
www.alzheimer-europe.org/conferences   #29AEC