First of all, I would like to wish our friends at Association Luxembourg Alzheimer (ALA) a very happy 30th birthday! 2017 also marks 25 years of ALA’s Fondation Alzheimer and 10 years since the opening of its dementia nursing home and day care centre. Our friends in Luxembourg have an exciting programme of events planned, to celebrate this momentous year. See our members’ news section for more details of this and plenty more national member organisations’ news.

I am also delighted to announce that the call for abstracts for our 27th Alzheimer Europe Conference (27AEC) in Berlin, Germany from 2 to 4 October is now open and the submissions deadline is 30 April. Please read the abstract submission guidelines carefully before submitting an abstract! As you can imagine, with the call now open, a lot of focus is already going on plans for our October conference. Online registrations will be opening in the next few days, so watch this space!

As well as the conference, we have been busy this month with a number of the EU-funded projects in which we are involved. Many are making great progress, as you will see in our heavily-laden projects news section.

On a less positive note this month, we were disappointed to hear the news that Merck/MSD has had to call a halt to its experimental Alzheimer’s disease (AD) drug verubecestat in a late-stage trial. The phase 2/3 EPOCH study was for people with mild to moderate AD. The company is, however, continuing with research into this drug in another trial, the APECS study, for people with prodromal AD. It is always disappointing when late-stage trials fail, but we can take heart from the many drug trials and other interventions currently being researched and the many collaborative research projects and partnerships working hard on both prevention and cure.

On the clinical trials front, we have just added another trial to our Clinical Trials Watch service: Hoffmann-La Roche’s CREAD study. The study is investigating the drug Crenezumab as a treatment for AD. You can find out more on page 2 of this newsletter or by visiting our website. Please bear in mind that the information provided by AE should not be interpreted as a recommendation to use a treatment, nor to participate in a study.

We are ending the month with a series of meetings in Luxembourg: a Board meeting on 27-28 February, a Company Round Table on 28 February and March kicks off with a one-day Public Affairs meeting, bringing together our national members organisations. I look forward to discussing our projects and plans for 2017 with sponsors and members, and to hearing about national campaigning activities and events. You can read all about them in our March edition!

Jean Georges
Executive Director
On 26 January, we received news that the task force writing the Guidelines on Summaries of Clinical Trial Results for Laypersons, in which Alzheimer Europe (AE) has been involved since its launch at the European Medicines Agency (EMA) in 2015, has received the green light on its final version, which is expected to be published soon.

Alzheimer Europe is pleased to have contributed to this important project.

15 February: Alzheimer Europe opens call for 2017 conference abstracts

Alzheimer Europe and Deutsche Alzheimer Gesellschaft (the German Alzheimer association) are pleased to announce that the call for abstracts for the 27th Alzheimer Europe Conference (27AEC) is now open. The conference will take place in Berlin, Germany from 2 to 4 October 2017.

Abstracts for oral and poster presentations are welcome in the following categories:

- **Living with dementia:** People with dementia; Carers of people with dementia; Sexuality and dementia; Migration and dementia.
- **Dementia care:** Post-diagnostic support; Residential care; Care training; Home care and support.
- **Medical aspects:** Diagnosis; Behavioural and psychological symptoms of dementia; People with dementia in hospitals; Treatment and management of dementia.
- **Legal and ethical issues:** Ethical issues linked to dementia research; Proxy-decision making systems; Ethics of assistive technologies; End-of-life care and decisions.
- **German session:** Seltene Demenzformen; Neue Wohnformen; Demenz und Autofahren.

Please read the abstract submission guidelines carefully before submitting an abstract. The submissions deadline is 30 April 2017.

More information is available on our website: http://www.alzheimer-europe.org/Conferences/Berlin-2017

Conference registrations will open from 1 March, via our website. For other important dates related to 27AEC, see: http://www.alzheimer-europe.org/Conferences/Berlin-2017/Important-dates

27 February: AE adds Roche’s CREAD trial to its Clinical Trials Watch

In September 2016, Alzheimer Europe (AE) launched the Clinical Trials Watch (CTW) – a service with up-to-date, accessible information on clinical trials. During February 2016, AE added another clinical trial to the service: Hoffmann-La Roche’s CREAD study. The study is investigating the drug Crenezumab (a monoclonal antibody that specifically recognises Aβ), as a treatment for Alzheimer’s disease (AD). The study is active in 11 EU countries, will include around 750 participants worldwide and is expected to run until 2021.

The purpose of the CTW is to provide accessible and up-to-date information on clinical trials (i.e. studies) that are investigating drugs for AD and/or dementia. We hope that this information is useful to affected people, their families, carers and anyone with an interest in dementia research. This is not an exhaustive resource of information. It contains information about clinical trials that are:

- Currently recruiting participants
- Conducted in at least two European countries
- In phase III - in these trials the drug/treatment is tested in large groups of people, involving from several hundred to several thousand participants. These trials are conducted to provide stronger evidence of the effectiveness and safety of the new drug/treatment.

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

Further information about the CREAD study is available on: http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch/CREAD-study

Please note this information should not be interpreted as a recommendation to use a treatment, nor to participate in a study.

For more information about the CTW please contact Cindy Birck, Project Officer: cindy.birck@alzheimer-europe.org

EU PROJECTS

18-26 January: SyDAD organises course on Synapse Methodology

The European Training Network Synaptic Dysfunction in Alzheimer Disease (SyDAD) arranged a course on Synapse Methodology in Bordeaux, from 18 to 26 January. The course took place at the Bordeaux School of Neuroscience, which is a laboratory equipped with advanced instrumentation solely dedicated to training.
Students performed two mini-projects of four days, learning the methods of their own choice. As instructors, SyDAD had collected the best expertise in each method among the network’s senior researchers.

The course gave the opportunity for the students to learn methods not normally performed at their home universities and was also a good opportunity for students and researchers to interact with each other.

A similar workshop, more focused on AD preclinical methods, will be arranged during 2018 and will be open also for other PhD students.

3 February: MOPEAD features in Catalonia’s leading newspaper

On 3 February, an article about the MOPEAD project appeared in Spanish daily newspaper La Vanguardia. La Vanguardia is printed in Spanish and since 3 May 2011 has also been printed in Catalan. It has its headquarters in Barcelona and is Catalonia’s leading newspaper. The article can be read here: http://www.lavanguardia.com/vida/20170203/413977727949/destinan-4-millones-a-encontrar-un-sistema-de-diagnostico-precoz-de-alzheimer.html

Also this month, project coordinators Fundació ACE and Eli Lilly wrote a blog post about the project, published on the Lilly website on 13 February and in Slovenia, an article about MOPEAD was published in leading newspaper DELO on 9 February.

The Lilly blog is here: https://lillypad.eu/entry.php?e=3038

MOPEAD (Models of Patient Engagement for Alzheimer’s Disease) is a 33 month project aiming to deliver a step-change in Alzheimer’s disease patient engagement strategies and a paradigm shift from late-stage diagnosis to early-stage diagnosis. It began in 2016 and will come to an end in 2019. This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under Grant Agreement No 115985. This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations.

http://www.mopead.eu/

13 February: PACE researchers publish article discussing the value of QALYs in palliative care

The PACE project - Palliative Care for Older People in care and nursing homes in Europe – is very happy to present its very first article published in the journal Palliative Medicine. The paper, about the use of the quality-adjusted life years (QALY) in palliative care, was penned by researchers belonging to Work Package 5 (WP5) in The Netherlands.

The QALY is the most often used outcome measure of effectiveness in cost-effectiveness analyses in health care.

However; a debate concerning the appropriateness of its use in palliative and end-of-life care is ongoing. Because of the importance of this discussion, and to reflect on PACE’s own choice to use the QALY, the pros and cons of using it in palliative care as brought forward in the debate were systematically mapped for this study, and the value of QALYs for palliative care discussed in some depth.

http://journals.sagepub.com/doi/full/10.1177/0269216316689652

13-14 February: EPAD WP6 team makes plans for 2017

Members of the European Prevention of Alzheimer’s Dementia (EPAD) Work Package 6 (WP6) communication and dissemination team met on the Novartis Campus in Basel on 13 and 14 February. The team discussed the project’s communication strategy, focus plan and activities for 2017, and made plans for the EPAD General Assembly planned in May.

AE contributes as co-lead to the disseminations activities for the EPAD project.

The meeting was attended by Sean Knox (Novartis), Lennert Steukers (Janssen), Ana Belen Collado Gill (BBRC), Alzheimer Europe Executive Director Jean Georges, Communications Officer Kate Boor Ellis and Project Officer Cindy Birck.

http://ep-ad.org/

21 February: EMIF-PLAT coordinators give us an update on progress - “Building a Platform for the Future”

Nigel Hughes, EFPIA Coordinator of EMIF-PLAT, Janssen Pharma R&D and Professor Johan Van Der Lei, Academic Coordinator of EMIF-PLAT, Erasmus University sent us the following update on The European Medical Information Framework (EMIF) programme:

EMIF is one of the largest and most complex programmes under IMI (grant agreement 115372): it includes two disease foci, in Alzheimer’s Disease (EMIF-AD), and in Metabolic diseases (EMIF-MET), both tasked with early biomarker development, combined with a technology and governance framework, or platform (EMIF-PLAT) that is a critical development focus now and for the future.

Now in its fifth and final official year of the programme, EMIF-PLAT is developing, evaluating and deploying a framework that can support the identification, assessment and evaluation and then (re)use of health data for research, from diverse sources in the primary and secondary care settings (such as electronic health records (EHRs)), regional and payer databases, and cohorts. The cohorts are often disease specific, smaller in patient record numbers (hundreds to thousands), but with targeted and focussed variables, over a prescribed longitudinal period. The EHR settings are usually significantly larger (millions of patient records), covering multiple diseases,
episodes and outcomes, and often denoted as population data.

As the sources and routes to eventual (re)use of health data is delineated along two paths, population or cohort, there are effectively two architectural paths in development within EMIF-PLAT, as denoted in figures 1, with areas of commonality and certain domain specific features.

Figure 1: Detailed EMIF-PLAT Architectural View

The cohort architecture, as outlined in Figure 1, is currently aiming to support EMIF-AD and incorporates the Catalogue (though nominated as the Cohort Selection Tool, and which is now accessible outside of EMIF since 16th January), with two harmonisation methods. The first is via a ‘switchbox’, a single interface mapping tool that would allow for single connectivity from each cohort to multiple data tools, and then utilisation of a participant selection tool (PST), a variable selection tool (VST), and others, such as Prepad (used by the IMI programme EPAD, also known as Café Variome), and then ultimately a private remote research environment (PRRE) for the derived data and/or analytics for the researcher. A second harmonisation approach using ‘Knowledge Objects’, based on triple stores, is an area of methodological research which is assisting with EMIF-AD in its cohort-based biomarker studies, and is utilising the tranSMART platform as a PRRE currently. This framework could be supported by other tools, such as TASKA, and contracting and financing.

Underpinning the technology is an Ethical Code of Practice (ECoP), incorporating many of the standards set across data regulation within the EU, as well as ancillary materials for data collaboration, access, (re)use and allied requirements. Also supporting the architectural development are multiple research use cases which have provided invaluable insights into the current approach to conducting studies with multiple data sources and in addressing pivotal steps in the research process.

We believe the work conducted by, and the developments within EMIF-PLAT are unique in the European setting, and it is due to the considerable enthusiasm and determination of its partners that we have made the progress we have to date. As we move in the late phase of EMIF to deployment and eventual use of the EMIF-PLAT architecture by researchers in the Alzheimer’s domain, we will be able to further evaluate our success, but also our legacy for EU-based health and life sciences research.

22 February: The INDUCT project is researching how technology can improve the lives of people living with dementia

The use of arts in dementia care has already been established as useful in recent research. We already have results which show that the use of the arts have benefits and positive effects in quality of life. However, for part of the population, the access to art-related activities is still restricted. Most of these people are living in care facilities, and they sometimes do not have access to cultural and creative activities that most people have in the outside world.

Fortunately, a few researches are looking for ways to include more arts in people’s lives. One possible solution is through the use of art applications (apps) in touch-screen technology. This topic is being researched in the University of Nottingham by Early Stage Researcher (ESR) Aline Cavalcanti Barroso (pictured).

Ms Cavalcanti Barroso is part of the Interdisciplinary Network Using Current Technology in Dementia (INDUCT) project, a network that researches how technology can improve the lives of people living with dementia. Her research aims to identify the best touchscreen apps on digital arts and crafts for people living with dementia. She will conduct an online survey to check which art apps are more popular and used in care settings in England, Sweden and The Netherlands. This survey will also identify barriers and incentives to adopting touch-screen technology to create arts and crafts in care settings. At a later stage, people living with dementia will be invited to join the study and will use the most promising art apps found through the survey.

“I believe that the use of digital arts apps can engage and stimulate, improve quality of life and socialisation, bringing benefits to people with dementia” commented Ms Cavalcanti Barroso.

If you have any queries, suggestions or comments please email: aline.cavalcantibarroso@nottingham.ac.uk
23 February: The MinD project completes its first year

The MinD project is completing its first year of research into designing for people with dementia. The first year was given over to the development of the mindful project framework, of data collection with people with dementia to provide a basis for the design development, and of the mindful design approach: The project framework introduces ideas of mindfulness to support people with dementia with regard to increasing subjective wellbeing and self-empowerment in social context. It focuses on people’s emotions and values and how to support them in social context to support meaningful and fulfilling social interaction. The data collection research with people with dementia and their carers in three countries (The Netherlands, Germany and Spain) is now nearly completed, and results will be presented to the Alzheimer Europe working group for discussion in May. Also, the project has begun to develop a mindful co-design approach for the design development phase in the second year of the project where the aim will be to develop design interventions in response to the data collection results.

Already the interviews in the first year are offering important preliminary insight into understanding the needs, perceptions and aims of people with dementia, highlighting the importance of trust, humour and positive language in dealing with subjective wellbeing and social engagement in dementia. Furthermore, the qualitative interviews emerged as very important in their own right for giving people with dementia a voice within scientific study, because currently there are few qualitative studies with people with dementia that focus on their subjective wellbeing. Existing research is for the most part focussed on functional support and safe-keeping from the perspective of the carer. References to decision-making and empowerment are predominantly related to action planning for dementia care or advance care planning. References to care and social interaction show that caregivers tend to take a deficit-oriented perspective, and occupation of people with dementia is often associated with doing ‘something’, with no focus on meaningfulness. Therefore, in its second year, the MinD project will explore how to address some of these shortcomings with the help of design.

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 691001. http://designingfordementia.eu/

Alzheimer Europe networking 2017

On 1 February (London, United Kingdom), Jean attended the NILVAD Steering Committee Meeting.
On 7-11 February (Vilnius, Lithuania), Gwladys attended the CONVENE Forum.
On 13 and 14 February (Basel, Switzerland), Jean, Kate and Cindy attended an EPAD project communications meeting.
On 21 and 22 February (Brussels, Belgium) Dianne and Ana attended the EFGCP conference.
On 22 to 24 February (Manchester, United Kingdom) Jean attended the IMI EMIF-AD General Assembly / Joint DPUK Meeting.
On 27 and 28 February (Luxembourg, Luxembourg), the Alzheimer Europe Board met.
On 28 February (Luxembourg, Luxembourg), Alzheimer Europe organised a Company round table with its sponsors and member organisations.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 127, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

Austria: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP).
Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).
Bulgaria: Andrey Kovatchev (EPP).
Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomasić (ECR).
Cyprus: Costas Mavrides (S&D); Eleni Theocharous (EPP).
Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP).
Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D).
Estonia: Urmas Paet (ALDE).
Finland: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Mia Petra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP).
France: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D).
Germany: Angelika Niebler (EPP); Udo Voigt (NI).
Greece: Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL).
Cyprus: Lianna Nicolaou (S&D); Yorgos Kyriakides (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Sypromski (EPP); Eleftherios Synadinos (NI); Elisavet Vozemberg-Vrioni (EPP).
Hungary: Ádám Kósa (EPP).
Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers.
In 2011, the European Parliament encouraged the EU member states to set up national action plans on Alzheimer’s and other forms of dementia. Their objectives are wide-ranging: to reduce the risk of dementia but also to create a more inclusive society for affected people who will be more visible in aging European societies.

“In March 2016, the second Joint action on Alzheimer’s, known as ACOVE, was launched focusing on post-diagnostic support, use of medical products and care for family carers.

“The goal we want to reach one day is to be able to treat underlying disease and stop or delay cell damage, which leads to the worsening of symptoms. This vision requires financial support for research from the state but also enough volunteers to complete clinical trials, whose absence is often identified as one of the main obstacles”

Mr Mikolášík has also been active on this subject in the European Parliament, and was amongst a group of cross-party MEPs who submitted a written Parliamentary Question (E-006673-16) to the Commission on 2 September, 2016 to follow up on the Netherlands EU Presidency conference on dementia -“Living well with(out) dementia”. The group of MEPs asked the Commission the following:

Has this conference led to any concrete recommendations on how to move the European dementia agenda forward?

How is the Commission taking stock of the various recommendations that EU Presidencies have made on dementia and the findings of research programmes such as ACOVE — the EU Joint Action on Dementia?

Will the Commission propose a European dementia strategy in the near future?

On the 27 October 2016 Mr Andriukaitis, European Commissioner for Health and Food Safety, gave the answer below on behalf of the Commission:

The Commission works in close relationship with the Member States, through the Governmental Expert group on Dementia. Following the completion of the first joint action on Dementia
(ALCOVE), a second joint action on dementia under the EU-Health Programme was launched in March 2016. The new joint action focuses on post-diagnostic support, crisis and care coordination, quality of residential care and dementia-friendly communities.

The Commission further supports the European Innovation Partnership on Active & Healthy Ageing, which facilitates the exchange of good practices in prevention of frailty, integration of care and age-friendly environments, areas which highlight the importance of early diagnosis and screening for physical and cognitive decline, coordination of health and social care and support to patients and carers(1). These activities are in line with the Council Conclusions on ‘Supporting people living with dementia: improving care policies and practices’(2) and the conclusions of the Netherlands EU Presidency conference on ‘Living well with(out) dementia’(3). The Commission’s approach is to address all chronic conditions and determinants in a holistic manner, in line with the United Nations and the World Health Organisation actions on non-communicable diseases(4) and to support Member States implement good practices. As such, the Commission is not planning to develop a specific strategy on dementia.

On 31 January, The European Disability Forum (EDF), AGE Platform Europe and ANEC called in costs of medicines and the Council to explore new measures to control prices and to increase cooperation on access to medicines between Member States.

The report is an important step towards a renewed dialogue, to ensure no one is “left behind”, where access to medicines is concerned. The increase in costs of medicines and the reduction in health budgets make this a more important issue than ever. This is why the outcome of the vote on this report was so important in taking steps towards people having access to essential and affordable medicines, and towards properly addressing rare illnesses.

Ms Cabezón Ruiz, a member of the European Alzheimer’s Alliance (EAA) said:

“The pharmaceutical industry is one of the most competitive and profitable sectors in Europe. During the past few decades
prices of new medicines have risen to a level where they become unaffordable for many patients and threaten the sustainability of health budgets. Clearly, we have to review the pharmaceutical system to address the shortages of essential medicines, to move from profit-oriented to patient-driven research, to improve transparency of research data and costs and look into the potential of generics.”

2 February: European Commission publishes mid-term review of the European Disability Strategy

On 2 February, the European Commission presented its progress report on the implementation of the European Disability Strategy 2010-2020. The strategy is the main instrument to support the EU’s implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

As the EU population is getting older, the number of Europeans with disabilities is rising significantly. People with disabilities remain consistently disadvantaged in terms of employment, education and social inclusion, as discrimination is still a major obstacle.

This year Alzheimer Europe will continue to develop its European Dementia Ethics Network (EDEN) and will look at the ethical implications of recognising dementia as a disability.

The full report can be read here.

MEMBERS’ NEWS

26 January: Alzheimer’s Society UK unveils engaging new brand to make dementia impossible to ignore

Dementia is the biggest health challenge facing society today, but it doesn’t get anywhere near the attention it deserves. On 26 January, Alzheimer’s Society’s new brand was launched. A new brand that will make dementia impossible to ignore, and which matched our mission: to change the landscape of dementia forever.

Our previous brand achieved so much, and was well-respected, but people told us it was a bit passive, impersonal and cold. It wasn’t standing out and grabbing people’s attention. And that means we weren’t reaching everyone affected by dementia, and weren’t attracting the support we need to really make a difference.

It also didn’t reflect many of the people affected by dementia today. One of our ardent supporters, Shelagh, who is living with dementia, said: “Dementia often begins to show itself in the 70s. Think of what that means historically. We are the children of the 60s who listened to and loved the Beatles, The Rolling Stones. Is this reflected in the way we look at people with dementia?”

We involved people affected by dementia throughout the process of developing the new brand to make sure that we created something that was accessible and that resonated with them. This included referring to all available research on accessibility and dementia-friendly design.

One thing that came across loud and clear, in both our conversations with people affected by dementia and our research among supporters and members of the public, was the need for a tangible and meaningful icon that could be used to demonstrate their support for our cause and their solidarity with people affected by it. The forget-me-not flower – long-associated with dementia – was the natural and popular choice.

Our stylised forget-me-not and other elements of our visual identity, like the vibrant colour palette, reference graffiti, ‘Pop Art’ and grass-roots change, expressing the need to be bolder and disrupt the status quo.

Our new strapline – united against dementia – communicates that we all have a role to play in beating dementia once and for all. We are committed to driving forward the growing movement for change which has already seen over 1.8 million people become Dementia Friends and over 200 communities working to become dementia friendly.

Read more about how people affected by dementia redesigned our website here.

7 February: Dr Jannine Williams delivers lecture on Human Resource Management for Dementia Friendly Workplaces in Iceland

On 7 February, Dr. Jannine Williams (pictured), a lecturer in Human Resource Management and Organisational Behaviour at the University of Bradford School of Management, UK, delivered a lecture at The University of Iceland. Dr Williams was invited by Alzheimer Iceland to speak about “Developing Good Practice: Human Resource Management for Dementia Friendly Workplaces”.

She passed on current knowledge about working with dementia to the delegates and shared the findings she and her
colleague Dr Sue Richardson have so far and how they plan to proceed with their research. 

There is no doubt that more research is needed on working with dementia. Findings thus far reveal that people are expected to stop working shortly after they receive a dementia diagnosis and there is not much knowledge and/or support in the workplace.

The findings in Dr Williams’ research so far show, however, that it is quite possible to continue working with a dementia diagnosis if the individual and the workplace as a whole are willing to make some changes. They can be anything from minor changes in daily tasks to taking on another role within the company. The most important elements identified so far are: the inclusion of the team the person works most closely with and the open minded-ness of managers. As always, more knowledge and accessible information on dementia for co-workers and superiors increases the likelihood of people being able to continue working with dementia.

Alzheimer Iceland was very happy to meet Dr Williams and hear her thoughts on the matter. It hopes this will be the first step towards helping people with dementia continue to work for as long as they want to. For further information on the research please contact Dr Williams directly at j.williams20@bradford.ac.uk

9 February: Larissa Association of Alzheimer’s disease and related disorders opens new day care centre

On 9 February, the Larissa Association of Alzheimer’s disease and related disorders in Greece opened its new Day Care Centre for people with Alzheimer’s dementia, which will work with volunteers doctors, nurses, caregivers and has support from the Mayoralty Social Policy of the Municipality of Larissa.

9 February: CEAFA has revamped its website

The new design aims to provide website visitors with relevant information about Alzheimer’s disease (AD) and about CEAFA itself, as well as giving news updates on both. As well as the content, usability has been improved too, with an emphasis on easier, more intuitive navigation, making the site as a whole more accessible. 

http://www.ceafa.es/

15 February: The Alzheimer’s Society of Ireland represented at National Dementia Care Conference

On 15 February, Helen Rochford Brennan, member of The Alzheimer Society of Ireland (ASI)’s Irish Dementia Working Group, and Laura Reid, Vice-Chair of the ASI’s Dementia Carers Campaign Network, were on hand at Ireland’s National Dementia Care Conference to share their experiences and highlight issues affecting people with dementia and their families. Ms Rochford Brennan spoke passionately about the urgent need for Ireland to ratify the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and highlighted the Charter of Rights for People with Dementia, which was launched by the ASI and the Irish Dementia Working Group in 2016. Ms Reid highlighted her experience as a carer for her mum Nora, who is 63 years old and living with Posterior Cortical Atrophy, a rare form of dementia. During her presentation, she called for a “Fairer Deal for Dementia Carers”, one that would allow carers to support their loved to remain at home by providing access to adequate home and respite care. CEO Pat McLoughlin (pictured), also presented at the conference, providing an outline on the future of dementia care and highlighting the need for increased investment in home care for people with dementia. These presentations are available to watch on Periscope, just click here.

16 February: Association Luxembourg Alzheimer celebrates 30 years

This year, Association Luxembourg Alzheimer (ALA) celebrates its 30th birthday. 2017 also marks 25 years of the Fondation Alzheimer and 10 years since the opening of the association’s dementia nursing home and day care centre “Beim Goldknapp” in Erpeldange-sur-Sûre. To mark this momentous year, a variety of events are planned, involving the general public, healthcare professionals and people with dementia and their families. The programme
includes seminars, a birthday party, an art festival, an open day and an academic session, among others. Some of the highlights of the celebration will be:

A limited edition 30th anniversary stamp (pictured) will be available at national post offices as of 1 March. Seminars for families and professionals will take place in March and April.

On Luxembourg’s national day, 23 June, an art festival “Konschtfestival” will open in Lellingen. The theme will be “l’art rend visible” (art makes us visible) and exhibited works will be exclusively by people living with dementia.

On World Alzheimer’s Day (21 September), the Beim Goldknapp nursing home/day care centre will host a 10th birthday party, inviting the residents and their families.

On 23 September the ALA will host its annual Memory Walk, starting from the place Clairefontaine in the capital city of Luxembourg.

On 18 October, there will be a special seminar held, called “Donnons la parole aux spécialistes de la démence” (let’s hear from the dementia experts). People living with dementia will share their thoughts and experiences. The seminar will involve the speakers’ families and other carers and professionals and will particularly emphasise the importance of avoiding isolation and of supporting rather than taking control for people with dementia.

To see further details of what is planned, please see the attached PDF (in French), or visit the ALA website http://ala.lu/

17 February: Portugal now has a network of 13 Memory Cafés

In Portugal, the Memory Café Network is an initiative of Alzheimer Portugal and the company Sonae Sierra within the scope of its sustainability policies. It is supported by several institutional partners such as the Calouste Gulbenkian Foundation, the Montepio Foundation and the Institute of Health Sciences of the Catholic University of Portugal.

The Portuguese model is inspired by the English Memory Café concept and experience, because it is very widespread there and was identified many years ago as a well-suited activity for people with dementia and their caregivers.

The first two Portuguese Memory Cafes were opened in April 2013. In order to develop this initiative geographically, several local partners have joined the network, such as municipalities, third sector organisations, and companies from the business sector, who provide the necessary human resources, financial and logistical support for the sessions.

Alzheimer Portugal has also recruited and trained 322 volunteers who have dedicated 7,888 hours to this project so far. This spirit of partnership and community commitment is one of the main factors to which Alzheimer Portugal attributes the success of this project.

In Portugal, Memory Cafés are helping to reduce social isolation and improving quality of life for many people with memory problems or dementia, as well as for their respective family members and caregivers. The Cafés also have a role in raising awareness about dementia, reducing the stigma that is still too prevalent in the country.

Today, there are 13 Memory Cafés in Portugal. From the launch of the project in 2013 until the end of 2016, 290 sessions have been held and the Portuguese Memory Cafés have so far included 1,586 participants and a total of 5,095 appearances, most of these from family and caregivers of people with dementia. In 2017, Alzheimer Portugal plans to continue to expand this project to other areas.

Another current objective is to conclude a research study about the impact that attending Memory Café sessions has on caregivers and volunteers’ lives. The hope is that the results of this study will contribute to reinforcing and spreading this initiative in Portugal and other European countries.

18 February: First Croatian textbook on Alzheimer’s disease is published

Croatia has received its first university textbook on Alzheimer’s disease called “Alzheimer’s disease and other dementias - early detection and protection of health” (Medicinska Naklada, Zagreb, 2017. ISBN: 978-953-176-767-5). The need for such a book was initiated by the Alzheimer Croatia and the Office of health of the City of Zagreb.

Among the authors, distinguished members of the Alzheimer Croatia stand out: N. Mimica, M. Kušan-Jukić, M. Dajčić, as well as M. Boban, F. Borovečki, N. Klepac, P. Presečki and G. Šimić. As stated in the preface, this textbook is aimed at students and professionals who deal or will deal with the protection of health of geriatric and psychogeriatric patients with Alzheimer’s disease, including students and postgraduates in medicine and specialists in dementia care, ranging from general practitioners and nurses to specialists in family medicine, geriatrics, neurology, psychiatric and geriatric nursing, as well as social workers, physical and occupational therapists, nutritionists, dentists and finally lawyers involved in the protection of the elderly people.

20 February: Norwegian Health Association awards 2017 Dementia Research Award to Professor Tormod Fladby

The Norwegian Health Association’s annual Dementia Research Prize has been awarded to Professor Tormod Fladby (pictured).

Prof. Fladby (57) was awarded the
prize for his work identifying risk factors using biomarkers in cerebrospinal fluid and the use of PET. His research has helped improve diagnostics and clinical treatment. Prof. Fladby has excelled in combining scientific work in the field of Dementia and Neurology, with clinical practice. He was among the first to investigate the link between Alzheimer’s disease and cardiovascular diseases.

He currently works as Senior Consultant and Head of The Department of Neurology at Akershus University Hospital, Norway. The Professor had a central role in founding The Norwegian Neuropsychiatric Association. He is also Chair of Nansen Neuroscience Foundation.

Prof. Fladby’s work is recognised globally and his academic work has been widely published. His contribution towards the creation of a scientific environment for Dementia Research has been of great significance in furthering the understanding and treatment of patients with dementia.

**21 February: The Alzheimer’s Society reports on UK Sustainability and Transformation Plans**

The Alzheimer’s Society sees the integration of health and social care, through England’s new Sustainability and Transformation Plans (STPs), as a unique opportunity to transform care and support for people affected by dementia.

George McNamara (pictured), the Society’s Strategic Lead for Integration, confirmed, “The Society believes that STPs can help to resolve the complex web of care, which can result in people with dementia navigating up to 20 services to receive the care they need. These plans can also help in the development of dedicated support for those affected by dementia through new specialist teams.”

The STPs take forward an agenda for integrated health and social care that has featured in national government policy for the past two decades. The 44 STPs across England are the key initiative of NHS England’s shared vision, the Five Year Forward View (FYFV), launched in 2014. The FYFV looks to deliver new ways of working in order to provide better outcomes for service users and communities, and resolve systemic challenges relating to fiscal and performance-related objectives.

Integrated care for dementia is already being delivered in some European states, such as the Netherlands. These examples provide the Society with valuable insight into the potential gains for people with dementia through the development and delivery of integrated care.

The Alzheimer’s Society has created an animation outlining its vision for integrated dementia care and support and is engaging with STPs to call for all sites to:

- Commit to improving dementia provision across the whole dementia care pathway
- Engage with leading dementia care and support providers
- Co-produce and co-design all plans with people with dementia
- Appoint a Dementia Champion in the governance structure to make the case for dementia

The Society aims to ensure dementia is a priority for STPs and is looking to support sites to improve local dementia care. The Alzheimer’s Society will continue looking to best practice across Europe to evidence how this can be most effectively achieved and highlighting that the complexity of dementia means an integrated system working for people with dementia will work for everyone.

See the animation [here](#).

**21 February: Alzheimer Hellas co-organises two successful conferences in Thessaloniki**

Alzheimer Hellas, in cooperation with the Panhellenic Institute of Neurodegenerative Diseases, successfully organised the 10th Panhellenic Conference on Alzheimer’s disease and Related Disorders (PICAD) and the 2nd Mediterranean Conference on Neurodegenerative Diseases (MeCoND), which took place during February in Thessaloniki, Greece.

The combination of these two conferences a) hosted the most renowned scientists in the field, who presented and shared the results of the latest scientific research, pharmaceutical and non-pharmaceutical trials and the application of new technologies, and b) provided an opportunity for various healthcare professionals to present their contribution to patients and caregivers.

Over 650 clinicians (neurologists, psychiatrists and geriatricians), neuroscientists (molecular geneticists, neuropathologists, neurobiologists, neuropsychologists and pharmacists), psychologists, social workers, physiotherapists and representatives from biomedical and pharmaceutical companies, patients, families and their caregivers participated in the conferences.

During the conferences, several themes in relation to dementia were developed, such as: new technologies, newer data, legal and social issues, research programmes, day care centres, non-pharmaceutical interventions etc. 335 papers were presented at 69 roundtables, 17 lectures were given, 10 workshops, 18 debates and 26 poster presentations.

Professor Magda Tsolaki, the Chair of the conference organising committee and the President of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders said: “It was another very good opportunity for health professionals, patients, caregivers and stakeholders, to meet each other, exchange new experiences, new knowledge and future directions. More than 650 participants joined their efforts in order to improve the quality of life of Greek, Cypriot...
and other Mediterranean people with Alzheimer’s and related disorders and their caregivers”.

21 February: Alzheimer Society of Finland offers insight into the views of people with memory diseases on social engagement

The Alzheimer Society of Finland (Muistiliitto) conducted a small-scale online study (n=50) during 2016, which examined the social engagement of people with younger-onset memory diseases (dementia). Responses made both alone and in cooperation with another person were accepted. The survey addressed ten themes, such as feelings of social exclusion, decision-making opportunities, employment after diagnosis, and the role in the family.

Even though only a few respondents were able to continue working with memory diseases, the survey results show that, according to most of them, life with memory diseases wasn’t that much different from what it was before. Most felt that their role in their family, possibility to pursue hobbies, and their right to independent decision-making hadn’t changed, when compared with the time before their diagnosis. However, the respondents emphasised that there is still work to be done on awareness raising, when it comes to issues with younger onset memory diseases in general. Because of the small amount of responses, the results aren’t generalisable, but nonetheless, they offer knowledge of real-life experiences from a group whose views hasn’t been visible enough so far.

The Alzheimer Society of Finland has also gathered professionals from its network of Memory pilot experts and support centres, to strengthen the participation of people with memory diseases in their work. This was a start of a year-long process during which the network will create a shared vision of participation and compile the tools to strengthen and promote the social engagement of people with memory diseases.

21 February: The Alzheimer Society of Finland publishes support materials for children and teenagers

The Alzheimer Society of Finland has published three brochures for children of different ages, whose have a parent/s living with a memory disease.

For small children, there is a fairytale called “Island of the Seahorse”; for older children, there is a comic book “When Daddy Forgot”; and for teenagers there is a brochure on “Memory Disease in the Family”.

The aim is to help children and the whole family to go through the issues and emotions caused by a parent’s memory disease, using children’s language.

These brochures, written in cooperation with a family psychotherapist, have proved to be a useful tool for memory associations, school nurses and other health professionals. They are available in Finnish and Swedish.

23 January: Jersey launches Disability Strategy Consultation

Jersey Islanders are being asked for their views on proposals which will form the basis of a Disability Strategy for Jersey.

A consultation document has been put together after extensive research and discussion with key organisations and individuals throughout 2015 and 2016. Research included the Health and Life Opportunities household survey, which looked at the profile and prevalence of disability in Jersey and went out to more than 10,000 households. The research also included a large qualitative study that involved talking to nearly 100 islanders about their experience of living in Jersey with a disability.

The strategy is for the whole island and as such, seeks to engage islanders as well as the business and voluntary and community sectors. It focuses on improving the overall wellbeing of islanders and its aim is to help ensure people living with disability in Jersey enjoy a good quality of life. It identifies five priority areas:-

- supporting communication and access to information
- having greater access to the Island
- good health and wellbeing
- access to education, employment & enriching activities
- equal rights and equality.

A series of actions have been proposed by the States to help achieve these priorities. The actions that are being consulted on reflect what disabled people, carers, friends and families have said would help them to enjoy a good quality of life. Alongside the strategy, later this year, work will begin on the development of disability discrimination legislation, which should come into force in 2018. Disability will become one of the ‘protected characteristics’ under the Discrimination (Jersey) Law 2013.

Islanders can give their views on the proposals by viewing the online consultation document and completing an online survey on www.gov.je/consult before 10 March 2017.

27 February: Ireland campaigns to ratify CRPD

Ireland is the only country in the European Union not to have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). All other Member
States and the EU as a whole have ratified the treaty. The Netherlands and Finland were the latest countries to ratify the CRPD in 2016. The CRPD promotes, protects and strengthens the human rights of all people with a disability throughout the world. There are laws that need to change to make sure Ireland can fulfil all of the human rights of people with disabilities before it can ratify the Convention. However the Irish government said this would be done before the end of 2016 but ten years after it was adopted by the United Nations (UN), Ireland still hasn’t ratified the CRPD. A petition is now underway in Ireland to push the Government to ratify the treaty which would show that it is fully committed to an equal society where the human rights of people with disabilities are fully respected and upheld. The Alzheimer’s Society of Ireland is supporting this petition. It is important to make sure the rights of people with dementia are also recognised. The petition can be signed [here](#).

**BEHIND THE HEADLINES**

15 February: Signs of dementia found in the brains of football players – Alzheimer’s Society UK comments

There were a number of media reports on 15 February, saying that signs of dementia have been found in the brains of a small number of former footballers. Four of the footballers studied had signs of a form of dementia called chronic traumatic encephalopathy, which has previously been linked to head injuries sustained during collision sports such as boxing and American football. So far there is not enough evidence to know whether head injuries that occur during football, such as when heading the ball, are linked to an increased risk of dementia.

**What did the research show?**

The study involved 14 former footballers with memory problems who were identified by the Old Age Psychiatry Service in Swansea, Wales, UK. The researchers gathered clinical information about the footballers, including the number of head injuries they sustained that resulted in a concussion. The brains of six of those footballers were examined by the researchers after they passed away. It was found that four of the people examined had signs of a form of dementia called chronic traumatic encephalopathy (CTE). All six of them also had signs that indicated the presence of Alzheimer’s disease.

**What do these results mean?**

Whilst the study showed evidence of dementia in the brains of former footballers, the results do not prove that head injuries sustained during football lead to an increased risk of dementia. Perhaps the most important question to answer is whether footballers are at a greater risk of dementia than the general population. This study can’t answer that question, but a few small studies have looked at the evidence and found that footballers do not appear to be to have a higher risk of dementia. It is also important to note that the number of people studied was very small. In order to draw informed conclusions, we need to see data from a large number of people - preferably hundreds. Another point is that the study presented today also only looked at the brains of footballers who had memory problems. We need to compare these results with those from footballers who did not have memory problems in order to understand the differences between these two groups.

There is also a large amount of essential information that is missing from this study. We do not know anything about the footballers’ genetics, or detailed aspects of their lifestyle. These factors are both known to influence a person’s risk of dementia. Without this knowledge, it is hard to unpick whether head injury could have contributed towards the dementia that these players experienced.

Other issues that need to be taken into account include whether there is a difference between using older, heavy leather footballs and modern, lighter footballs. The person’s age when they first start playing may also be a factor in how their brains respond to injury. The type of injury also needs to be taken into account – whether it is heading the ball that is the main cause of injury or whether it is due to other collisions that occur during the game. We also need to account for other injuries sustained outside of the sport.

**What will happen now?**

It is clear that the link between playing football and dementia requires further investigation. The issues outlined above will all need to be addressed before we can make any conclusions regarding football and dementia. There is a long road ahead though, with barriers in areas like funding, resources and finding participants to take part in research that will need to be overcome.
What does this mean for people who currently play football?
There is currently not enough evidence to be able to give any advice surrounding playing football and risk of dementia. Evidence shows that exercise is one of the best ways to reduce your risk of dementia, and it is important that everyone playing any kind of sport can do so safely.

https://blog.alzheimers.org.uk/research/signs-of-dementia-found-football-players/

**SCIENCE WATCH**

18 January: INTERDEM editorial on social health in dementia published in Aging & Mental Health journal

On 18 January, a special issue of the journal Aging & Mental health (A&MH) was published, including an editorial by two researchers from the INTERDEM network - Rose-Marie Dröes and Marjolein de Vugt. This special edition was on social health in dementia and the editorial was titled “Social health in Dementia. Towards a positive dementia discourse”.

You can read the full editorial and access the special edition of A&MH here:

28 January: Recent study reveals a subtype of astrocytes may contribute to neuron death in brain injury and diseases

In a study published in the journal Nature on 26 January, scientists from Stanford University School of Medicine in California, US and the University of Melbourne, Australia reported that astrocytes may contribute to damaging and destroying neurons, instead of helping them during injury or disease. Astrocytes, the most numerous cell type within the brain, are considered to provide support and guidance to neurons. Over the past several decades, astrocytes have been recognised as support cells having a wide variety of diverse roles in the healthy as well as in the injured brain.

Following inflammation or disease, astrocytes undergo morphological changes to become reactive astrocytes with altered features. Previous findings have reported two forms of reactive astrocytes: A1 and A2 astrocytes.

In the published study, the researchers revealed that under certain conditions a subtype of reactive astrocytes could transform into a highly toxic state and kill other types of brain cells. The authors found A1 astrocytes in a variety of injuries and disease including Alzheimer’s disease. They suggested that A1 astrocytes may be harmful. Indeed, these cells lost their ability to promote neuronal survival and could induce the death of neurons and oligodendrocytes. In addition, inhibition of A1 astrocyte formation prevented death of neurons.

http://www.nature.com/nature/journal/v541/n7638/full/nature21029.html

30 January: Small biotechnology company Accera is advancing its AD treatment Phase 3 clinical trial

Accera is a US clinical stage biotechnology company developing therapies for neurodegenerative disease including Alzheimer’s disease (AD). Research findings have shown that people with AD have a deficiency of brain glucose metabolism, so the company is looking to address the low levels of glucose through the use of ketone bodies - an alternative energy source to the brain. Accera’s product candidate AC-1204 is an orally administrated therapy containing medium chain triglycerides able to stimulate ketone production.

A previous Phase 2 study revealed an improvement in cognition, correlated with increased levels of ketone bodies. Accera is advancing its first sequential Phase 3 study to determine the drug’s efficacy. AC-1204 is currently being studied in approximately 400 participants during 6 months. The clinical trial is a randomised, placebo-controlled and double-blind study, assigned for people with mild to moderate AD. Associated data is expected in March and there is already a second pivotal Phase 3 study planned for a further 6 months, to measure the response durability.

http://medcitynews.com/2017/01/accera-phase-3-trials-alzheimers-disease/?rf=1

31 January: Research suggests brain metabolism might benefit from grape consumption

Research funded by the California Table Grape Commission has examined the effect of grape consumption on brain metabolism and cognitive skills.

The article, published in the January 2017 edition of the journal Experimental Gerontology, discussed the effects of 72g of daily grape intake during 6 months in people with mild decline in cognition.

Grapes contain (i.a.) a natural compound called resveratrol, which is known for its antioxidant and anti-inflammatory properties. Oxidative stress, which can be reduced through the consumption of anti-oxidants in foods, leads to accelerated ageing.

The scientists, from the University of California, Los Angeles, US conducted the study with a very small sample of 13 individuals ranging from 66 to 82 years of age, either ingesting a placebo or grape powder. Three of the participants withdrew during the study, leaving only ten datasets to analyse. A plus for the quality of the study was that, during the experiment,
neither the participants nor the experimenters knew who was administering the placebo and who was taking the grape powder. The brain scans led to the assumption that grapes may provide metabolic benefits for consumers. They showed a metabolic decline in the placebo group and no significant change in decline of brain metabolism in the grapes group. No significant differences in cognitive performance was seen between the two groups.

This study cannot yet be considered as a reliable recommendation to boost brain metabolism through the consumption of grapes, as compared with a healthy diet. Future research with larger samples, including additional information on the participants’ diets and following up over a longer period of time might help to elucidate further information.

http://dx.doi.org/10.1212/WNL.0000000000003577

31 January: Study suggests strong link between antiretroviral drugs and neuronal damage

Scientists at the University of Pennsylvania, US have completed a study, showing that the use of some HIV treatments may have toxic effects on the brain. Although protease inhibitors are effective antiviral HIV therapies (reduced mortality by 50%), some of them have side effects including damage to neurons. Indeed, antiretroviral drugs may lead to the production of beta amyloid, a protein associated with Alzheimer’s disease (AD) and thought to be responsible for neuronal degeneration.

The study, published in the January 2017 edition of the American Journal of Pathology, was led by Professor Kelly Jordan-Sciutto. Prof. Jordan Sciutto and her team used two types of animal model (macaque and mouse) to demonstrate that the protease inhibitors ritonavir and saquinavir led to the production of the beta amyloid peptide. In fact, its expression was significantly upregulated in treated groups compared to controls. In addition, the same results were observed in cultures, when drugs were administrated to rodent neuroglia and Chinese hamster ovarian cells. Additionally, the inhibition of the enzyme responsible for beta amyloid production was shown to protect against neuronal damage.

“Our findings may cause us to rethink how we’re using these drugs and even consider developing an adjunctive therapy to reduce some of these negative effects”, Prof. Jordan-Sciutto commented.

http://ajp.amjpathol.org/article/S0002-9440(16)30409-6/abstract

8 February: Research on the roundworm might lead to new approaches to address neurodegeneration

On 8 February, researchers from Rutgers University, US published findings on problems that occur in the brain cells of roundworms, in the journal Nature. The research team from The State University of New Jersey carefully investigated roundworms, engineered to produce human disease proteins associated with Huntington’s disease and Alzheimer’s disease.

Their investigation led them to the interesting observation that the neurons of the engineered worms threw out more “trash” consisting of neurodegenerative toxic materials. These materials were degraded to some extent by neighbouring cells, but more distant ones seemed to scavenge a part of it, which caused them to die.

A more refined assessment of the exact mechanism behind the disposal of neurodegenerative toxic materials and the uptake through neighbouring cells could eventually lead to a new approach to address neurodegeneration.

http://www.nature.com/nature/journal/v542/n7641/full/nature21362.html

8 February: Lundbeck experimental AD drug candidate fails in two late-stage clinical trials

On 8 February, Danish pharmaceutical company Lundbeck announced that its experimental Alzheimer’s disease (AD) drug idalopirdine failed in its two remaining Phase 3 trials, STARBEAM and STARBRIGHT. Idalopirdine, also known as Lu AES8054 is a selective 5-HT6 receptor antagonist. This receptor is mainly expressed in brain regions involved in cognition and the drug aimed to treat the cognitive deficits, which are an AD characteristic.

The STARBEAM study compared a dose of 10 mg to 30 mg once daily and the STARBRIGHT study compared 30 to 60 mg once daily. These programmes enrolled people with mild to moderate AD during 6 months. The failure of these two latest Phase 3 trials does not come as a surprise. In September 2016, the company had announced that the drug candidate failed its first Phase 3 study STARSHINE. In this clinical trial, people with mild to moderate AD were assigned to receive 30 or 60 mg of idalopirdine or...
placebo once daily. Although the drug was reportedly safe and well-tolerated, it failed to show efficacy and significant improvements compared to the placebo.

The Phase 3 results are in contrast with positive Phase 2 results, which had been very encouraging. The company expects to present details of the failed studies later this year.

On 8 February, researchers from the Lund University in Sweden published an article on the relationship between beta-amyloid plaques and gut bacteria, in the journal Scientific Reports.

At the beginning of their study they assessed the gut microbiota composition in both healthy and diseased mice. In the diseased mice beta-amyloid plaques occurred, which are directly related to neurodegeneration in Alzheimer’s disease (AD).

In the first instance the scientists found that the composition of gut bacteria is different in both groups. In order to further investigate the link between the bacteria and the illness, they also studied mice that completely lacked bacteria.

The first thing they noticed was that the mice without any intestinal bacteria had smaller amounts of beta-amyloid plaques in their brain. The researchers then investigated further and transferred gut bacteria from the diseased mice to the so far bacteria-free mice. The result was that the mice then developed more plaques than before.

These findings led the team to the conclusion that a precise analysis of the role of bacteria in AD could potentially lead to new types of preventive strategies. Because of this the research group expanded and now includes researchers from Germany and Belgium. The new collaboration received a SEK 50 million (EUR 5.27 million) EU grant and will continue further investigation.

On 13 February, Axovant Sciences announced that nelotanserin has demonstrated positive preliminary results on the first 11 people with Lewy body dementia involved in the Phase 2 study. Preliminary results showed treatment benefit with significant improvements for nelotanserin compared to placebo. Signs of dementia were evaluated through interview and clinical observations such as a motor examination and evaluation of activities of daily life (speech, hygiene, handwriting, etc.). In addition, no major side effects were reported.

This clinical trial was a randomised and double-blind study including people with either Lewy body or Parkinson’s disease dementia. Participants received the drug or the placebo once-daily by oral administration.

The company plans to expand patient recruitment and to present detailed results at a meeting during 2017. Furthermore, the company expects to begin its Phase 3 study in the second half of the year.

The recent introduction of a chocolate pill containing concentrated flavanols, raised a lot of media attention. Some newspapers even hailed it as the new dementia pill. But what do we really know about its benefits?

An article published in June 2013 in the journal Neuroscience and Biobehavioral Reviews, took a closer look at benefits related to cocoa consumption. The overview, conducted at the University of Tübingen, Germany concluded that this research field is still at an early stage. Studies have shown that, indeed, cocoa products contain potent antioxidant and anti-inflammatory agents with established benefits for cardiovascular health. On the other hand, evidence about more immediate action of cocoa flavanols remains limited and inconclusive, but warrants further research.

The European Food Safety Authority (EFSA), funded by the European Union, provides scientific advice to member authorities on existing and emerging risks in food safety. In July 2014, the EFSA recognised that a cause-and-effect relationship exists between the consumption of flavanols and the preservation of elasticity of blood vessels in humans. According to their conclusion, at least 200 mg of cocoa flavanols would need to be consumed daily, to obtain the claimed effect.

Following on from this and other previous results, researchers from Harvard Medical School and Brigham & Women’s Hospital are launching a large scale, four-year, 18,000-person, randomised controlled trial called “COSMOS”. The name is derived from “COCoa Supplement and Multivitamin Outcomes Study.” The study aims to determine whether cocoa extract or a multivitamin can reduce the risk of cancer, heart disease, stroke, cognitive decline, diabetes and hypertension.

https://doi.org/10.1038/srep41802

FEBRUARY 2017

13 February: Axovant presents positive preliminary results from experimental dementia drug Phase 2 study

Axovant Sciences is a clinical-stage biopharmaceutical company developing novel therapeutic solutions to treat dementia by comprehensively addressing the cognitive, behavioural, and functional components of dementia. The company is currently developing a novel compound, nelotanserin. This investigational drug candidate is a potent and highly selective inverse agonist of the SHT2A receptor, a serotonin receptor associated with motor symptoms and neuropsychiatric disturbances including visual hallucinations.

On 13 February, the company announced that nelotanserin has demonstrated positive preliminary results on the first 11 people with Lewy body dementia involved in the Phase 2 study. Preliminary results showed treatment benefit with significant improvements for nelotanserin compared to placebo. Signs of dementia were evaluated through interview and clinical observations such as a motor examination and evaluation of activities of daily life (speech, hygiene, handwriting, etc.). In addition, no major side effects were reported.

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The company plans to expand patient recruitment and to present detailed results at a meeting during 2017. Furthermore, the company expects to begin its Phase 3 study in the second half of the year.

13 February: EU regulators have approved cocoa as a medicinal food, but can it improve cognition?

The recent introduction of a chocolate pill containing concentrated flavanols, raised a lot of media attention. Some newspapers even hailed it as the new dementia pill. But what do we really know about its benefits?

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14 February: Merck halts late-stage trial of its AD drug due to lack of efficacy

On 14 February, the US pharmaceutical company Merck - known as MSD outside the United States and Canada - announced the halt of its experimental Alzheimer’s disease (AD) drug verubecestat in a late-stage trial. This Phase 2/3 study, also known as the EPOCH study, was a randomised and double-blind study for people with mild to moderate AD. The purpose of the trial was to evaluate the safety and efficacy of two oral doses of verubecestat (12 and 40 mg) administered once daily.

Merck halted the study following the recommendation of an external data monitoring committee. The independent monitors determined no chance of a positive result and recommended ending the study.

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. Merck said its APECS study, which is evaluating verubecestat in people with prodromal AD, would continue and results are expected in February 2019.


20 February: Pre-Conference Workshop at World CNS Summit paves the way for a Europe-US platform on AD

On 20 February, in Boston, US the Pre-Conference Workshop Day of the World CNS Summit 2017 took place, aiming at discussing the basis of a roadmap to improve the cooperation for joint calls and shared protocols, placebo databases, analysis tools, and other resources among pre-competitive European and US Public-Private entities leveraging open science for the discovery of novel targets and development of effective biomarkers for use in drug development against Alzheimer’s disease (AD). These entities comprise the European Innovative Medicine Initiative (IMI) as well as important stakeholders based in the US such as the National Institute on Aging (NIA) and National Institute of Health (NIH), Coalition Against Major Diseases (CAMD/C-Pat), National Institute on Aging (NIA) - National Institute of Health (NIH), Accelerating Medicines Partnership - Alzheimer’s Disease (AMP-AD).

20 February: Recent study reveals that CCR5 activation by HIV proteins could contribute to cognitive deficits

In a recent study published in the journal eLife, scientists from Cardiff University, UK and the University of California, US reported that a mouse model with better memory lacked a type of protein called the C-C chemokine receptor 5 (CCR5).

Previous findings have underlined the role of CCR5 in inflammatory responses and in the human immunodeficiency virus (HIV) infection. Indeed, HIV can bind and activate CCR5 to infect immune cells and create inflammation. It has also been shown that this protein could affect the brain and could be involved in AIDS-related dementia.

In the published study, the researchers revealed an important suppressor role for CCR5 in learning and memory. The scientists demonstrated that animals with better learning and memory lacked the CCR5 protein, while the overexpression of this receptor causes learning and memory deficits.

Cardiff University’s Professor Kevin Fox, a senior author on the paper, explained: “Armed with the new knowledge that the CCR5 protein in neurons affects learning and plays a major role in AIDS-related dementia, we can now look at ways to...
suppress it for treatment of the disease and investigate whether its reduction can also benefit other forms of dementia and even aid recovery for stroke victims.”

The original research paper, “CCR5 is a suppressor for cortical plasticity and hippocampal learning and memory” was published in eLife on 20 December 2016.

https://elifesciences.org/content/5/e20985

23 February: Sugar’s “tipping point” may be linked to Alzheimer’s disease

On 23 February, scientists from the University of Bath, UK, in collaboration with King’s College London, published an article about the molecular link between blood sugar glucose and Alzheimer’s disease (AD) in the journal Scientific Reports.

Preceding research has shown that people with diabetes have a higher risk of developing AD, when compared to the general population. It was also already known that glucose (a form of sugar) and its products can damage proteins in cells through a reaction called “glycation”. So far, however, the link between AD and glucose has remained unclear.

During their study, funded by the Dunhill Medical Trust, the researchers (pictured) specifically examined brain samples of people with and without AD, using a special technique to detect glycation.

In their article, the team described how they discovered that in the early stages of AD, glycation harms an enzyme called MIF (macrophage migration inhibitory factor). MIF is usually a part of the immune response to abnormal proteins in the brain.

During their examination it seemed that, as AD progressed, glycation of the enzyme increased, which caused it to lose some of its functions. According to the researchers, this insight will be vital to develop a chronology of how AD progresses, and they hope it will help them to better identify people at risk as well as lead them to ways to prevent the disease.

https://doi.org/10.1038/srep42874

LIVING WITH DEMENTIA

EWGPWD member Nina Baláčková writes about her trip to Asia Pacific Alzheimer’s conference

At the Conference of ADI in Budapest I was invited by the Chairperson of the Alzheimer Society New Zealand to the Asia Pacific Alzheimer’s Conference. It took place in Wellington in November 2016.

There were many specialists from the whole world at that conference, as usual at such big conferences. I was happy to meet many people with dementia and their carers, mainly from New Zealand, Australia and my colleagues from Dementia Alliance International. I heard their useful and interesting information about the Alzheimer’s Society of New Zealand and Australia too. For example I was surprised to hear that there were some cases of late diagnosis of dementia. The family and friends realised that their loved ones are changing - worse memory, sometimes bad orientation in place and time, no patience. But their tests at the doctors were good. Only after 2-3 years the doctor reached a diagnosis of dementia!

At one workshop, patients with dementia complained how difficult it is for them when they need to be in the hospital. Then I was proud to share my experience from the Czech Republic. As I was in the hospital in summer last year and all the staff spoke slowly and clearly with me, explained to me everything. I felt very comfortable and with dignity, not like several years ago. Later I realised through the Czech Alzheimer’s Society that some hospitals educate their staff about how to speak and act with people with dementia. Travelling so far away was tiring, but the Conference was great. I was grateful to be there.

Nina Baláčková, member of the EWGPWD, Czech Republic.

“Getting involved in Cultural Activities even when we have Dementia” - by Idalina Aguiar, member of the EWGPWD

This text was written with the visual aid of photos of the event described and supported by the psychologists that work with me during cognitive stimulation sessions.

In January 2017, I visited the Ethnographic Museum of Madeira (pictured) with other people with dementia that attend activities in the Madeira Delegation of Alzheimer Portugal.

We know that many people with dementia often don’t participate in social activities, and reason can be the stigma and the fear. I know we must combat it. I never left these kinds of activities and my family and friends have always motivated me to do anything I loved to do.

Last Christmas, me and my colleagues in the Delegation built a recycled Christmas Tree for the Ethnographic Museum of Madeira. I had an idea: Visit the Museum (that is a little far away from where we are), combat the stigma showing that we are willing to participate in social activities, and to talk about European Working Group of People with Dementia (EWGPWD), to which I belong.
My proposal was very well received and everybody got excited. I felt that I was doing something for the people with dementia and their integration in society.

My colleagues in the Delegation loved the trip and as soon we got to the museum, the other visitors and the community that were present there (the museum receives students from local schools) were very curious about us and some exclaimed “do they really have dementia?” Yes, we have, but we are still people involved in their society.

We loved visiting the recycled Christmas tree exhibition, and we could identify ours and then we saw the permanent collection. With this last visit, we remembered how life was many years ago, how we cooked in old kitchens, how the ladies knitted big rugs...So it was a visit to show how we exist and love these cultural visits and to remember.

At the end, I explained what the EWGPWD is, and the work of this group.

Idalina Aguiar, member of the EWGPWD, Madeira, Portugal.

2 February: Alzheimer’s Society UK publishes dementia guide

A new dementia guide published by the Alzheimer’s Society UK is intended for anyone who has recently been diagnosed with dementia. It aims to help people understand more about dementia and the treatments, support and services that are available to them. It includes information about how to live as well as possible with dementia and about making plans for the future. It also contains helpful information for anyone taking on a caring role.

The dementia guide existed previously, but has been updated to include sections on living alone, technology, coming to terms with a diagnosis, communicating and changes to relationships.

For more information or to download this second edition of the guide, visit:

https://www.alzheimers.org.uk/info/20111/publications_about_dementia/790/the_dementia_guide?source=CHAINmail

3 February: University of Nottingham Dementia Centre publishes The Dementia Quality of Life Scale for Older Family Carers

The University of Nottingham’s Dementia Centre has published its Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) - an age- and dementia-specific, multidimensional and validated tool for measuring subjective quality of life in older family carers of people living with dementia.

The DQoL-OC is a 22-item scale that measures the impact of caregiving on the quality of older family carers’ social relationships; financial situation; psychological health; independence, control over life events, and freedom; leisure, social, and solo activities; physical health; general health; energy and vitality; satisfaction with life and caregiving; identity; and life in general.

http://www.nottingham.ac.uk/research/groups/dementia/projects/dqol-oc/index.aspx

NEW PUBLICATIONS AND RESOURCES

31 January: EUPATI issues guidance on patient involvement in R&D

In January, the EUPATI project published a set of guidance documents to facilitate patient involvement in research and development (R&D). The documents focus on interactions between patients and regulatory agencies, health technology assessment (HTA) bodies, ethics committees and the pharmaceutical industry.

The guidance documents suggest approaches to allow structured interaction with patient organisations at national and European level and will support the integration of patient involvement across the entire process of medicines research and development.

They were developed on the basis of an extensive consultation with patient advocacy groups, regulators, pharmaceutical companies, HTA bodies, academic groups and clinicians, and incorporate feedback gathered during these reviews.

https://www.eupati.eu/guidance-patient-involvement/

JOB OPPORTUNITIES

9 February: NUI Galway seeks established Chair in Nursing

Dementia research and research in healthy and active ageing is one of the key research areas in the School of Nursing & Midwifery at the National University of Ireland, Galway (NUI Galway).

The School is seeking an academic leader and scholar to become the Established Chair in Nursing in the School of Nursing & Midwifery at NUI Galway. Salary: €106,515 to €136,275 p.a.

Closing date for receipt of applications is 17:00 (Irish Time) on 30 March 2017.

For more information and Application Form please see http://www.nuigalway.ie/about-us/jobs/
### AE CALENDAR 2017

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
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<tr>
<td>1 March</td>
<td>AE Public Affairs meeting (Luxembourg, Luxembourg)</td>
<td>AE Board and staff</td>
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<tr>
<td>2 March</td>
<td>PACE (telephone conference)</td>
<td>Dianne</td>
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<tr>
<td>3 March</td>
<td>EFPIA Think Tank, (Brussels, Belgium)</td>
<td>Vanessa and Cindy</td>
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<tr>
<td>6-7 March</td>
<td>PredictND (Copenhagen, Denmark)</td>
<td>Jean and Dianne</td>
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<tr>
<td>14 March</td>
<td>European Brian Council, Brain Awareness Week lunch debate (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>14 March</td>
<td>PredictND Interim review meeting (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>14-15 March</td>
<td>HCPWP Joint meeting organised by the European Medicines Agency (London, UK)</td>
<td>Ana</td>
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<tr>
<td>15-16 March</td>
<td>IMI Meeting “Collaboration in Alzheimer’s disease” (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>16 March</td>
<td>Expanding brain research in Europe – A societal need? (Strasbourg, France)</td>
<td>Vanessa</td>
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<tr>
<td>16-17 March</td>
<td>MOPEAD (Brussels, Belgium)</td>
<td>Jean and Chris</td>
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<tr>
<td>16-17 March</td>
<td>JA meeting on residential care (Sofia, Bulgaria)</td>
<td>Dianne</td>
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<tr>
<td>23-24 March</td>
<td>ROADMAP (Barcelona, Spain)</td>
<td>Jean, Dianne and Chris</td>
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<tr>
<td>29 March</td>
<td>Human Brain Project (webinar)</td>
<td>Dianne</td>
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<tr>
<td>30 March – 01 April</td>
<td>M&amp;I Spring Forum 2017, Paris, France</td>
<td>Gwladys</td>
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<tr>
<td>31 March</td>
<td>Actifcare (Brescia, Italy)</td>
<td>Dianne</td>
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### CONFERENCES 2017

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
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<tbody>
<tr>
<td>23-26 March</td>
<td>11th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmed.com/cony/2017/default.aspx">http://www.comtecmed.com/cony/2017/default.aspx</a></td>
<td>Athens, Greece</td>
</tr>
<tr>
<td>29 March-2 April</td>
<td>13th International Conference on Alzheimer’s and Parkinson’s Diseases and Related Neurological Disorders (AD/PD), <a href="http://adp2017.kenes.com/">http://adp2017.kenes.com/</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>26-29 April</td>
<td>32nd International Conference of Alzheimer’s Disease International, <a href="http://www.ad2017.org">www.ad2017.org</a></td>
<td>Kyoto, Japan</td>
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<tr>
<td>24-27 June</td>
<td>3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>16-20 July</td>
<td>Alzheimer’s Association International Conference (AACIC), <a href="https://www.alz.org/aacic/">https://www.alz.org/aacic/</a></td>
<td>London, UK</td>
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<tr>
<td>26 July</td>
<td>The First Montessori Aging &amp; Dementia Symposium Prague 2017, <a href="http://agingsymposium.com/">http://agingsymposium.com/</a></td>
<td>Prague, Czech Republic</td>
</tr>
<tr>
<td>2-4 November</td>
<td>Clinical Trials on Alzheimer’s Disease (CTAD), <a href="http://www.ctad-alzheimer.com/ctad-2017">http://www.ctad-alzheimer.com/ctad-2017</a></td>
<td>Boston, US</td>
</tr>
<tr>
<td>22-25 March 2018</td>
<td>12th World Congress on Controversies in Neurology (CONy)</td>
<td>Warsaw, Poland</td>
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27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017
www.alzheimer-europe.org/conferences  #27AEC

The Alzheimer Europe newsletter received funding under an operating grant from the European Union’s Health Programme (2014–2020). The content of this newsletter represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.