WELCOME

Let me start this editorial by thanking MEP Deirdre Clune (Ireland) for addressing the European Commission and asking for additional clarification on its decision to disband the Commission Expert Group on Dementia. At a time when more European countries are recognising dementia as a priority and starting the development or implementation of national dementia strategies, this group was an ideal platform for government experts to exchange good practices and to learn from one another. It will be interesting to see how the Commission responds to Deirdre Clune’s question.

As an organisation, we have also continued to support initiatives with other patients’ and public health organisations which have campaigned for a continued role of the EU in health and to prioritise health in the development of the next multiannual financial framework. Find out more about the EU4Health campaign in this newsletter. April has also been busy on the research front and although we have to report on yet another phase III failure, we also cover news of new trials starting in Europe. The new research criteria launched by the NIA-AA on 10 April will hopefully provide an important framework for future trials and research.

In this newsletter, we also include two “behind the headlines” stories which provide much needed context to some of the more misleading research stories covered by some UK media. According to some of the headlines, ibuprofen could “wipe out Alzheimer’s” and “just ONE bad night’s sleep” could increase your chances of developing Alzheimer’s. The importance of providing scientific developments without sensationalising them cannot be overstated and I hope that publications like our newsletter contribute to disseminating research news in an objective and easy-to-understand fashion.

I hope you will enjoy reading our April newsletter.

Jean Georges
Executive Director
9 April: Alzheimer Europe supports joint statement on Europe doing more for Health

The European Union (EU) must continue to invest in health and put health first in the next EU budget. This is the key message in a joint public statement from 12 stakeholders including Alzheimer Europe as part of the ongoing #EU4HEALTH campaign. This statement follows on the work developed under the #EU4HEALTH Campaign during last year. The #EU4HEALTH campaign statement “Europe, let’s do more for Health!” calls for strong European Leadership with effective EU action on health. Importantly the statement asks for a framework for tackling non-communicable diseases and to address the challenges related to an ageing population. This demographic change puts health systems at risk and Member States have requested support from the EU in this fight against non-communicable diseases including dementia.

On 17 April, AE added the LUCIDITY clinical trial bringing the total of clinical trials currently reported in the database to 11. The LUCIDITY study is a 6-month double-blind and placebo-controlled trial evaluating the safety and efficacy of TRx0237 in people with mild AD. The study is actively recruiting participants in UK and the company TauRx Therapeutics Ltd anticipates sites in Belgium and Poland to start recruiting within the coming weeks.

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

24 April: 28AEC gets the support of 3 airline groups

OneWorld, Lufthansa Group and Skyteam are offering their meetings programmes for delegates of this year’s Alzheimer Europe Conference in Barcelona.

Further information on how to take advantages of the discounts they are offering all Alzheimer Europe delegates is available on http://www.alzheimer-europe.org/Conferences/Barcelona-2018/Official-carriers-travel-information

Alzheimer Europe Networking

On 4 April, Dianne took part in a telephone conference for the ethics work package of the ROADMAP project.

On 10 April 2018 (Stockholm, Sweden), Jean attended a meeting of the Nordic Dementia Council.

On 16-18 April (Brussels, Belgium), Dianne attended the EMIF project final meeting and public symposium.

On 18 April (Brussels, Belgium), Chris attended the IMI-EMIF Symposium.

On 23 April (London, UK), Chris attended the DPUK conference.

On 23 April (Brussels, Belgium), Dianne attended a meeting for RADAR-AD.
On 23-24 April (Antwerp, Belgium), Ana and Dianne attended the PACE consortium meeting. On 25 and 26 April (Barcelona, Spain) Dianne, Jean and Chris attended the 5th ROADMAP General Assembly meeting.

1 April: EPAD Longitudinal Cohort Study marks best month to date for recruitment of research participants

The European Prevention of Alzheimer’s Dementia (EPAD) consortium is delighted that March was the most successful month to date with 66 new research participants enrolled in the EPAD Longitudinal Cohort Study. The month of March was a fantastic month for the EPAD study and exceeded the mark set in February with 53 research participants recruited. It is the second time this year that CITA (San Sebastian, Spain) is the trial delivery centre of the month. Congratulations to the team who screened 15 research participants in March for their inclusion in the EPAD study, making it the most successful centre that month. A special mention goes to Bruno Vellas’s team in Toulouse (France) and Jose Luis Molinuevo’s team in Barcelona (Spain) who recruited respectively 12 and 11 new research participants in March.

2018 has had a great start! The study already recruited 155 new participants in 2018 and opened several new sites in Europe. EPAD now has 13 sites enrolling and a total of 571 research participants screened. The project team is pleased that Paris Nord (France) became the latest addition to the EPAD family (pictured) in March and recruited its first research participant over the weekend. Four additional sites are expected to become operational in France and UK in the coming days – stay tuned.

5 April: Health Economics team of the ROADMAP project publishes two protocols on systematic literature reviews on economic models in Alzheimer’s disease

Since the beginning of 2018, ROADMAP’s Health Economics team published two of three protocols on the methods for systematic literature reviews they are currently conducting. This work is part of an information gathering and combination process with the purpose to inform a new economic model throughout the whole span of Alzheimer’s disease (AD). The model aims to integrate information on disease progression, quality of life and the use of resources. According to the protocol published on 23 January, the first review aims to systematically combine information on the utilisation of resources and costs which arise from the
preceding preclinical stage of dementia on until the end of life. It specifically focuses on patients and their caregivers, and integrates health and social care services. In addition, it intends to identify the main drivers of costs and resources used.

In their conclusion the team stated that; “this review aims to address the economic impact of dementia, globally recognised as a health priority not only in terms of the impact it has on older people’s health but also on health and social care systems worldwide. Understanding the economic implications of this disease will allow policy-makers to devise better health and social care plans for both patients with dementia and their caregivers”. As reported in the protocol published on 30 March, the second review aims to systematically identify and combine the measurements of health-related quality of life (HRQoL) for people with, and their caregivers across the full spectrum of, dementia from its preceding stage of predementia to end of life.

Discussing its potential impact, the authors stated that; “the results of this review could inform models assessing interventions on dementia for both patients and their caregivers by providing information about patient’s and caregiver’s perspective on treatment benefits. Additionally, this synthesis of HRQoL measurements for dementia patients and their caregivers can help policy-makers better understand the impact of this staggering clinical condition”.

Read more about the project here.

10 April: PredictND project report published on European Commission website

On 10 April, the European Commission published a report of the PredictND project (2014-2018) on its “Aging well with ICT” policy pages. Here is the introduction (the full report can be read via the link below):

Using machine learning and artificial intelligence, the 4-year EU-funded project PredictND has developed tools for earlier, evidence-based diagnosis of neurodegenerative diseases. This can lower healthcare costs by 20% and on average people can stay one year longer at home.

Solving the huge challenge to lessen the increasing burden of dementias on our society requires more efficient solutions in diagnostics and more effective treatments.

Additionally, treatments need to be combined in an optimal manner - the right treatment for the right individual at the right moment. The results of a given treatment in a particular patient depend on a wide range of factors, including age, physical condition, gender, fitness, previous exposure to illness and more.

Although medical professionals can now be much better informed on their patients’ conditions, such data also complicate their work. ICT tools can help gather these data and analyse them.

The report elaborates on the following import aspects of the project:

- Early diagnosis matters
- Saving €300 per patient on average
- Already being used in clinical practice
- Virtual Physiological Human (VPH) concept.

The full report is here: https://goo.gl/P4KBzp

You can download the PredictND factsheet here: https://goo.gl/MYKLpm

10 April: First PARADIGM Open Patient Engagement Forum is held in Brussels

The PARADIGM (Patients Active in Research and Dialogues for an Improved Generation of Medicines) consortium is led by EPF (European Patients’ Forum) and EFPIA (European Federation of Pharmaceutical Industries and Associations) and comprises a mix of partners from patient organisations, regulatory bodies, universities, non-for-profit organisations, SMEs, trade associations to pharmaceutical companies. PARADIGM’s mission is to provide a framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) throughout three key decision-making points of the development of medicinal products: the research priority setting; the design of clinical trials and the early dialogues with regulators and HTA bodies.

The project will build on existing tools, fill knowledge gaps, define how to make all tools available to those who need them, raise awareness amongst those who think they do not need them and build a sustainable roadmap for patient engagement. Alzheimer Europe is a partner in this project and, together with Fundacio Sant Joan de Déu (FSJD), represents the voices in the consortium of potentially vulnerable patients’
groups. PARADIGM was launched on 1 March 2018 and will run for 30 months.

The first PARADIGM Open Forum on Patient Engagement took place in Brussels on 10 April. The Forum was organised jointly with two other patient engagement initiatives: EUPATI (European Patients’ Academy on Therapeutic Innovation) and PFMD (Patient Focused Medicines Development). During the morning of the Forum, delegates heard about the aims and governance of PARADIGM. Different stakeholders referred to the reasons PE was important to their organisation and their motivation and expectations for joining the project.

Delegates also had the chance to hear about PFMD and EUPATI and to discuss about the links between PARADIGM and these and other existing initiative and projects. In the afternoon, four interactive parallel workshops took place. Alzheimer Europe, together with FSJD, EURORDIS, EFPIA and the pharmaceutical company Servier, co-led Workshop D. The workshop, was entitled “Getting the most of the survey - which stakeholders and what methodologies” and addressed the different ways to work with vulnerable populations in PE and how to reach out to them through the existing networks and different structures. The workshop was also dedicated to mapping out and understanding better the departments and people within pharma companies who should complete the survey. Ana and Dianne attended the event on behalf of AE.

16 April: EPAD paper reviews expectations of living with Alzheimer’s disease risk based on focus group research conducted in UK and Spain

A new paper by the European Prevention of Alzheimer’s Dementia (EPAD) initiative entitled “At, with and beyond risk: expectations of living with the possibility of future dementia” has examined expectations of the implications of learning test results related to dementia risk, based on focus group research conducted in UK and Spain.

The article, published in the Journal of Sociology of Health & Illness on 16 April, was led by Richard Milne from the University of Cambridge (UK). Alzheimer Europe is happy to have contributed to this paper with Project Officer Ana Diaz being among the authors.

https://bit.ly/2HHJb8k

24 April: INDUCT project is investigating implementation trajectories of e-health interventions for caregivers of people with dementia

Despite a wealth of efficacy research on eHealth interventions for caregivers of people with dementia, little research has been done on their sustainable implementation outside of the trial context. In particular, there is a lack of studies assessing organisational and contextual determinants of successful implementation. In the context of her first secondment within the Interdisciplinary Network for Dementia Using Current Technology (INDUCT) project, ESR 10 Hannah Christie (pictured) spent three months with Mindtech to better explore these issues from an intersectorial perspective. Mindtech is a national centre focusing on the development, adoption and evaluation of new technologies for mental healthcare and dementia, based at the University of Nottingham. Together with Professor Martin Orrell, Dr Jennifer Martin and other members of the Mindtech and INDUCT teams, she is now working on a collaborative paper investigating what happens to interventions after their trial phase.

The goal of this study is to provide information on typical implementation trajectories of E-health interventions for caregivers of people with dementia. This will result in the identification of strategies and factors that contribute to successful implementation in practice. The resulting paper will contain recommendations for future intervention developers. Final results are expected in July and the authors hope to present their findings at the 2018 Alzheimer Europe conference in Barcelona in October. If you have any questions, please contact: hannah.christie@maastrichtuniversity.nl

EU project acknowledgement

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Members of the European Alzheimer’s Alliance

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

**Austria:** Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP). **Belgium:** Mark 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 (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); Liisa Jakonsaari (S&D); Anneli Jätteenmäki (ALDE); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **Finland:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); François GROSSETETÉ (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); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Ellissavet Vozemberg-Chrysogonos (GUE/NGL); Kostas Mavrides (S&D); Eleni Theocharous (EPP). **Hungary:** Ádám Kösa (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marián Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Stefano Zanni (EPP); Andrey Kovatchev (EPP). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Gerber-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Georgiu-Deac (S&D); Kira Ryabova (NI). **Russia:** Andrey Kovatchev (EPP); Pioneer Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). **Spain:** Carolina Coelho (EPP); Isabel García Tejerina (S&D); Pablo Iglesias (S&D). **Sweden:** Ida Aro (S&D); Per Filipsson (ALDE); Anna Záborská (EPP); Jana Žitňanská (ECR). **Slovenia:** Franca Vavpotic (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Soltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Iñaki Bilbao Barandica (ALDE); Soledad Cabezas (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girault (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Pablo Balda Bidegain (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (NI); Rick Boardman (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).

EUROPEAN ALZHEIMER’S ALLIANCE

28 March: Deirdre Clune, MEP submits European Parliament Written Question on the Dismantling of the Commission Expert Group on Dementia

Deirdre Clune, MEP, member of the European Alzheimer’s Alliance has submitted a written question to the Commissioner to address the question of why the Expert Group on Dementia was disbanded. This happened at the same time as the disbandment of the expert groups on cancer, rare diseases and mental health. Instead of these specific disease groups the Commission has created a new group called the Steering Group on Prevention and Promotion.

Question for written answer to the Commission

**Subject:** Dismantling of the Commission Expert Group on Dementia

Dementia is a major public health issue. By 2060, 28% of the population will be aged over 65 and 12% aged over 80. In 2015, dementia affected some 10.5 million citizens aged between 30 and 95+ years of age in Europe. This number is estimated to increase to 13.42 million people by 2030. Dementia accounts for 11.9% of the years lived with disability due to a non-communicable disease. There is still no cure for dementia.

1. With regard to these figures and the growing public health threat of dementia, why has the Commission dismantled the Government Expert Group on Dementia, which included the participation of Member States and civil society and enabled them to go back to their respective national and European authorities to share expertise and good practice?

2. How does the Commission now intend to encourage Member States to share expertise and good practice and to adopt national strategies regarding Alzheimer’s?
3. How is the Commission now taking stock of the various recommendations that EU Presidencies have made on dementia and the findings of research programmes such as the Joint Action on Alzheimer Cooperation Valuation in Europe (ALCOVE) and the 2nd EU Joint Action on Dementia?

Alzheimer Europe is disappointed to see the expert group on dementia disbanded. The group provided an ideal platform for government representatives to share good practices on the dementia policies and national dementia strategies which different countries are and were in the process of developing or implementing. The group was also helpful in bringing together Commission representatives from DG Research and from DG Social Affairs to explore how to better coordinate work across different Commission services. In addition, the group provided an important link with the 2nd European Joint Action on Dementia which is coordinated by the Scottish Government and supported by the health programme and which looks into timely diagnosis and post-diagnostic support, care coordination and crisis management, residential care and dementia-friendly communities. The group was also able to link up with the important work done by the World Health Organization and by OECD in the field of dementia and explore synergies between EU and more global initiatives. Finally, Alzheimer Europe had consultative status with the group and could update government representatives on its initiatives and projects. At a time where a growing number of EU Member States recognise the importance of dementia as a public health priority this Commission decision to disband the expert group unfortunately took away a very important mechanism for these countries to exchange on policy initiatives and learn from one another.

http://www.corbel-project.eu/open-call.html

7 April: EU Health Commissioner Vytenis Andriukaitis calls for “Universal Health Care” on World Health Day 2018

7 April was World Health Day 2018 and to mark the occasion, EU Health Commissioner Vytenis Andriukaitis wrote a press release on the state of access to healthcare for EU citizens, published on the European Commission website.

While we can be proud, he said, of the progress made in protecting EU citizens’ health and in raising the overall life expectancy, he urged all national authorities to make sure that every single person in the EU has access to health care, citing the continued growth of European Reference Networks and The European Pillar of Social Rights as important steps in the right direction.

You can read his full statement here: https://goo.gl/9m9GLM

17-18 April: EMA holds a PCWP / HCPWP joint meeting in London

The joint meeting of the Patients’ and Consumers’ Organisations (PCWP) and Healthcare Professionals’ Organisations (HCPWP) Working Parties took place on 17-18 April. Delegates received information and had the opportunity to discuss on the topics of digital media and health, electronic product information and mHealth. Some of the results of the IMI-funded project WEB-RADR were presented as the EMA had participated in this project. Another relevant topic discussed during the first day of the meeting, was real world evidence (RWE). The discussions revolved around how RWE is relevant for the medicines regulatory system and how it can be used in the benefit-risk evaluation of medicines to support early access to medicines. The last part of the first day was dedicated to social media and presentations focused on EMA’s approach to social media and how to amplify current outreach. During the second day, delegates were updated about the EMA relocation to the Netherlands. Delegates were informed by the EMA Deputy Executive Director, Mr Watchion, about the plans and work related to the EMA relocation to Amsterdam in 2019. Delegates were also updated on the clinical trials regulation and the portal that the EMA is currently developing. The portal is planned to be audited in January 2019, and then, 6 months after the result of the audit is published by the European Commission.
Commission, the clinical trial regulation will become applicable. There was also a presentation during the day on the preliminary results of an online survey on pharmacovigilance and awareness among different stakeholders of the additional monitoring concept that has been carried out by the EMA. The results of this survey will be published in coming months. During the afternoon, the topics moved to access to medicines (shortage and availability of medicines, and EMA-EUnetHTA collaboration) and feedback on the work carried out by various EMA committees (COMP, CAT, PRAC, CHMP, PDCO, HMPC). Ana attended the meetings on behalf of AE.

18 April: IMI organises a consultative workshop on disease interception

On 18 April, the Innovative Medicines Initiative (IMI) organised a consultative workshop in Brussels on disease interception, a concept developing drugs that work at earlier time points in the disease process. The meeting was an opportunity to gather key stakeholders involved in drug development and healthcare decision-making to discuss the opportunities and challenges of drug development and usage in disease interception setting.

The morning was dedicated to the understanding of definition of disease interception and to share case studies of ongoing relevant IMI projects supporting a molecular level approach to disease in early intervention settings. Key stakeholders gave afterwards their perspectives linked to disease interception and an interactive open floor discussion took place to align the understanding on concept definition, key opportunities and identified challenges.

The afternoon session concentrated on three parallel breakout groups to list challenges and opportunities for early therapeutic intervention and to propose tangible solutions. Finally, the audience listed some preliminary recommendations on actions to address including those suitable for ongoing IMI projects as well as for future IMI initiatives.

The event brought together patient advocates, pharmaceutical companies, regulators, healthcare professionals, HTA bodies, payers, academics, European commission, FDA, EFPIA and IMI. Project Officer Cindy Birck represented Alzheimer Europe at the meeting.

MEMBERS’ NEWS

19 March: Fusion-Care-A pilot project combining the three sides of the caring triangle: the person with dementia, the family, and the foreign care-giver

In Israel 95% of people with dementia are living at home. Caring for the person can be very challenging, and often the family cannot cope. Many families employ foreign care-givers, mostly from Asian countries, allowing people to remain at home much longer with better care. Along with the positive aspects of 24-hour care, many difficulties arise, that are often brought up at support groups and the hotlines. Most female spouses do not want a stranger in the house, especially if the worker is male. It is very difficult for many of the family care-givers to give orders and train the workers when they never had help before. The cultural differences include diverse religions, behaviours, values, customs, and food. For example, in Israel people speak directly and in some Asian cultures people say yes just out of courtesy when they don’t mean it. Many workers don’t speak good English and very little Hebrew causing language and communication problems. Also in many situations there is resistance from the person with dementia to accept help from a stranger, especially when he thinks that he can do things independently. Many families go through a number of workers till the find the right one.

"Emda"- Alzheimer ‘s Association Israel decided to develop a model project of a seminar to combine the three sides of the caring triangle in order to improve the care and well-being at home and bridge the cultural gap and diverse needs of all three sides through fusion.

There are many insights after finishing the pilot and receiving feedback from the participants. There is a great need for knowledge and skills about working with a person with dementia especially from the workers. It is important to have separate meetings focusing on individual needs and joint meetings that support cooperation. Active participation with personal examples helped make improvement in the daily care. Workshops are important for new workers to help define the working contract, demands of job, and learn good dementia care. For the families new with employing paid care-givers, they can receive guidance and counselling to integrate the worker into their home and train them.

The results of the project were improved mutual understanding and team work between the families and the care-givers. The care-givers gained knowledge and skills that helped them cope, communicate, and collaborate better. The families felt they had a better relationship with the care-giver and their loved one.

It is very important to help family members and foreign care-givers to gain knowledge, work together and emphasise the unique quality of each person in the caring triangle. This approach helps to improve the quality of life for all sides and reduce care-stress.

21 March: Alzheimer Nederland encourages support for people with dementia for voting

Every citizen in the Netherlands aged 18 or over has the right to vote. On 21 March there were local elections in the
Netherlands. For people with dementia, voting can be quite an issue because of the difficulties people experience when they visit the polling station. Sometimes it is difficult to understand how to use the voting paper and members of polling stations are not always aware of the problems people with dementia have with understanding the procedures.

That’s why Alzheimer Nederland made an instructional video. You can watch it here: https://goo.gl/pU5cy5

Alzheimer Nederland has also been encouraging polling stations to become dementia friendly: be friendly and calmly support people with dementia, asking if you can be of any assistance in informing them how the voting paper works.

According to the Convention on the Rights of Persons with disabilities, people with disabilities have the right to get assistance, but in the Netherlands, this type of assistance is reserved for those with a physical impairment. When you have a mental impairment, you are not entitled to such assistance at the polling booth, which is a very frustrating hurdle for people with dementia and their carers. Karin Hildur Olöngren, Minister of Internal Affairs is aware of this problem and is willing to try to find a solution. This will be the next step for people with dementia to remain full members of society, with their right to participate respected, including voting.

29 March: Social Cluster Association Hungary secretary Dr Norbert Vajda awarded Fulbright Scholarship in Dementia Care

The Social Cluster Association, which is the Hungarian member of Alzheimer Europe, is pleased to announce that its secretary, Dr Norbert Vajda has been awarded with a Fulbright Visiting Scholarship to the US. The Fulbright Program is a highly competitive merit-based international exchange programme, one of the most widely recognised and prestigious scholarships in the world.

Dr Vajda’s academic research concentrates on the social interactions of people who live with dementia, with a special focus on close family members’ and caregivers’ communication. The research also investigates how residents in institute-based dementia care can make their individual decisions. During Dr Vajda’s five-month long visit to South Florida he will also provide lectures related to his former studies. Within this topic area, he points out the necessity of interprofessional collaboration between social and health professionals in proper dementia care.

11 April: Alzheimer Society UK holds faith, culture and dementia conference

On 11 April 2018 Alzheimer’s Society hosted The Prime Minister’s Champion Group’s first ever conference on faith, culture and dementia in London. Over 100 people attended from various faith groups, the conference focused on understanding how identity, faith and dementia interact. Other topics discussed during the day included the barriers and challenges that people living with dementia face when practicing their faith and the ways in which faith communities can support them in doing so. The conference also offered a great opportunity to celebrate the range and breadth of work currently underway and being achieved in this area.

Jeremy Hughes opened the conference, followed by three key note speakers who provided powerful accounts of their experiences of dementia and faith. Shelagh Robinson, Alzheimer’s Society ambassador living with dementia, spoke eloquently about how her faith helped her to accept her diagnosis. Rabbi Junik offered accounts of times he has experienced faith to allow people with dementia to reconnect with themselves and others. Balvinder Kaur provided a very honest account of her personal experience of a family member living with dementia, the difficulties in finding the right support and the stigma she experienced within her Sikh community.

Attendees were able to explore these topics further through interactive workshops focusing on (i) dementia-friendly services, sermons or prayers; (ii) becoming a dementia-friendly place of worship and supporting the wider community and (iii) finding solutions to the challenges people with dementia face to enable them to continue interacting with their faith and cultural communities.

During the day, attendees were also encouraged to write their own dementia-friendly prayers and personal pledges to action to take away from the day in addition to a call for commitment to dementia on the part of faith leaders.

Input from this event will help to shape our future work, and we will soon be launching a number of dementia-friendly faith leaflets to support communities. For more information please contact programmepartnership@alzheimers.org.uk
“...it is really important and interesting”. The hard work done on equality and inclusivity is also a continuing focus as the group continues to encourage new members from under-represented groups as well as ensuring that the wider membership understand the particular barriers faced by these communities: “As long as you have dementia, you should be welcome to and represented by the group” says Vice-Chair Anne Macdonald. The group’s committee is proud of their role as representatives of a diverse dementia community, and will continue to work towards ensuring that membership is reflective of the diverse range of people living with dementia in Scotland.

**25 April: The Karelleion Integrated Alzheimer and related disorders Unit organise educational activities**

Among the educational activities and initiatives, organized by the Karelleion Integrated Alzheimer and related disorders Unit, of the “Apostoli” charitable organization, of the Holy Archdiocese of Athens, a psychoeducational program of seminars on dementia and Alzheimer’s disorder takes place, within the context of the community, three times per year.

The above mentioned activity is carried out by members of our Unit’s scientific team, who study, investigate and present to relatives, paid and unpaid carers of patients, students and other healthcare professionals, theoretical issues about dementia as well as practical advice on what to do and how to take care of a person with dementia. Each psychoeducational seminar is comprised of several scientific but on layman’s terms as well, presentations on a weekly basis, by our psychiatrist, psychologist, occupational therapist, physiotherapist, nurse and social worker. In more detail the presentations are on “The nature of dementia and what we can do about it”, “The function of memory and dementia: prevention, non- pharmaceutical approaches, management of emotions”, “Mobility impairment and dementia: a physiotherapeutical approach”, “Everyday activities of people with dementia”, “Providing nursing care for people with dementia” and “Problems of the third age, care and social security programs”.

The main purposes of these psychoeducational seminars are to thoroughly educate on dementia, anyone who is interested, and at the same time to give them the possibility of free expression of their feelings or inner thoughts. Also, to diminish the stigmatization and prejudice associated with Alzheimer’s disorder and dementia in general. The warm welcome to our initiative and the very positive feedback we are continuously receiving by people, show us that the community has already embraced it. Our local parish has and continues to help us very much, by informing and activating its members as well as...
Imagine three people, all affected by dementia in different ways. One lives in Scotland, one in Germany and one in Malta. They are all awake late at night and feel completely alone. Searching for answers online, they find Talking Point, an English-speaking online support. They sign up, log in and see hundreds of conversations posted by people from all over the world, all with similar fears and doubts. Feeling hopeful, each of them bites the bullet and posts a message about their situation. Replies start to come in from other members, reassuring them that they’ve come to the right place. They no longer feel like they are alone.

Whatever you are going through, chances are there is someone on Talking Point who will be able to offer support. The community provides spaces for people dealing with various situations at all stages of dementia, including for those with memory concerns and dealing with loss. It gives people affected by dementia the opportunity to talk to others in similar situations, ask questions, share experiences and crucially know that there are people who understand.

As one member recently said on Talking Point’s birthday, celebrating 15 years since it was first set up: “The last three years have been the loneliest, most frightening and darkest days of my life. Talking Point has been my only form of true understanding of dementia ... my only source of comfort, and a listening ear from other carers who are battling the same isolation, fears and stress. Happy birthday Talking Point. I’m very glad you were born.”

Talking Point is free, open day and night, and you only need an internet connection to read discussions and start your own.

www.alzheimers.org.uk/talkingpoint

**POLICY WATCH**

**21 March: Fundació ACE calls for improvements to care systems and more research funding to meet rising cost of Alzheimer’s in Catalonia**

The cost of Alzheimer’s disease will rise dramatically in Catalonia in the next 30 years, to between 7,000 and 7,700 billion euros according to a study carried out by Fundació ACE-Barcelona Alzheimer Treatment & Research.

The study highlights the high costs faced by Catalan society to absorb the direct and indirect costs of Alzheimer’s dementia, which is already the fourth biggest health issue worldwide.

In a press release on 21 March 2018, Fundació ACE warned that “we are facing a real worldwide epidemic in the coming years" and that to face it, it is essential to adapt the health system, the social services system and ensure greater investment in medical research. Fundació ACE is critical of the fact that, despite Alzheimer’s being one of the most common diseases in our society, there is still less emphasis on it and less funding than for other disease areas.

“30 times more is invested in cancer research and 15 times more in research on cardiovascular diseases than in Alzheimer’s”, said Antoni Gelonch, director of corporate relations at Fundació ACE. He believes it is paramount to develop a global consensus, preventive and long-term strategies and policies.

**30 March: Alzheimer Research UK publishes report on implementing future dementia treatments**

A new report entitled “Thinking differently Preparing today to implement future dementia treatments” has been published by Alzheimer Research UK The report looks at the potential impact of a new treatment for Alzheimer’s disease and the impact it could have on health systems.

Alzheimer Research UK is helping develop the evidence on which to base future discussions about how the UK can prepare for new treatments The aim of this report in bringing together different stakeholders, so that once a treatment is available patients can access it quickly. To provide evidence of the potential impact and to highlight the need to prepare now for future treatments, Alzheimer’s Research UK commissioned the London School of Economics and Political Science (LSE) Personal Social Services Research Unit (PSSRU) to model five hypothetical treatments for Alzheimer’s disease, the most common cause of dementia.


**1 April: Good news for carers in Scotland as Carers (Scotland) Act 2016 comes into force**

Scottish Government statistics show that there are in the region of 788,000 unpaid carers in Scotland. In reality, this figure could be much higher, given that many unpaid carers do not see themselves as carers and so do not register with organisations. For these unpaid carers, there was good news on 1 April 2018, when the new Carers (Scotland) Act 2016 came into force, which should ensure that their rights are further recognised and reinforced. The Carers (Scotland) Act identifies the duty of local authorities in supporting carers and ensuring more consistent and better support is available, promoting health and

**26 April: UK Alzheimer Society’s Talking point celebrates 15 years**

Imagine three people, all affected by dementia in different ways. One lives in Scotland, one in Germany and one in Malta. They are all awake late at night and feel completely alone. Searching for answers online, they find Talking Point, an English-speaking online support. They sign up, log in and see hundreds of conversations posted by people from all over the world, all with similar fears and doubts. Feeling hopeful, each of them bites the bullet and posts a message about their situation. Replies start to come in from other members, reassuring them that they’ve come to the right place. They no longer feel like they are alone.

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**www.alzheimers.org.uk/talkingpoint**
wellbeing. The introduction of Adult Carer Support Plans will help to identify carers’ needs and provide person-centred support to help cope in times of difficulty. The Act also highlights the responsibility of local authorities to provide an information and advice service specifically for carers, appropriate to their needs, including: carers’ rights, income maximisation, emergency and future care planning, along with advocacy.

The Act has the potential to play a fundamental role in improving quality of life by providing the opportunity for carers to maintain a life outside of their caring role. Its introduction should ensure unpaid carers are recognised and supported for the important role they play. To find out more, see: http://www.gov.scot/Topics/archive/CarersBill

**SCIENCE WATCH**

**29 January: Study assesses association of preclinical Alzheimer’s disease and sleep disorder**

On 29 January, scientists from Missouri published an article on the potential association of preclinical Alzheimer’s disease (AD) and circadian rest-activity pattern changes in the journal JAMA Neurology.

Circadian rest-activity pattern changes are part of the family of sleep disorders. People affected by it have a disrupted sleep pattern. This means that their time of sleep is for example abnormal in length or that they are unable to sleep or wake at normal times.

Previous evidence has shown that circadian rhythm disturbances manifest in AD. Further, they may contribute to the development of the disease itself as well. So far it is still not known if the disturbances already occur during the phase when symptoms are not present yet.

In order to shed further light into this, the team conducted a cross-sectional study with 205 cognitively normal participants whose rest/activity cycles were monitored during 7 to 14 days. In addition, the participants underwent longitudinal clinical assessment, amyloid imaging and cerebrospinal fluid biomarker collection to assess preclinical AD.

The team then excluded information of 16 people from the analysis because data was missing. They then analysed the information from the remaining 189 people and found sings of AD through biomarkers in 50 cases. Looking at the participants’ sleep wake activity, the scientists signalled that there was more disruption in those with biomarkers.

Although having successfully gathered evidence that there is a correlation between having AD biomarkers and a disrupted sleep pattern, the cause and effect direction still remains unclear. While these findings are less relevant to the public, they are important for scientists because they might lead to identify circadian rest-activity pattern changes as a potential new biomarker.


**15 February: Study with transgenic Alzheimer’s disease mice investigates the influence of caffeine to inform future coffee-derived treatments**

On 15 February, an international group of researchers from Spain and Sweden published an investigation on the effect of treating mice with caffeine in the journal Frontiers in Pharmacology.

Their aim was to assess the effects of low but continuous caffeine treatment in a mouse model for Alzheimer’s disease (AD) characterized by a cognitive but also Behavioural and Psychological Symptoms of Dementia (BPSD)-like profile.

For their investigation, the researchers set up four groups with 8 - 10 mice each, totaling 38 mice. Two groups consisted of:

- Transgenic AD mice (with access to caffeinated water).
- Transgenic AD mice (without access to caffeinated water).
- Age-matched non-transgenic mice (with access to caffeinated water).
- Age-matched non-transgenic mice (without access to caffeinated water).

When the mice were 13 months old, the scientists carried out diverse tests to evaluate their physical and behavioural profiles. Their results showed significant effects on behaviour (especially anxiety related behaviour). Further, the scientists observed that caffeine had a different effect on the AD mice, it resulted in an aggravation of the BPSD profile. In addition, learning and memory was strongly influenced by anxiety, leading only towards little benefit from caffeine.

In their conclusion, the team stated that their “observations of adverse caffeine effects in an AD model together with previous clinical observations suggest that an exacerbation of BPSD-like symptoms may partly interfere with the beneficial cognitive effects of caffeine”. It is clear that these observations cannot be directly transferred from mice to humans. While they do not provide recommendations on whether people with AD should or shouldn’t consume coffee, the results might inform scientists for when they will develop and test new coffee-derived potential medicines for dementia.


**22 March: Use of antiepileptic drugs may increase risk of AD and dementia**

In the study published on 22 March in the journal of the American geriatrics society, researchers from University of Eastern Finland and the German Center for Neurodegenerative Diseases reported that the use of antiepileptic drugs might be associated with an increased risk of Alzheimer’s disease (AD).
and dementia. Scientists used data from the Finnish public health register (people with AD) and German health insurance (people with dementia) to investigate the association between regular use of antiepileptic drugs and incident dementia risk. They observed a greater risk of incident dementia and AD with use of antiepileptic drugs in both countries. They also described a significantly greater risk with the use of antiepileptic drugs with known cognitive adverse effects. In addition, researchers found a potential dose-response relation. The regular use of antiepileptic drugs was associated with a greater risk of incident dementia in the Finnish data but the trend was not detected for AD in the German data.


23 March: US survey assesses features of stigma attributed to Alzheimer’s disease dementia

On 27 March, a team of researchers from Philadelphia (USA) published survey results in the Journal Alzheimer’s & Dementia. The survey aimed to progress the understanding of beliefs, attitudes and expectations about Alzheimer’s disease (AD) dementia. For their investigation the researchers did a secondary analysis of reactions of 317 adults to the description of a fictive a man with mild AD dementia.

Amongst other common expectations attributed to the example (such as that he would not remember most recent events), their analysis showed that half of the respondents thought that the man would be discriminated against by his employers. In addition to this, that due to having received the diagnosis of AD dementia his health insurance would be limited (either on the basis of data in the medical record, a brain imaging result or a genetic test result).

Discussing the results, the authors argued that the enrolment into clinical trials is likely to be hindered by such negative expectations. Following on that the team concluded that there is a need for public education and policies to address concerns about employment and insurance discrimination. At the same time, they stated that studies are needed to find out how advances in diagnosis and treatment may change Alzheimer’s disease (AD) dementia his health insurance would be limited (either on the basis of data in the medical record, a brain imaging result or a genetic test result).

1 April: Recent study suggests new AD genetic risk factors in the Chinese population

Findings from a recent whole-genome sequencing study on Chinese people with Alzheimer’s disease (AD), mild cognitive impairment (MCI) as well as healthy participants, suggested that GCH1 and KCN115 may be associated with AD. In addition, researchers discovered that these risk factors were associated with changes of the immune-associated gene signatures in the brain and blood, suggesting a role of the immune system in AD pathology.

The research was conducted by scientists from The Hong Kong University of Science and Technology and published in the journal Proceedings of the National Academy of Sciences.

http://www.pnas.org/content/early/2018/02/02/1715554115

3 April: Neighbourhoods & Dementia project plans first dementia friendly community for Sweden and updates on DEMTRAIN progress

On 3 April, the Neighbourhoods & Dementia project circulated the seventh issue of its newsletter. Apart from other interesting updates, the project reported on their great success in securing different exciting funding opportunities throughout their Work Programmes.

One of them was obtained by the team from Linkoping University (Sweden). The fund is vital to start the first dementia friendly community for Sweden. The team is currently collaborating with local service providers and people with dementia to plan and set up this initiative over the course of the next three years.

In addition to this, the Work Programme 5, who is developing the evidence base for evaluating dementia training in NHS hospitals (entitled DEMTRAIN), also reported on some good progress. They recently launched a staff survey across 24 hospitals and registered a protocol in PROSPERO on a review they are currently carrying out. Further, they thanked Angela Rippon CBE, co-chair of The Prime Minister’s Champion Group on Dementia Friendly Communities and Alzheimer’s Society Ambassador for her support. In addition to her work as a
DEMTRAIN advisory group member, she recently recorded a short film about the DEMTRAIN study. You can find the video and further information on the project here.

4 April: Scientists report an imaging method to evaluate astrocyte-neuron proximity

Astrocytes, the most numerous cell type within the brain, are considered to provide support and guidance to neurons but also described to play an important role in the pathogenesis of some neurological diseases. However, it is unclear how astrocytes interact with synapses to execute important brain functions and how these interactions change over time in healthy and pathological conditions.

In the study published on 4 April in the journal Neuron, US researchers from University of California Los Angeles reported a new imaging method to access the proximity and the dynamics of astrocyte processes with synaptic elements in live mouse brain preparations. This new approach could lead to determine how these astrocyte-synapse interactions could change during neurological disorders such as Alzheimer’s and Huntington’s disease.

http://www.cell.com/neuron/fulltext/S0896-6273(18)30180-6

4 April: Oryzon Genomics receives approval to initiate Phase 2a trial for ORY2001 in people with mild and moderate AD

On 4 April, the biopharmaceutical company Oryzon Genomics, which develops epigenetics-based therapeutics in oncology and neurodegenerative diseases, announced that it has received approval to start a Phase 2a clinical trial with ORY-2001 in participants with Alzheimer’s disease (AD) in Spain. The study will also be conducted in France and UK once the approvals will be obtained.

ORY-2001 is an oral and brain penetrant drug that may reduce cognitive impairment, memory loss and neuroinflammation. The drug appeared safe and well tolerated in the Phase 1 trial conducted last year in healthy participants.

The ETHERAL Phase 2a trial is a randomised, double-blind and placebo-controlled trial to evaluate the efficacy and safety of ORY2001 in 90 participants with mild and moderate AD. The company expects to start the recruitment this quarter.


6 April: Researchers suggest a blood test to detect AD with 86% accuracy

A new study suggests that a blood test measuring the amount of amyloid-β in the human blood could detect people at risk of developing Alzheimer’s disease (AD).

Using data from the Swedish BioFINDER cohort, scientists found that the new test could detect the amyloid-β alterations in the blood of participants with prodromal AD that correlated with abnormal amyloid deposits observed using brain scans. Then using data from the German ESTHER cohort study, researchers investigated if the blood test could detect AD before the first symptoms appeared. Using blood samples from people who developed later AD, scientists reported that the new blood test could detect early-stage AD with 86% accuracy and 8 years before AD clinical diagnosis.

The study was conducted by German researchers from Ruhr-University Bochum and was published in the journal EMBO Molecular Medicine. Authors reported that the test needs to be further validated in a multicentre clinical AD study.

http://embomolmed.embopress.org/content/early/2018/04/04/emmm.201708763

9 April: vTv Therapeutics’ experimental AD drug fails to meet its co-primary endpoints in Phase 3 study

On 9 April, vTv Therapeutics, a clinical-stage pharmaceutical company focused on the discovery and development of human therapeutics to fill unmet medical needs, announced that its experimental drug azeliragon failed to meet its co-primary endpoints in the first STEADFAST Phase 3 study.

Azeliragon is an active small molecule inhibiting the RAGE receptor, which may contribute to the pathogenesis of Alzheimer’s disease (AD).

The STEADFAST study included two independent and identical Phase 3 trials. The first study was a 18-month randomized, double-blind and placebo-controlled trial evaluating the safety and efficacy of azeliragon in people with mild AD. Although the experimental drug was generally well-tolerated, results showed that it did not improve cognitive and functional primary outcomes compared to the placebo. The company is discontinuing its clinical trials evaluating azeliragon and will do further analyses from its two independent STEADFAST Phase 3 studies.


11 April: Scientists report findings on the incidence of Alzheimer’s and other neurodegenerative diseases at focus meeting

International scientists provided updates on their recent research at the Advances in Alzheimer’s and Parkinson’s Therapies Focus meeting (AAT-AD/PD), held on 15 - 18 March in Turin (Italy). Predicting the future occurrence and commonness of Alzheimer’s disease and other neurodegenerative diseases is both complicated and
diverse, since they are tied to many different environmental and individual factors.

During the meeting Walter Rocca (Mayo Clinic – Minnesota, USA) explained that findings from his research group suggest that the incidence of Parkinson’s disease (PD), amyotrophic lateral sclerosis as well as early onset AD are rising. This might also become the case for late-onset of AD.

Speaking about the decrease in all-cause dementia over the past decades, the scientist argued that the diminished cases of vascular dementia as well as stroke could hide an increasing rate of AD.

Findings from the 90+ study presented by Claudia Kawas (University of California - Irvine, USA), showed that vascular disease conferred twice as much dementia risk in the oldest old as did having Alzheimer’s disease pathology.

These results not only highlight the role of vascular diseases in the context of brain health. They also underpin the need to distinguish underlying biologic mechanisms of neurodegeneration and to address specific risk factors accompanying them.


13 April: National Institute of Health study investigates the link between sleep deprivation and beta-amyloid

On 13 April, scientists from the National Institute of Health (NIH) published a small study on the effect of sleep deprivation on amyloid levels in the journal PNAS.

Previous researchers have been looking at the effect of sleep deprivation in mice and found that it causes beta amyloid levels to rise (a protein associated with Alzheimer’s disease - AD).

Following on these results, the NIH funded a study that investigated the effect of sleep deprivation (for about 31 hours) in 20 healthy people aged from 22 to 72 years. The brains of the participants were scanned using a non-invasive method to identify the beta-amyloid levels before and after sleep deprivation.

The results showed, that the levels of beta-amyloid increased for about 5 percent after sleep deprivation in brain regions associated with memory functions and AD (such as the hippocampus). Although intriguing, these results need to be interpreted with caution since it is unknown if the increase in beta-amyloid would subside after a normal night of sleep.

The researchers stated that due to the small number of participants, their results are not generisable and need to be followed by larger studies. However, the results may still be helpful to better understand the role of sleep in the clearance of beta-amyloid.

http://www.pnas.org/content/early/2018/03/29/1721694115.full

24 April: Recent study investigates hospital dementia diagnosis accuracy

Scientists from University College London, UK, investigated the accuracy of dementia diagnosis in general hospitals in UK. On 24 April, results were published online in Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association. Results showed that hospitals are treating patients without realising that they had been diagnosed with dementia.

The study identified people who went to hospital within one year of being diagnosed with dementia and examined hospitals admissions from 21,387 people between 2008 and 2016. Findings identified an improvement in dementia diagnosis in hospitals over time. At the start of the study, in 2008, 48.7% of dementia cases were detected, improving to 61.5% in 2016. In addition, researchers found that hospital staff were less likely to diagnose dementia in people from minority ethnic groups, single people, younger people and those with physical illness.

https://www.alzheimersanddementia.com/article/S1552-5260(18)30066-9/fulltext

25 April: Alkahest launches Phase 2 trial for GRF6019 in people with mild to moderate AD

On 25 April, the US clinical-stage biotechnology company Alkahest, which develops innovative therapies to treat age-related diseases, announced the launch of a new Phase 2 trial investigating GRF6019 in people with mild to moderate Alzheimer’s disease (AD).

The ALK6019-201 Phase 2 study is a randomized, double-blinded dose response trial to evaluate the safety and tolerability of GRF6019 infusions in 40 people with mild to moderate Alzheimer’s disease.


BEHIND THE HEADLINES

28 March: Claims ibuprofen “will wipe out Alzheimer’s” are misleading, says NHS Choices

The study that prompted such an optimistic headline was in fact a small piece of research that looked at a saliva test that measures the amount of a protein called amyloid beta protein 42 (Abeta 42).

Some experts, such as the
current researchers, think that having higher than average levels of Abeta 42 could be an initial warning sign of the development of Alzheimer's disease.

But the test was only used on 23 people with Alzheimer's and 31 without, which isn't a large enough sample size to have any confidence in the results. Even if the test were to prove accurate, there isn't enough evidence about any preventative treatments.

The potential preventative treatment suggested by the researchers is a group of drugs known as non-steroidal anti-inflammatory drugs (NSAIDs), rather than ibuprofen specifically, as the headlines imply.

This study didn't test the ability of ibuprofen for preventing or slowing down the progression of Alzheimer's disease, either.

NSAIDs can cause serious side effects, such as gastrointestinal bleeding. Before they can be used in combination with a test that detects Alzheimer's disease early, well-designed clinical trials need to be conducted using larger sample sizes.

Based on the limited results presented in this study, there's currently no evidence that taking ibuprofen or other NSAIDs can prevent Alzheimer's disease.

You can read the full commentary here: https://bit.ly/2JbzzCj

10 April: Don't lose sleep over reports that one bad night can spark dementia, says NHS Choices

Following recent media headlines claiming, for example that “Just ONE bad night’s sleep ‘increases your chances of Alzheimer’s’” (The Sun newspaper, 9 April 2018) we looked to the NHS Choices website for a more grounded look “behind the headlines”. Here is their commentary on this and similar headlines:

The study that prompted the claim involved only 20 people, none of whom had Alzheimer's disease. They were tracked over the course of just two nights of monitored sleep. During that time they were allowed to sleep as much as they wanted for the first night, and then on the second night they were kept awake by a nurse.

The researchers then used brain scans to measure levels of a protein called beta-amyloid that builds up naturally in the brain. This protein is found in larger amounts in people with Alzheimer’s disease, although it is not clear if simply having higher levels of it for a short time increases the risk of Alzheimer’s.

The study showed that people had slightly higher (5%) levels of beta-amyloid in their brains after a night of sleep deprivation compared with their levels after a good night’s sleep. This brief assessment provides no proof these middle-aged people would go on to develop Alzheimer's if they continued to have sleepless nights. We don't know how their levels of beta-amyloid may vary over time.

We can’t draw any conclusions about the relationship between sleep and Alzheimer’s disease from this research. All we can say is that generally, getting a good night’s sleep brings other important physical and mental health benefits – you can read here about how to sleep better.

You can read the full commentary here: https://bit.ly/2Haomq

DEMENTIA IN SOCIETY

13 April: NHS and police encourage Scottish citizens to download app to help find people with dementia if they lose their way

Purple Alert is a community-minded app to help people look out for their neighbours. It was designed by people living with dementia and carers, Alzheimer Scotland staff, Police Scotland, Social Work, Dementia Friends Scotland, Health and Social Care Partnerships and telecare services during 2017.

Regional branches of the National Health Service (NHS) for Scotland, as well as Policy Scotland are now actively encouraging people to download and use the app, which aims to help find people living with dementia if they are lost.

The app allows carers to share details about a person living with dementia if they lose their way, which alerts registered users within a 30 mile (approx. 50km) so they can help find the missing person

Purple Alert is the first app of its kind in the UK and is available for free download to iOS and Android smartphones. NHS Grampian and Alzheimer Scotland dementia nurse consultant Lyn Irvine said:

“Staying independent within the community is very important for the well-being of people with dementia. This freedom can sometimes come with risks - bustling high streets, shopping centres and busy parks can quickly become overwhelming for some people with dementia and they might want to get away from the high noise levels or overcrowding. That can lead to people becoming lost or disorientated and is one of the biggest concerns we hear from people living with dementia, their families and their carers. This app is aimed at helping to change that.”

“It has already been a big hit with people living with the condition, families, carers and volunteer agencies but for it to be truly effective we need members of the wider public to do their bit by downloading and installing the app.”

To find out more about Purple Alert or to download the app, visit purplealert.org.uk
LIVING WITH DEMENTIA

28 March: Idalina Aguiar, member of the EWGPWD, is campaigning for a Statute for informal carers in Portugal

I have lived with dementia for several years now and I am very grateful to my family for their care and support. In particular, to my daughter Nélida who is a partial and occasional caregiver, because she needs to keep working, she has to reconcile her professional activity with the provision of care. She often has to work 12 hours a day, and does not take weekends or holidays, so as to compensate for leave taken to support me.

Caring for a relative or friend can be a very rewarding experience but can also be very challenging. As a person with dementia, I think it is important to recognise the role of the many informal carers providing care and support to people with many different conditions. This is particularly important in countries, such as Portugal where existing services and support is scarce and most of the care is provided by relatives, neighbours and/or friends. It is thus urgent that we put in place the “Statute of the Informal Caregiver”, which could recognise the importance of their dedication and work, and at the same time, protect them and guarantee certain rights. Portugal should learn from other European countries where this already exists.

March was an important milestone in the lives of many of these caregivers: A public petition for the creation of the Statute of the Informal Caregiver was discussed in Plenary in the Assembly of the Republic. I gave, once again, my small contribution, together with my daughter Nélida as we joined this fight.

Being part of the European Working Group of People with Dementia (EWGPWD) has allowed us to have a much more optimistic view about the possibility of living well with dementia, as well as fighting for the rights we are all entitled to. Together we are stronger! Here is to the success of our campaign for this Statute in Portugal! Idalina is supported by her daughter Nélida, to whom we are grateful for her help in translating Idalina’s words to English.

NEW PUBLICATIONS & RESOURCES

26 March: COFACE Families Europe publishes report on the challenges and needs of family carers

This report summarises the findings of a major data collection COFACE Families Europe carried out to take stock on the needs and challenges of family carers in Europe in 2017. With more than 1,000 answers from family carers from 16 European countries, the study provides a better understanding of the situation in Europe and offers policy recommendations from family carers to better meet their needs and tackle their social exclusion. Family carers are Europe’s invisible workforce, and they represent one of the most silenced, socially excluded groups. This study takes a closer look at who family carers are, and what are the main challenges they face, when it comes to accessing resources, services and flexible time arrangements. The full report is available here.

10 April: Alzheimer’s Association and National Institute on Aging release new research framework towards a biological definition of Alzheimer’s disease

On 10 April, a group of international academic, advocacy, government and industry experts published an update on the 2011 NIA- AA (National Institute on Aging - Alzheimer’s Association) workgroup recommendations in the journal Alzheimer’s & Dementia.

The update is a renewed unification of the 2011 recommendations, intended to be in line with today’s understanding of the Alzheimer’s disease (AD) continuum. The team presented drafts online and at various scientific meetings such as the Alzheimer’s Association International Conference 2017, to gather feedback and ideas that informed the published document.

Leaving room for biomarkers in future, the framework defines AD by brain changes including three groups of biomarkers;
beta amyloid deposition, pathologic tau and neurodegeneration but not symptoms. This system could potentially help moving research towards personalised medicine to tailor future treatments more targeted to individuals.

One of the major changes from the 2011 recommendations is that the publication is not meant for general clinical practice since it needs further testing. Its intention is to act as “research framework” for the scientific community towards the development of a biologically based definition of AD, rather than guidelines or diagnostic criteria. Publication: http://www.alzheimersanddementia.com/article/S1552-5260(18)30072-4/pdf

NIA commentary: http://www.alzheimersanddementia.com/article/S1552-5260(18)30082-7/pdf

19 April: Short animated film made about rare form of dementia called PCA - “Do I see what you see?”

How do changes in the brain cause us to see differently? Experience the world through the eyes of people living with Posterior Cortical Atrophy (PCA), a rare form of dementia which affects the visual areas of the brain, in this short, animated film directed by Simon Ball and developed in partnership with the Alzheimer’s Society (UK).

The film features 6 personal stories and aims to recreate what it feels like to live with the knowledge that your brain might be “playing tricks on you” with regards what you are seeing, as compared with how others see, or how you might have previously seen things. Everyday tasks such as making a cup of tea, reading, driving and walking down stairs are beset with obstacles.

DONATE NOW! Help us make dementia a priority

23 April: IMI is recruiting a Scientific Project Officer

The Innovative Medicines Initiative (IMI) is recruiting a Scientific Project Officer to join their team. The Scientific Project Officer will be assigned duties and responsibilities within the scientific operations team related to the planning, management and implementation of research and development activities and the follow-up of the entire cycle of projects.

The deadline for applications is 21 May 2018. You can find more information about the position and the recruitment process here.

23 April: The School of Nursing and Human Sciences DCU launches two new training programmes

The School of Nursing and Human Sciences of the Dublin City University (DCU) will run two new streams from September 2018 on Dementia Nursing practice (DC763) and Dementia Healthcare practice (DC764). Both trainings, at level nine on the National Framework of Qualifications, are part-time that allow students to obtain a Master degree or exit with a Graduate Diploma or Graduate Certificate if they do not wish to continue to Masters.

Applicants must have a primary degree in dementia with a minimum 2.2 grade. In addition applicants should ideally have a minimum of one year’s practical experience, with three months experience in dementia care and a current experience working a minimum of 20 hours per week in dementia care.

For more information visit https://www.dcu.ie/snhs/postgraduate-listings.shtml or contact snhsenquires@dcu.ie or louise.hopper@dcu.ie

AE CALENDAR

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<tr>
<td>7-8 May</td>
<td>Scientific Advisory Committee of Neighbourhoods and Dementia Study (Manchester, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>7-8 May</td>
<td>SyDAD annual meeting (Milan, Italy)</td>
<td>Cindy</td>
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<tr>
<td>9-11 May</td>
<td>Workshop “Harmonising Neuropsychological Assessment for Dementia in Europe” (Geneva, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>12-16 May</td>
<td>ICCA AES – IMEX (Frankfurt, Germany)</td>
<td>Gwladys</td>
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<tr>
<td>18 May</td>
<td>AE ethics meeting on intercultural care and support for minority ethnic groups (Bradford, UK)</td>
<td>Dianne and Jean</td>
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<tr>
<td>23-25 May</td>
<td>EPAD General Assembly Meeting (Amsterdam, The Netherlands)</td>
<td>Dianne, Cindy, Jean</td>
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<tr>
<td>28 May</td>
<td>Living with dementia in rural Ireland (Connemara, Ireland)</td>
<td>Dianne</td>
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<tr>
<td>29-31 May</td>
<td>Joint Action Programme Board (Utrecht, Netherlands)</td>
<td>Jean</td>
</tr>
<tr>
<td>Date</td>
<td>Meeting</td>
<td>Place</td>
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<tr>
<td>2-4 May</td>
<td>24th Nordic Congress of Gerontology (24NKG), <a href="http://www.24nk.no">www.24nk.no</a></td>
<td>Oslo, Norway</td>
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<tr>
<td>24-26 May</td>
<td>Research in Palliative Care for Older People: Overcoming methodological research challenges, <a href="http://eapm2018.forskningsweb.org/">http://eapm2018.forskningsweb.org/</a></td>
<td>Bern, Switzerland</td>
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<tr>
<td>6-8 June</td>
<td>8th Kuopio Alzheimer Symposium, <a href="https://www.uef.fi/fi/web/kuopioadssymposium">https://www.uef.fi/fi/web/kuopioadssymposium</a></td>
<td>Kuopio, Finland</td>
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<tr>
<td>7-8 June</td>
<td>HammondCare International Dementia Conference - Mission Impossible? Truth and Lies in the Age of Choice, <a href="http://www.dementiaconferene.com">www.dementiaconferene.com</a></td>
<td>Sydney, Australia</td>
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<tr>
<td>7-8 June</td>
<td>BestCare4Dem - Sharing effective community-based support in dementia, <a href="https://www.meetingdem.eu/">https://www.meetingdem.eu/</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>4-6 July</td>
<td>British Society of Gerontology Annual Conference, <a href="http://www.britishgerontology.org">www.britishgerontology.org</a></td>
<td>Manchester, UK</td>
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<tr>
<td>7-11 July</td>
<td>11th FENS Forum of Neuroscience, <a href="http://www.forskningsweb.org/">http://www.forskningsweb.org/</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>26-29 July</td>
<td>International Conference of Alzheimer’s Disease International (ADI), <a href="https://www.adiology.org/">https://www.adiology.org/</a></td>
<td>Chicago, USA</td>
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<tr>
<td>18-19 October</td>
<td>2nd MINC Symposium, <a href="http://www.minc.org">http://www.minc.org</a></td>
<td>Köln, Germany</td>
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<tr>
<td>24-27 October</td>
<td>11th Clinical Trials on Alzheimer Conference (CTAD), <a href="http://www.ctad-alzheimer.com">www.ctad-alzheimer.com</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>11-14 November</td>
<td>11th International FTD Conference <a href="https://conferences.eventair.com/QuickEventWebsitePortal/icftd2018/cs">https://conferences.eventair.com/QuickEventWebsitePortal/icftd2018/cs</a></td>
<td>Sydney, Australia</td>
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<tr>
<td>22-25 October</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague, Netherlands</td>
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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.