WELCOME

The Alzheimer Europe team has just returned from Brussels, where we had a series of successful meetings - a Board meeting, Company Round Table, Public Affairs meeting and a meeting of the European Working Group of People with Dementia (EWGPWD) – which were a great opportunity to catch up with sponsors, national members and members of the EWGPWD, regarding ongoing projects and our upcoming conference #29AEC. On the subject of the conference, I am delighted to report that registrations as at the end of the Early Bird period (30 June) are at an all-time high, with over 600 delegates registered already!

Just a few days prior to these meetings, we convened a second meeting of the Governmental Expert Group on Dementia. 20 European countries were represented, as were the 2nd European Joint Action on Dementia (Act on Dementia/DEM2), the World Health Organization (WHO) and Alzheimer Europe.

Also on the EU front, I am pleased to announce a newly-formed European Alzheimer’s Alliance (EAA) for 2019-2024. Thanks to the hard work of our members, campaigning in the run-up to the elections, the EAA will start its new term with 89 members, from 26 countries. You can read more in the European Alzheimer’s Alliance section and also in the newly-published 30th issue of our Dementia in Europe magazine.

In less positive EU news, we have learned that decisions have again been postponed in relation to the action on the EU’s long-term budget 2021-2027 - the Multiannual Financial Framework (MFF) - until the end of 2019.

On a happier note, I would like to thank the Innovative Medicines Initiative (IMI) for inviting me to join a panel at its annual Stakeholder Forum. The Forum took place in Brussels under the theme “Brain health and disease in the digital era - 2020 & beyond” in mid-June, and it was an honour and a pleasure to be a part of this event. I would also like to highlight that the IMI is currently looking to strengthen the role and voice of patients in its activities by creating a pool of patient experts.

On the global front, congratulations to our friends in Canada, who have just launched their first national dementia strategy. This brings the primary target of the WHO’s global dementia action plan - to have 146 of the 194 WHO Member States develop a national response plan to dementia by 2025 - one step closer, although there is still a very long way to go.

Finally, I would like to give a special mention to one of the members of the EWGPWD, Chris Roberts (the group’s Vice-chairperson), who has received a “Continued contribution award” at the People Awards, held annually by the Alzheimer’s Society (UK). Congratulations, Chris!

As in recent years, we will combine July and August into one summer newsletter. In the meantime, enjoy the sunshine!

Jean Georges
Executive Director
ALZHEIMER EUROPE

25 May: Chris Roberts receives “Continued contribution award” for his advocacy work

Chris Roberts, Vice-chairperson of the European Working Group of People with Dementia (EWGPWD), has received a “Continued contribution award” at the People Awards, which are held annually by the Alzheimer’s Society (UK). The People Awards celebrate outstanding contributions by people working with and for people with dementia and Mr Roberts received his in recognition of his advocacy work for people affected by dementia. This year’s awards ceremony was hosted by the Alzheimer’s Society’s Royal Patron, Her Royal Highness Princess Alexandra, the Hon. Lady Ogilvy, at St. James’ Palace, London, on 25 May.

Chris Roberts is from Wales. He was diagnosed with mixed dementia (Alzheimer’s type and vascular dementia) in early 2012 but has not let this diagnosis get in the way of leading a full life. Much of his time is spent providing education about dementia and advocating for the rights of people with dementia, as well as campaigning for better services. Mr Roberts has been an ambassador for the Alzheimer’s Society since 2014 and has been Vice-chairperson of the EWGPWD since 2016.

Alzheimer Europe would like to congratulate Mr Roberts on his well-deserved award and thank him for all the hard work he does, both at national and European level.

Pictured: Chris Roberts and HRH Princess Alexandra at the People Awards 2019

20 June: 30th edition of Dementia in Europe magazine published

We are pleased to present the 30th edition of our Dementia in Europe magazine. The magazine, which is largely focused on dementia policy, details some of our recent efforts to ensure dementia remains a European priority. We discuss the recent European Parliament elections and our #DementiaPledge2019 campaign, which sought to engage as many MEPs as possible, to ensure dementia is a priority for the EU. We are hugely grateful to our national member organisations and members of the European Working Group of People with Dementia (EWGPWD) for their vital support, without which the campaign could not have been a success. We also thank all 230 MEP candidates that signed the pledge, and look forward to working with those elected MEPs now in the 2019-2024 European Alzheimer’s Alliance.

We also report on our most recent European Parliament lunch debate, which looked at dementia research as a European priority. Presentations were given by Pierre Meulien of the Innovative Medicines Initiative (IMI), Mikko Hiltunen of the University of Eastern Finland and from Stéphane Hogan of the European Commission. Some of our own involvement in dementia research is presented, with Another aspect of our EU-level work is our involvement in different EU-funded research projects and in this edition of the magazine, we take a look at three of these: We introduce a new project, RADAR-AD (Remote Assessment of Disease and Relapse in Alzheimer’s disease); we talk to some of the stakeholders in PARADIGM - Patients Active in Research and Dialogues for an Improved Generation of Medicines – about why they became involved in the project; and we speak to the project coordinators of the recently-finished AETIONOMY project, about its outcomes and impact.

The European Disability Forum tells Dementia in Europe readers about its European election campaign, which sought to break down voting barriers, both legal and physical. The World Health Organisation and WHO Europe shares progress made on the Global Action Plan on Dementia so far and we also take a look at Horizon Europe - the successor to the Horizon 2020 research programme. The latest Brexit developments and their implications for different aspects of European policy and practice are also explored and at national level, we look at Spain’s new National Alzheimer’s Plan.

In our society section, we cover a range of policy-related activities both from our national members in Finland, France and Scotland, and from other stakeholders, including an article looking at four different carers’ networks across Europe. Additionally, EWGPWD member Petri Lampinen (Finland) shares with us his experience of using the new European Disability Card. You can buy the magazine via our E-shop: http://alzheimer-europe.org/Publications/E-Shop.

Past issues can be freely downloaded here: http://alzheimer-europe.org/Publications/Dementia-in-Europe-magazines
24-25 June: Alzheimer Europe Board meets in Brussels

The Alzheimer Europe Board members convened in Brussels on 24-25 June 2019. The meeting agenda included various financial and operational matters, including preparations for the 29th Alzheimer Europe Conference “Making Valuable Connections” in The Hague, Netherlands. The Board also analysed the outcomes of the recent European Parliament elections and discussed the relaunch of the European Alzheimer’s Alliance as well as the general progress of the organisation’s 2019 activities (prevalence of dementia in Europe, involvement of people with dementia in research).

The Board approved the 2020 Work Plan and Budget for Alzheimer Europe which will be presented and further discussed at the Annual General Meeting of the organisation in The Hague. The Board also checked different quotes for the 2022 Annual Conference and opted for Helsinki, Finland as the venue for its conference.

The next Board meeting will take place in The Hague on 23 October, prior to the Annual Meeting and the conference.

25 June: Alzheimer Europe holds Company Round Table in Brussels

On 25 June, Alzheimer Europe (AE) held a Company Round Table meeting in Brussels (Belgium). Four representatives from three sponsor companies (Roche, Biogen, Lundbeck), sixteen representatives from AE member organisations, nine AE Board members and six AE staff members attended.

AE Vice-Chair, Iva Holmerová welcomed participants and introduced AE Project Officer Cindy Birck. Cindy updated sponsors and other delegates on recent developments on AE’s Clinical Trial Watch. Following this, Martin Traber from Roche presented some recommendations on how to communicate negative research results and shared some experiences of Roche. Participants also heard about the European Parliament elections, which took place in May 2019 and gave feedback on this. AE Policy Officer Owen Miller gave delegates a presentation on the election’s results and next steps. Owen closed then the meeting with a presentation about the European Dementia Monitor, comparing EU country data around national dementia strategies and policies.

The next Company Round Table meeting will be in Brussels on 10 December.

26 June: Alzheimer Europe holds Public Affairs meeting in Brussels

On 26 June 2019, Alzheimer Europe (AE) hosted a Public Affairs meeting in Brussels, Belgium. 25 representatives from AE member organisations, 6 AE staff members and an expert speaker from the University of Vienna were in attendance. AE Chairperson Iva Holmerová led the meeting.

The agenda focused on:

- recent European developments (EU4health Campaign; Government Expert; BREXIT)
- reconvening the European Alzheimer’s Alliance following the European Parliament elections
- the involvement of national members in AE’s policy work
- European legislation on data protection and its implications for health research and data sharing
- data sharing in European research projects and at national level
- our 2019 publications, and
• the status of national dementia plans in Spain, Germany and Sweden, as well as other national developments.

Alzheimer Europe is looking forward to meeting with its national member organisations again, at its AGM on 23 October in The Hague, as well as at the annual Alzheimer’s Association Academy on 10-11 December in Brussels.

**25-27 June: European Working Group of People with Dementia meets in Brussels**

Members of the European Working Group of People with Dementia (EWGPWD) and their supporters met in Brussels, from 25 to 27 June 2019. During the meeting, the group discussed and provided feedback on different issues linked to Alzheimer Europe (AE) activities such as the work on ethical issues in dementia research and dementia-friendly communities that AE is currently developing.

Members of the EWGPWD also dedicated some time to the preparation of their Special Symposium at the 29th AE Conference (#29AEC) in The Hague, and updated the group’s internal guidelines for participating in meetings.

All members actively contributed to several EU projects, such as RADAR-AD (Remote Assessment of Disease And Relapse – Alzheimer’s Disease) (ethical issues and dissemination), AD Detect-Prevent and SPAN+. Hannah Fitzgibbon from the Alzheimer’s Society (UK), Sébastien Libert from the INDUCT (Interdisciplinary Network for Dementia Utilising Current Technology) project and Federica Lucivero from RADAR-AD took part and contributed to different sessions in the meeting.

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**#29AEC - MEET THE SPEAKERS**

**Henry Brodaty, Australia**

Professor Brodaty is a researcher, clinician, policy advisor and advocate for people with dementia and their carers. At UNSW Sydney (the University of New South Wales), he is Scientia Professor of Ageing and Mental Health, Co-Director of the Centre for Healthy Brain Ageing, and Director, Dementia Centre for Research Collaboration. He has over 500 publications in refereed journals, is senior psychogeriatrician and Head of the Memory Clinic at POW Hospital.

He is an officer of the Order of Australia and a Ryman Prize winner.

Prof. Brodaty is one of the speakers in Plenary 1, on 24 October.

**Dag Aarsland, Norway**

Professor Dag Aarsland is Head of Department of Old Age Psychiatry, Institute of Psychiatry, Psychology and Neuroscience at King’s College London and the National Institute for Health Research (NIHR) Biomedical Research Centre Dementia Theme Lead.

Before this post, he was Professor of Clinical Dementia Research at the Alzheimer’s Disease Research Centre at the Karolinska Institute in Sweden. He founded and still leads the section of geriatric psychiatry and the Centre for Age-Related Disease at Stavanger University Hospital, Norway.

Prof. Aarsland is one of the speakers in Plenary 2, on 24 October.
Bernd Heise, Germany

Bernd Heise joined the European Working Group of People with Dementia (EWGPWD) in 2018. He is married and lives in Munich, Germany with his wife. For 34 years, he had worked as a development engineer of semiconductor devices in the telecommunications industry, until he was diagnosed with Alzheimer’s disease in early 2016.

He is also a member of the Advisory Board of People Living with Dementia, founded by the German Alzheimer association (Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz).

Mr Heise is one of the speakers in Plenary 3, on 25 October.

Wiesje van der Flier, Netherlands

Professor Wiesje van der Flier is Head of Clinical Research at the Alzheimer Center of the VU University Medical Center in Amsterdam (VUmc), where she has worked since 2004. She studied neuropsychology at the University of Utrecht. In addition, she is a clinical epidemiologist.

She is head of the Amsterdam Dementia Cohort, an ongoing memory-clinic based cohort, including over 6,000 patients with deep phenotyping (MRI, EEG, CSF biomarkers, and PET) and linked biobank (blood, DNA, CSF). The Amsterdam Dementia Cohort is at the basis of many of the studies performed at the VUmc Alzheimer centre.

Prof. van der Flier is one of the speakers in Plenary 1, on 24 October.


30 June: Early Bird registrations for Alzheimer Europe Conference reach an all-time high

Early Bird rates for the 29th Alzheimer Europe Conference (#29AEC) have now ended and we are delighted to announce that we already have over 600 delegates registered, with many more expected between now and close of online registrations, on 13 October 2019. The number of registrations so far has exceeded all previous years. We are excited to see everyone there, for what promises to be a diverse and engaging conference.


Alzheimer Europe networking

On 1-2 June (Brussels, Belgium), Owen attended the European Disability Forum’s (EDF) Annual General Assembly where the organisation reviewed its past and work.

On 4 and 5 June (Vienna, Austria), Jean participated in the Task Force of the European Academy of Neurology for its guideline on medical management issues in dementia.

On 4 June (Brussels, Belgium), Ana attended the EFPIA Patient Think Tank Strategy Workshop.

On 5 June (Brussels, Belgium), Angela attended an EFPIA patient think tank meeting.

On 12 June (Brussels, Belgium), Jean and Cindy attended the Innovative Medicines Initiatives (IMI) Stakeholder Forum.

On 17 and 18 June (Amsterdam, Netherlands), Jean and Owen attended the meeting of the European Governmental Expert Group on Dementia.

On 18 June (Amsterdam, Netherlands), Jean attended the Programme Board of the 2nd Joint Action on Dementia.

On 24 and 25 June (Brussels, Belgium), the Alzheimer Europe Board met.

On 25 June (Brussels, Belgium), Alzheimer Europe organised a company round table meeting.

From 25 to 27 June (Brussels, Belgium), Dianne and Ana participated in the EWGPWD meeting.
29 May: Commission publishes guidance on processing mixed datasets containing non-personal and personal data

Following the entry into force of the Free Flow of Non-Personal Data Regulation (FFDR) on 28 May 2019, the European Commission has published new guidance on interactions between this new regulation and the General Data Protection Regulation (GDPR), which covers personal data. The FFDR is a central part of the legal framework supporting the EU data economy, enabling non-personal data to be stored and processed throughout the EU without unjustified restrictions. The Commission’s new guidance will be particularly important for companies and institutions that process mixed datasets which contain both non-personal and personal data.

Non-personal data is defined as data that cannot be attributed to an identified or identifiable person, such as data on recycling from waste management centres, or fully anonymised health research data. Conversely, personal data can be attributed to an identified (or identifiable) individuals, for example ‘pseudonymised’ data from participants in clinical research studies. Mixed datasets, such as electronic health records or data collected by mobile health apps, are becoming increasingly common in the data economy.

The European Commission’s new guidance clarifies that the GDPR applies to the personal data parts of mixed datasets, while the FFDR applies to the non-personal data part of mixed datasets. Importantly, where non-personal and personal data are ‘inextricably linked’ or indivisible, the heightened data protection rights and obligations under the GDPR apply to the entire mixed dataset – even if the personal data component represents only a small part of the whole dataset.


31 May: Open access science initiative delayed by one year

Plan S, a coordinated approach by research funders and organisations aiming to improve access to the findings of publicly-funded research, is to be delayed by a year, with 2021 now the intended commencement date.

Following consultation between members of “Coalition S” (organisations which support the proposals) about how the open access initiative should work, the delay has been agreed as a way to allow greater time for researchers, institutions, publishers, etc. to make the required changes.
From 1 January 2021, funding agencies including UK Research and Innovation, Science Foundation Ireland and the Research Council of Norway, will require scientists who receive grants from them to make the resulting papers free to read immediately on publication, as well as allowing others to download, translate and reuse the work.

Additionally, 13 of Europe’s national funding agencies have joined Coalition S, as well as the Wellcome Trust and the Bill & Melinda Gates Foundation. The funders say they will commission an analysis to find out which disciplines need more open access outlets. More information on the revised timescales, as well as Plan S itself, can be found at:

https://www.coalition-s.org/revised-implementation-guidance/

5 June: European Commission sets out country-specific recommendations on research

As part of its European Semester process (the EU’s yearly cycle of economic, fiscal and social policy coordination), the European Commission has adopted proposals for country specific recommendations. Recommendations for all 28 Member States have been issued, primarily focused around the need to increase investment in research and innovation.

Of particular interest, three Member States, Greece, Poland and Slovakia, had specific recommendations in relation to healthcare-related research. Also of note, the recommendations for Denmark noted the country’s focus on research in the fields of pharmacology and biotechnology.

The Commission’s proposals for country-specific recommendations will now be discussed in the Council, where EU countries have until early July to vote on their final adoption. Following the approval of the recommendations, their implementation will be monitored.

You can read the full recommendations here:

5 June: European Commission sets out country-specific recommendations on health

As part of its European Semester process (the EU’s yearly cycle of economic, fiscal and social policy coordination), the European Commission has adopted proposals for country specific recommendations, including some specifically focused on health. There are 16 Member States for whom health specific recommendations have been made, focused on a range of themes including, investing in national health systems, improving health system effectiveness and increasing accessibility and resilience of health systems.

Member States are responsible for their own health policy and the organisation and delivery of care. As part of the European Semester, however, the EU can give a recommendation to an EU country on certain aspects of its health system, which relate to general economic, fiscal and social policies.

The Commission has identified the need to address investments in Member States as a priority for this year, particularly in light of ongoing negotiations about the future Multiannual Financial Framework for 2021 to 2027. The Commission’s proposals for country-specific recommendations will now be discussed in the European Council, where EU countries have until early July to vote on their final adoption. Following the approval of the recommendations, their implementation will be monitored.

The health-related recommendations are as follows:

| BO | Improve access to health services, including by reducing out-of-pocket payments and addressing shortages of health professionals. |
| CZ | Improve long-term fiscal sustainability of the pension and healthcare systems. |
| IE | Address the expected increase in age-related expenditure by making the healthcare system more cost-effective. |
| EL | Focus investment-related economic policy on, ..., health, ..., taking into account regional disparities and the need to ensure social inclusion. |
| CY | Take measures to ensure that the National Health System becomes operational in 2020, as planned, while preserving its long-term sustainability. |
| LV | Increase the accessibility, quality and cost-effectiveness of the healthcare system. |
| LT | Increase the quality, affordability and efficiency of the healthcare system. |
| HU | Improve health outcomes by supporting preventive health measures and strengthening primary health care. |
| MT | Ensure the fiscal sustainability of the healthcare and the pension systems. |
| AT | Ensure the sustainability of the health, long-term care, and pension systems. |
| PL | Focus investment-related economic policy on, healthcare, taking into account regional disparities etc. |
| FT | Improve the quality of public finances by prioritising growth-enhancing spending while strengthening overall expenditure control, cost efficiency and adequate budgeting, with a focus in particular on a durable reduction of arrears in hospitals. |
| RO | Improve access to and cost-efficiency of healthcare, including through the shift to outpatient care. |
| SI | Adopt and implement reforms in healthcare and long-term care that ensure quality, accessibility and long-term fiscal sustainability. |
| SK | Safeguard the long-term sustainability of public finances, notably that of the healthcare and pension systems. |
| FI | Improve the cost-effectiveness of and equal access to social and healthcare services. |
5 June: Patient Think Tank meeting held at EFPIA

On 5 June, the European Federation of Pharmaceutical Industries and Associations (EFPIA) held a patient think tank (PTT) meeting in Brussels. Big Data and data sharing featured throughout the PTT meeting, which included presentations on I^HD (enriching knowledge and enhancing care through health data) and Data Saves Lives projects. An overview of the general data protection regulation (GDPR) and the GDPR research exemption was also presented. Of particular relevance to Alzheimer Europe, Data Saves Lives is a multi-platform initiative co-created by the European Patients’ Forum (EPF), aiming to develop an information-rich interface for patients and members of the public that enables them to participate in conversations around health data use and sharing.

Finally, EFPIA presented an update on the patient remuneration principles being co-developed by EFPIA and the PTT. Alzheimer Europe Project Officer Angela Bradshaw attended the meeting.

12 June: IMI holds its annual Stakeholder Forum

On 12 June, the Innovative Medicines Initiative (IMI) held its annual Stakeholder Forum in Brussels under the theme “Brain health and disease in the digital era - 2020 & beyond”. The event gathered more than 400 delegates including policy makers, academics, pharmaceutical industry, patient representatives, regulators, SMEs and research-funding organisations to discuss how we could develop game-changing initiatives in the brain area.

Wolfgang Burtscher (Deputy Director-General, DG Research and Innovation, European Commission) and Dhaiwal Patel (Executive Vice President, Chief Scientific Officer, UCB) opened the event and highlighted the importance of public and private partnership across sectors to tackling brain disorders. They drew the attention to the fact that IMI is engaged in these important discussions and contributions for a decade. Pierre Meulien (Executive Director, IMI) then introduced the next IMI’s Calls for proposals, IMI2 Calls 18 and 19. Luca Pani (Professor of Psychiatry, University of Miami and Professor of Pharmacology, Università di Modena e Reggio Emilia) set the scene by giving a fantastic presentation. He underlined the availability of health (quantitative and qualitative) data, digital products used as biomarkers and artificial intelligence.

The morning was then dedicated to healthy lifestyles, prevention and diagnosis. Miia Kivipelto (Professor of Clinical Geriatric Epidemiology, Department of Neurobiology, Karolinska Institutet) underlined the importance of the prevention for Alzheimer’s disease. Discussions were hold on how different stakeholders are engaging with digital health technologies and they are demonstrating reliability and performance of these technology while assuring compliance with legal, regulatory and ethical requirements. Speakers also explored the potential of digital technologies to facilitate timely and accurate diagnosis. There were also an interesting discussion on benchmarking technologies.

The afternoon session concentrated on treatment and care discussing questions such as how can digital technologies enhance the development and delivery of pharmacological interventions or issues like usability, usefulness and acceptance of these technologies by the patients and their carers. Hilary Duxford (dementia Advocate) and her husband and supporter Peter Paniccia were among the panellists. Hilary is a former member of the European Working Group of People with Dementia (EWGPWD) – group launched by Alzheimer Europe (AE) and its member associations in 2012. She stated that anything that can be done to help patients and their carers would be appreciated. She also underlined the importance of engaging patients straight from the beginning.

The Stakeholder Forum ended with a high level panel discussion. Several key stakeholders were invited to discuss main points and questions raised in earlier sessions. AE Executive Director Jean Georges (pictured) was part of the panel and highlighted some achievements from IMI research projects such as EPAD, AMYPAD, ROADMAP and AETIONOMY where Alzheimer Europe is involved. He also stressed the importance of breaking down silos between and within projects. Project Officer Cindy Birck also attended the meeting.


17-18 June: Governmental Expert Group on Dementia holds second meeting

The European Group of Governmental Experts on Dementia held its second meeting on 17 and 18 June 2019 in Amsterdam, The Netherlands. 20 European countries were represented at the meeting, in addition to representatives from the 2nd European Joint Action on Dementia (Act on
Dementia/DEM2), the World Health Organization (WHO) and Alzheimer Europe.

The group met for the first time in December 2018 as a response to the decision of the European Commission to disband its condition-specific expert groups in favour of a broader health prevention of non-communicable diseases group. The health ministries of Italy, The Netherlands and Scotland (UK), along with Alzheimer Europe, agreed that such a platform was vital for the exchange of knowledge and expertise between countries.

At this second meeting, members of the 2nd Joint Action, provided members of the group with an update on the latest progress and findings from their respective work package areas: Diagnosis and post-diagnostic support; Crisis and care coordination; Residential care, and; Dementia-friendly communities.

Following each introduction, members of the group were able to contribute, sharing the work taking place in their countries, as well as asking questions of each other, to find out how barriers had been overcome in different areas. The WHO also updated members on the progress made in implementing its “Global action plan on the public health response to dementia 2017-2025”, including the publication of the iSupport resource for carers, and the progress of the Global Dementia Observatory.

The group will meet, for a third time, in December 2019 in Brussels, Belgium.

21 June: The Innovative Medicines Initiative is looking to strengthen the role and voice of patients in its activities

The Innovative Medicines Initiative (IMI) has always involved patients in its projects and activities, but it now plans to further strengthen the role and voice of patients in its activities at strategic and operational levels, by creating a pool of patient experts. Patients who are part of the pool would be invited on an ad hoc basis to:

- provide input on IMI’s scientific strategy (annual priorities, topic development etc.), for example by taking part in early consultations and workshops, Strategic Governing Group (SGG) meetings, etc.
- participate in panels to review project proposals
- participate in reviews of ongoing and closed projects
- review the content of documents prepared for patients and the general public
- participate in IMI events.

Benefits of becoming a member of the pool include the opportunity to:

- influence IMI’s activities on both strategic and operational levels
- work alongside experts from other sectors (academia, industry, regulatory, etc.)
- raise the profile of patients as equal partners in research in the IMI community and beyond
- learn first-hand about the latest research developments in your disease area.

Patients (and family members and carers) who wish to be part of the pool should submit an Expression of Interest via this form:


The deadline for submitting expressions of interest is 16 July 2019 at 17:00 CEST (Central European Summer Time / Brussels time). Find out more and apply to join the pool of patient experts, here:


24 June: EU delays finalisation of budget process until end of 2019

The EU has, again, postponed decisions in relation to the action on its long-term budget 2021-2027 - the Multiannual Financial Framework (MFF) - until the end of 2019.

At the most recent meeting of heads of government at the European Council, on 20 June 2019, it was agreed that the budget would be discussed again in October, with the aim of concluding a deal by the end of the year. Finance ministers and diplomats will continue negotiations, in the meantime.

The original plan had been for the process to be completed by May 2019, however, this had then been delayed until October 2019, before this most recent development at the European Council meeting.

The delay will shorten the time the European Commission has to prepare the next round of long-term spending programmes, such as the estimated EUR 94 billion for the future Horizon Europe research programme. As such, there is concern that there will be a knock-on effect, between the conclusion of the Horizon 2020 programme and the beginning of the Horizon Europe programme in 2021.
26 June: EMA-PCWP-HCPWP organise joint virtual meeting

On 26 June, the European Medicines Agency (EMA) Working Parties with Patients’ and Consumers’ Organisations (PCWP) and Healthcare Professionals’ Organisations (HCPWP) held a virtual meeting with all EMA eligible organisations. More than 50 attendees joined the meeting. An update on the relocation of the agency from London to Amsterdam and Brexit preparedness were provided to meeting delegates. During the meeting, the group discussed about the new mandate 2019-2022. June 2019 marks the start of the new mandate for both the PCWP and HCPWP. The working parties are composed of the following members: selected patient/ consumer, healthcare professional organisations that fulfil EMA eligibility criteria, scientific committees, EMA secretariat and observers. We were pleased to hear that the group is planning to reconvene face to face meetings in September 2019 in Amsterdam. In addition, the group pointed out the new mandate 2019-2022 and highlighted four key areas of work including 1) medicines development and evaluation, 2) information on medicines, 3) building trust and developing methodology and 4) public focus health area. Other topics discussed during the meeting included Patient-Reported Outcomes in scientific advice study and the protection of personal data within EMA. Cindy Birck represented Alzheimer Europe, a full member of the PCWP, at the meeting.

On 24 May, Alzheimer Europe received a positive outcome from a periodic EMA re-evaluation of eligibility. The letter states that AE “has been accepted as member of the PCWP group for the term 2019 to 2022”. AE is delighted to continue its collaboration within the PCWP and look forward to its active involvement over the next mandate of the group.

EUROPEAN ALZHEIMER’S ALLIANCE

28 May: New members of the European Alzheimer’s Alliance are announced

Following the European Parliament elections between 23 and 26 May, and the #DementiaPledge2019 campaign, Alzheimer Europe is pleased to announce the newly-formed European Alzheimer’s Alliance (EAA) for 2019-2024. Thanks to the hard work of Alzheimer Europe’s members and their efforts campaigning in the run-up to the elections, the EAA will start its new term with 89 members, from 26 countries.

Alzheimer Europe will be writing to MEPs in the new EAA, in the coming weeks, thanking newly-elected pledgees for their support in making dementia a European priority, as well writing to thank EAA members for the previous 2014-2019 term that were re-elected. In these letters, EAA members will be asked to use their positions to ensure dementia is a European priority, through a series of specific asks. Alzheimer Europe is delighted to announce that Sirpa Pietikäinen, MEP (Finland) has agreed to be the new Chairperson of the EAA, going forward. Thanks, also, to former MEP Françoise Grossetête, who was the first Chairperson of the EAA, from its beginnings in 2007, until May 2019, when she decided not to stand for re-election as an MEP. Alzheimer Europe formally reconvene the EAA, including a new Chair and Vice Chairs.

We will update our website with the new EAA members, in due course.

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MEMBERS’ NEWS

24 May: Alzheimer Portugal holds conference on involvement in clinical trials

A recent study from APIFARMA (Portuguese association of pharmaceutical companies) reveals that the number of clinical trials in Portugal may increase 3.7 times per million inhabitants. The study also claims that each euro invested in clinical trials would result in double the return for the national economy.

With the growing number of neurodegenerative diseases, mainly due to the ageing of the Portuguese population, it has become crucial to find new, safe, effective and innovative medicines for diseases such as multiple sclerosis (MS), Parkinson’s disease (PD) and Alzheimer’s disease (AD).

As far as AD is concerned, it must be stressed that, in spite of the number of failures in clinical trials in recent years, it is important not to give up but to continue to search for new answers that may contribute to quality-of-life for those living with AD.

With this in mind, a conference was organised by Alzheimer Portugal, on “Clinical Trials – For a Better Public and Patients Involvement”. In attendance, were people living with AD (as well as MS, PD and other neurodegenerative diseases), carers, pharmaceutical companies, researchers, legal experts, and the National Ethics Committee for Clinical Research (CEIC).

The conference was held in Lisbon on 24 May 2019, at Infarmed, the National Medicines Agency. During the opening session, the Chairwoman of Infarmed, Professor Maria do Céu Machado congratulated Alzheimer Portugal’s ongoing work to raise awareness about the importance of participating in clinical trials. One of the sessions, “Clinical trials with no secrets” encouraged delegates to ask any questions they might have – via an app (this allowed more people to participate, both down to reasons of efficiency and anonymity) - to help demystify trials.

Legal and ethical issues was the main focus of another session, looking at informed consent and the particular challenges it presents for people who lose their capacity. Advance directives are important tools to overcome some of the barriers of informed consent. Further discussion is needed on this issue, as Alzheimer Portugal believes the different stakeholders are not sufficiently aware of the need to respect the right of the participant to informed consent.

The main conclusions of the conference were:

- More literature is needed, to persuade people to participate in clinical trials and to avoid a situation where people make their decisions based solely on information given to them by their GPs.
- Efforts are needed to simplify the language used in informed consent files
- Patients should be invited to participate in the design of clinical studies.
- Participants want to know the results of studies in which they have taken part.
- Primary care may play an important role in the recruitment of participants.
- Stakeholders in research should develop networking, to help obtain better results.
- A global and multidisciplinary approach involving science, healthcare, ethics and law is needed to ensure the rights of current and future participants are respected.

25 May: Alzheimer Slovenia organises “In the Rhythm of the Human Brain” conference in Ljubljana

On 25 May 2019, Spominčica organised a conference, entitled “In the Rhythm of the Human Brain”, in Cankarjev dom (convention centre), Ljubljana. For the first time, five different neurological diseases - dementia, Parkinson’s disease, Multiple Sclerosis (MS), Huntington’s disease and Spinal Muscular Atrophy (SMA) - were presented and discussed together, at one event. More than 300 participants attended the conference, including members of the general public, people living with these diseases and their family members, experts and policy makers.

In her welcome speech, Štefanija L. Zlobec, President of Spominčica (Alzheimer Slovenia) stated, that recognition of early signs is possible in all five of the diseases mentioned, and that timely diagnosis is important, since more effective interventions and treatments to control these diseases and/or their symptoms are possible, leading to a better quality-of-life. In her conclusion, she stated, confidently, that a long-term care act would soon be adopted in Slovenia. She added that whole-system care options need to be revised and adapted, to offer more flexible and user-friendly services, especially in the respite care sector.
The conference was held under the honorary patronage of the Slovenian Prime Minister, Marjan Šarec (pictured), who also addressed the delegates, committing himself to the creation and adoption of a long-term care act. Dr Aiga Rurane, representative of the World Health Organisation (WHO) in Slovenia, stressed the importance of awareness-raising, reducing stigma and improving the lives of persons with dementia and other neurological diseases. Other guests at the conference were: Aleš Šabeder, Minister of Health; Dr Tomaž Pilberšek, Secretary of State; and Breda Božnik, State Secretary, Ministry of Labour, Family and Social Affairs.

Each session began with a different keynote speaker - a medical expert - who presented one of the five diseases being discussed. These lectures were followed by a panel discussion involving people living with the diseases/conditions, carers, experts and policy makers. The third and final section of each session was turned over to the audience, giving them a chance to voice relevant questions concerning diagnosis, treatment and living with a disease. Tomaž Gržinič, member of the European Working Group of People with Dementia (EWGPWD) and Mihela Španja, wife of the first Slovenian EWGPWD member Bojan Španja, participated in the dementia panel, together with Dr Milica Gregorič Kramberger (leader of the Slovenian contingent of IMI project MOPEAD), Ms L. Zlobec, and Janja Romih, a representative from the Ministry of Labour, Family and Social Affairs.

The conference succeeded in engaging people living with neurological disease and their carers, who were key in all the panel discussions. Their contributions can have a positive influence on the current gaps in social care and healthcare services, and contribute to a brighter future, in terms of affordable and user-friendly facilities and services that promote social inclusion, dignity and quality-of-life for each individual.

31 May: Alzheimer Larissa organises visit to Museum of Military Veterinary Service

Since ancient times, Thessaly has been famous for horse breeding. A horse portrait, as depicted on local ancient drachmas, has been adopted as part of the contemporary Larissa city seal, although the animal is not used in transportation or agriculture anymore. Several institutions share thematic collections, but the most important is that of the Larissa Museum of Military Veterinary Service, one of the few thematic museums worldwide dedicated to the horse in the Modern Age.

In May 2019, Alzheimer Larissa (Ε.Ε.Ν.Α.Λ.) invited people with dementia and locals to take a stroll around the old stables and blacksmith’s workshop, and arranged for a guided tour of the Military Veterinary Hospital and Training Center (Κ.Ε.ΝΟ.Κ.).

Civilian visitors had the opportunity to learn about the role of the horse in modern human history, as well as in the development and establishment of veterinary science in Greece. They were informed about the different species of equines that were hosted in the premises - exceeding 100,000 some decades ago - as well as their special features and everyday needs. A major aspect was the fabrication and repair of horseshoes, and a detailed demonstration, of farrier skills and tools, was provided. Visitors also inquired about the special laboratory and medical equipment used in animal therapy and reproduction. They discovered similarities to the equipment used in human care, and had the opportunity to discuss good personal and food hygiene practices.

Finally, the visitors met the hard-working military dogs. The centre is responsible for fostering and training these dogs, as well as giving them shelter in their old age, up to the end of life. Caring for animal welfare in advanced age further conveyed a positive message about care for older people in Alzheimer Larissa’s prefecture.

Alzheimer Larissa is grateful to Lieutenant Nik Dimzas for his professional guidance, his humour and for assisting those with mobility problems.
10-14 June: The Irish Dementia Working Group hits the stage at The Abbey Theatre in Dublin

The Irish Dementia Working Group (IDWG) is an advocacy group for people living with dementia that is supported by The Alzheimer Society of Ireland. In the first half of June, the IDWG had the opportunity to work with the Abbey Theatre, Ireland’s national theatre.

The Abbey Theatre put out a call, to work with communities who felt marginalised and silenced, to take part in their 5×5 development series. These projects received five days’ worth of space, technical assistance and EUR 5,000 to help in the development of a theatre piece.

The members of the IDWG know dementia is a topic which has inspired many artists in recent years, and have observed theatres, film-makers, visual artists and writers responding to this condition. Now, though, they wanted their own voices to be heard, by creating their own work, based on the lived-experience of dementia. They want to lift the lid on the complex realities of cognitive impairment.

During their week at the National Theatre, members of the IDWG participated in a series of workshops, facilitated by theatre producers Bow Productions, about issues which matter to them. The goal was to create a theatre piece which reflects the voice of people living with dementia.

Watch this space, as the week’s events were recorded and will be available to share in the near future.

11 June: National Partner event held in Ireland for Dementia: Understand Together campaign

Dementia: Understand Together is a public support, awareness and information campaign aimed at inspiring people from all sections of society to stand together with the half a million people whose families have been affected by dementia.

The campaign is gaining momentum as we highlight the role communities play in the lives of people with dementia and their families. At a recent National Partner event in Dublin over 40 representatives from the retail, transport, banking, health and voluntary and community sector came together to explore their collective role in making communities inclusive.

It was a deeply moving and motivational day with Vice-Chair of the Irish Dementia Working Group (IDWG) Kathy Ryan and member of the Dementia Carers Campaign Network (DCCN) Helena Quaid sharing their experiences of living with dementia and caring for a person with dementia, and how important “understanding communities” are to their health and well-being.

In his passionate address, Irish Social Entrepreneur and founder of the leading youth organisation SpunOut.ie, Ruairí McKiernan, joined their call for action and encouraged everyone to play a part in supporting a person with dementia and their families.

12 June: Alzheimer’s Society supports Channel 4 TV series, “The Restaurant that Makes Mistakes”

Aired on 12 June, “The Restaurant That Makes Mistakes” is a brand new four-part UK television series about a restaurant run by people with dementia.

Alzheimer’s Society supported the production of this ground-breaking TV series, which follows 14 restaurant staff, all living with dementia, at the pop-up restaurant in Bristol.

Over 40,000 people with dementia are under the age of 65 in the UK, yet only a fifth have continued to work after diagnosis. The Restaurant That Makes Mistakes shows how with the right support, and small adjustments, many people with dementia can continue to contribute to the workplace.

Alzheimer’s Society is calling on businesses, communities and individuals to play their part in creating a more inclusive UK for people affected by dementia. As part of this the Society recently launched Dining4Dementia, which was inspired by the TV show. Seven well-known restaurant chains came together to invite people living with dementia to volunteer front-of-house for one weekend (18-19 May).

Jeremy Hughes, Chief Executive at Alzheimer’s Society, said:
“In the UK someone develops dementia every three minutes, but life doesn’t end when dementia begins. The Restaurant That Makes Mistakes is a fantastic example of that – showing what is possible when people understand how best to include and support someone living with dementia.

“There are 850,000 people in the UK who live with dementia and our recent research shows that many feel isolated and lonely. A huge part of the show involves empowering people with dementia to live the life they choose, as well as raising awareness of the condition among employers and the wider community.”

Jelly Drops were invented by a young UK-based scientist called Lewis Hornby, after his grandmother with dementia was hospitalised with dehydration. They are sweets containing 90 per cent water that can help keep older people, especially those with dementia, hydrated. Alzheimer’s Society (UK) is partnering with the Jelly Drops team through its Accelerator Programme - a programme that funds innovations and inventions that help people with dementia. Memory problems can lead to a person with dementia forgetting to drink enough water, and the part of the brain which recognises that the body is in need of hydration may also be impaired by dementia. On top of this, some medications and dementia-related illnesses can make dehydration worse.

Inspired by his grandmother’s love of sweets, Mr Hornby designed the hydrating sweets to be bright, tasty and interesting to people with dementia. The firm outside also makes them easy to pick up. A full box of Jelly Drops is equivalent to drinking three cups of water, which is more than many people with dementia currently consume in a day.

Alzheimer’s Society partnership with Jelly Drops will last 12 months, during which they will support the product designers to learn from people affected by dementia, so that the best possible design is used. The society will also provide a network of links to care industry experts so that the final product can reach as many people affected by dementia as possible. With this support, plus funding of GBP 100,000, the aim is to have the product ready to take to market by the end of the partnership term.

Pictured: Lewis Hornby, with his grandmother, Pat

14 June: Dementia Carers Campaign Network organises Empowering Carer Advocates Event in Dublin, marking Carers Week 2019

The Dementia Carers Campaign Network (DCCN), which is supported by The Alzheimer Society of Ireland (ASI), hosted an event to empower carer advocates in Dublin to mark Carers Week 2019. In recognition of the importance of working together, during Carers Week, representatives and carer advocates from partner organisations were also invited to attend.

The aim of the event was to bring together family carers, to empower them to be a strong voice for carers. To give people the skills, confidence and knowledge to lobby, campaign and highlight the issues and challenges facing family carers.

Speakers included the coordinator of Carers Week, Kevin Deegan; The Alzheimer Society of Ireland CEO, Pat McLoughlin; and CEO of the Irish Cancer Society, Averil Power.

Carers also heard from journalist and author Teena Gates, who spoke of her recent successful campaign for a home care package to bring her 94-year-old dad, Terry, home from hospital. The final speaker, Jillian Garvey, senior manager with Carr Communications, was followed by focus groups discussing the value of the carer voice, and opportunities to work together.
The information from these focus groups will be shared with the 12 partner organisations that support Carers Week. It is hoped that this will inform how The DCCN and ASI engage with carer advocates and how best they can amplify the carer voice and their key messages.

17 June: Italy’s network of dementia-friendly communities now counts 24 territories

“Get to know dementia to eliminate stigma against patients and their families, allowing them to participate in the active life of the community and thus improve their life quality”, says Gabriella Salvini Porro, president of Federazione Alzheimer Italia, explaining the inspiring principle of the dementia-friendly community, “where listening, understanding and inclusion are key everyday words”.

24 dementia-friendly communities, all over Italy, have accepted the challenge set by Federazione Alzheimer Italia. They have all committed to creating a network of citizens, capable of welcoming and involving people with dementia. Each territory designs its own unique initiatives, to suit the local population and culture. These initiatives are achieving good results, both in the communities that have been dementia-friendly for three years now, since the project started, as well as those communities which have recently joined.

Gavirate (Varese) and Catanzaro (in particular in the historic centre), two very distant cities geographically, are now united by their recent decision to join this network. Their first steps are aimed at training professionals who regularly deal with the public and are, therefore, often in contact with people with dementia. Traffic wardens, shopkeepers and librarians are among those who will now have free training to learn what dementia is, how to communicate properly with people with dementia and their families, how to intervene in difficult situations, and how to respect the dignity of people with dementia at all times.

Courses for local police forces are still active in Villaricca (Napoli), Arzignano (Vicenza) and Cremona. At Bari Municipio 2, a training course for employees of the “Spesa Più” supermarket chain was launched as part of the more extensive “Let’s go to the supermarket” project. Various solutions were adopted after the markets had been inspected by people with dementia, such as a dedicated rooms to rest in, furnished with tables, chairs and magazines; special posters with bigger fonts; a special check-out and dedicated parking spaces.

In the town of Cavedine, Valle dei Laghi (Trento) the pedestrian streets contain a multisensory and cognitive stimulation path, with seven different workstations, located at strategic points (such as the main square, the post office, the health residence, the town hall)

There is a lot of focus on young people, especially in Abbiategrasso (Milano), which was the first dementia-friendly community in Italy, where the Bachelet High School students are active citizens in the service of the community, collecting information to identify obstacles and reference points. The teenagers of Albino (Bergamo) are also involved in dementia-friendly projects. In particular, in the CFP Hairdressing School, a specific project has just started, part of which involves providing haircuts for people with dementia, for a nominal fee, one day a week.

Alzheimer Cafés are also widely used. These are meeting places that become a territorial reference point for entire families. They exist in Carate Brianza and Lissone (Monza Brianza) Ivere (Torino), Recco (Genova). In Giovinazzo (Bari), the meetings are hosted by the most central cafes in the city and are open to anyone who wishes to participate.

The 24 dementia-friendly communities in Italy, are: Abbiategrasso (Milano), Alberobello (Bari), Albino (Bergamo), Arzignano (Vicenza), Bari Municipio 2, Carate Brianza (Monza Brianza), Catanzaro centro storico, Cicala (Catanzaro), Conegliano (Treviso), Cremona, Gavirate (Varese), Giovinazzo (Bari), Ivere (Torino), Lissone (Monza Brianza), Monza-Triante, Nomi (Trento), Pinerolo (Torino), Recco (Genova), Scanzorosciate (Bergamo), Tradate (Varese), Comunità della Valle dei Laghi (Trento), Valpolicella (Torino), Verona - San Zeno, and Villaricca (Napoli).

19 June: Jersey Alzheimer’s Association is updating its training course for family carers

The Jersey Alzheimer’s Association (JAA) has been running its “TIPSS 4 Carers Course” for three years. The course, for family carers, runs over four sessions of two hours each and covers topics such as “Dementia, Communication and Connection”, “Looking Beyond Behaviour” and “Enhancing an Enabling Environment”. The course is currently being revamped and updated. If you wish to be informed of the next dates and times, please contact:

michala@jerseyalzheimers.com

21 June: UK smartphone app technology aims to “replace” lost memories

The Alzheimer’s Society (UK) knows it needs to move fast to change the lives of people living with dementia today and that’s what its Innovation team work tirelessly to do.
This year, the Society is supporting new projects through its Accelerator programme and is very pleased to announce its support for the smartphone app “How Do I?” The app can help people with dementia to carry out everyday tasks like boiling a kettle, by flashing up “how to” videos when an object is scanned by their phone.

The videos not only provide prompt for daily routines - how to make a cup of tea or take a bath - but can also remind people with dementia of forgotten memories, with loved ones being able to record an explanation of a photo, and the memory it captures.

This type of technology is particularly important, as Alzheimer’s Society’s research shows that the number of people with dementia who are currently living alone (120,000 people in the UK) is set to double in the next 20 years.

“How Do I?” is the first of a number of projects the Society will be supporting in the coming years through its Accelerator programme. The programme, which received nearly 50 applications, invites as many people as possible - from all backgrounds and occupations - to develop products and services that will support people to live well and independently with dementia.

Alzheimer’s Society’s panel of experts and people affected by dementia worked with the Society to select Accelerator partners who receive GBP 100,000 (approx. EUR 112,000) to continue to develop their product and bring them to the people who need them, faster.

The Society will be working closely with the “How Do I?” team, over the next year, supporting them to work closely with people affected by dementia, to continue to develop the smartphone app and bring it to the market.

26 June: First dementia-friendly project in Bosnia & Herzegovina tackles signage in health institutions

A project has started in Bosnia & Herzegovina, taking the first step towards making the standard environment within health institutions more dementia-friendly. The name of this project is: “Establishment of cognitive friendly standards in the design of space inside health institutions”.

The term “standard environment” in most health institutions means uncustomised public spaces in which people move around. Current architectural standards for the design of such spaces are generally not dementia-friendly. Design standards for cognitive or dementia-friendly directions for the public, and the marking out of public spaces, do not exist, so every health institution designs in its own way.

In such an environment, people with cognitive impairments have difficulty finding their way around, recognising and understanding the signposts and general orientation inside health institutions. The additional stress factor influences their motivation to leave their homes and visit such institutions.

This new project gathers together various stakeholders, including: The Centre for dementia, the Institute for public health of the Canton of Sarajevo, the Federal agency for standardisation in the health sector – AKAZ, “Abdulah Nakaš” general hospital in Sarajevo, and the Health centres of the Canton of Sarajevo.

Public events will follow, shortly, at which this new initiative will be presented. Participants, such as students, architects, designers, people with cognitive impairments, and medical experts, will be encouraged to participate fully in a public call for proposals for the design and organisation of public spaces in health institutions. Following the submission of these designs, the plan is to carry out a pilot study in the main general hospital and in a health centre. Following this pilot study, recommendations will be made for official design standards in all health institutions. This will improve the situation of people with cognitive impairments, helping them to negotiate their way through these public spaces more easily, thereby also strengthening their position in society, says Bosnian Alzheimer association Udruženje AiR.

POLICY WATCH

23 May: UK campaign aims to end unfair “dementia penalty” on social care costs

The Alzheimer’s Society regularly hears from people in England who have spent all their savings on care. Because there is currently no cure for dementia, most people get help managing the symptoms of dementia from the social care system, but this is expensive. People would have to save for 125 years to pay the typical cost of dementia care, which is GBP 100,000 (EUR 113,000). The Society has published new research demonstrating that care for people with dementia is often 15% higher than standard social care, because of the complexity of care. They are calling this the “dementia penalty” - the extra cost to support the needs of people with dementia as a result of the health condition they developed.
The UK’s National Health Service (NHS) is committed to the principle of access based on clinical need, not on someone’s ability to pay. It is time people with dementia were treated the same as others, the Alzheimer’s Society stresses; and as part of its Fix Dementia Care campaign, they are calling for a GBP 2.4 billion (EUR 2.71 billion) Dementia Fund to be established. This would give extra funding to people with dementia, to end the penalty they face in paying for care. It would also help reduce the pressure on the NHS, with fewer people facing the crises that lead them to access emergency care. Finally, it would help care providers with the funding they need to provide innovative care, trained staff, and engaging activities.

There has been an enthusiastic reaction to the campaign, so far, with over 7,000 people emailing their Members of Parliament (MPs) to support the campaign, and over 100 MPs backing the call. The Alzheimer’s Society is calling on the Government to include a Dementia Fund in the forthcoming Spending Review, to break the deadlock on reforming social care and to end the unfairness people with dementia are facing.

“We’ve been waiting for decades for our government to properly reform social care - people with dementia cannot wait any longer”, said the society.

**23 May: WHO provides update on Global Action Plan on dementia**

As part of the World Health Organization’s (WHO) Global Action Plan on the public health response to dementia 2017-2025, the organisation has provided an update on developments in a number of areas of work.

**iSupport – skills and knowledge training programme**

The WHO’s iSupport is an online training programme for carers of people with dementia, including family members, relatives and friends, which can be adapted to national or local contexts and needs. Currently, iSupport is being adapted in eight countries. The WHO have now produced iSupport as a hardcopy manual, containing five modules and accompanying exercises:

- Introduction to dementia
- Being a caregiver

**WHO Guidelines on risk reduction**

Recently, the WHO published guidelines on risk reduction of cognitive decline and dementia, providing evidence-based recommendations on lifestyle behaviours and interventions to delay or prevent cognitive decline and dementia. The guidelines relate to action area three (dementia risk reduction) of the WHO Global Action Plan and focuses on preventative measures, such as a healthy diet, smoking cessation etc. as a means of risk reduction for dementia.

**Global Dementia Observatory Knowledge Exchange Platform**

The WHO developed the Global Dementia Observatory (GDO) as a data and knowledge exchange platform, to support countries in strengthening policies, service planning and health and social care systems for dementia.

The next step in this area is the GDO knowledge exchange platform which contains resources to support the implementation of the Global action plan and enhance countries’ response to dementia. The knowledge exchange platform will provide a space for stakeholders to share resources (e.g. examples of good policies, guidelines and good practice examples for dementia) to facilitate mutual learning and promote the exchange of good practices in the area of dementia.

A peer-review process consisting of experts by experience (i.e. people living with dementia or their families/friends) and experts by profession will ensure that submitted resources meet quality and good practice criteria. The WHO is currently looking for individuals to support the peer-review process. More information can be found here: https://extranet.who.int/dataform/456967?lang=en

**30 May: Ireland’s Minister for Health in discussions with The Alzheimer Society of Ireland**

Ireland’s Minister for Health Simon Harris attended The Alzheimer Society of Ireland’s 25th Anniversary of Tea Day, their largest annual fundraiser, at The Orchard Day Care Centre in Dublin, on 2 May 2019. Minister Harris made a commitment in front of staff, people with dementia and their families to meet with The Alzheimer Society of Ireland (ASI), to discuss dementia supports further.

The promised meeting took place at Government Buildings in Dublin, on 30 May, and it was very constructive, reports the ASI. Minister Harris gave the ASI an agreement to progress with the discussion on these issues and a further meeting will soon be arranged.

Members of The ASI team that attended the meeting were Board member and Chair of Advocacy and Public Affairs Committee Kieran McGowan; CEO Pat McLoughlin; Head of
18 June: Canada launches its first dementia strategy, bringing WHO global target one step closer

On 17 June 2019, the Government of Canada announced that it has launched a national dementia strategy, titled “A Dementia Strategy for Canada: Together We Aspire”. It includes a dedicated budget of CAD 3 million in 2019 (fiscal year) and CAD 12 million in each of the subsequent 4 years, which will be crucial in ensuring plans can realistically be implemented.

To help ensure that the strategy meets the needs of people living with dementia and their carers, the Government of Canada included the Alzheimer Society of Canada and a number of people living with dementia in its multi-stakeholder consultation process.

The strategy includes key targets for improving awareness, access to care, support and treatment, research and risk-reduction of dementia by 2025.

The primary target of the World Health Organization (WHO)’s “Global action plan on the public health response to dementia 2017-2025” is to have 146 of the 194 WHO Member States develop a national response plan to dementia by 2025. The target is currently falling far short of hopes, but the launch of Canada’s plan brings it one step closer.

You can read the full strategy, here: https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html

18 June: UK inquiry concludes that people with dementia are treated differently to those with other health conditions or disabilities

On 18 June, the UK All-Party Parliamentary Group (APPG) on Dementia, in partnership with the Alzheimer’s Society, launched a new report, “Hidden no more: Dementia and disability”. APPGs are informal cross-party groups formed by Members of the House of Commons and House of Lords, and the Alzheimer’s Society provides expert advice and administrative support to the APPG on Dementia. The APPG on Dementia and the Alzheimer’s Society coordinated a year-long inquiry on dementia as a disability.

Under UK domestic law and international convention, dementia is a disability. Thousands of people who responded to the inquiry agreed that they see dementia as a disability. Despite the clarity in legislation, the report reveals that society is lagging behind and failing to uphold the legal rights of people with dementia.

The evidence revealed that, across England, Wales and Northern Ireland, people with dementia are not having their disability rights upheld. Focusing on equality, non-discrimination, participation and inclusion, the report highlights the human impact this discrimination is having on people living with dementia. The public, employers, organisations, governments and public bodies need to be more aware of, and recognise, the rights of people with dementia, the Alzheimer’s Society stresses.

It revealed that 98% of the 2,521 survey respondents thought that people living with dementia are treated differently to those with other health conditions or disabilities. This is due to the progressive but “hidden” nature of dementia, the individuality of dementia and its symptoms, and the stigma surrounding the condition. The inquiry identified a range of societal barriers that are preventing people with dementia from living independent lives.

The report outlines that action needs to be taken across six key areas: employment, social protection, social care, transport, housing, and community life. The report makes recommendations for change that seek to increase awareness of the disability rights of people with dementia, as enshrined in the Equality Act (2010) and Convention on the Rights of Persons with Disabilities, and identify ways people can be supported to participate as equal citizens in society. It is time that the rights of people with dementia are finally recognised, just as all disabled people’s rights should be, the Alzheimer’s Society concludes.

23 May: Suven Life Sciences completes Phase II trial of SUVN-502 for moderate AD

On 23 May, Suven Life Sciences, a biopharmaceutical company developing therapeutics in central nervous system diseases, announced that the last participant has completed the last visit for its Phase II clinical trial of SUVN-502 for moderate Alzheimer’s disease (AD).

The Phase II trial is a randomised, double-blind and placebo-controlled study evaluating the efficacy and safety of two doses of SUVN-502 in people with moderate AD who are taking both Aricept (donepezil) and Namenda (memantine). The company reported that this is the first ever study to evaluate a triple combination therapy for the treatment of moderate AD. Top-line data are expected to be presented at the Alzheimer’s Association International Conference (AAIC) in July, in Los Angeles, USA.


28 May: ProMIS Neurosciences identifies new antibody candidates for AD

On 28 May, ProMIS Neurosciences, a biotechnology company focused on the development of antibody therapeutics targeting toxic oligomers implicated in the development of neurodegenerative diseases such Alzheimer’s disease (AD) announced the identification of several antibody candidates that selectively bind the toxic form of the Tau protein – one of the hallmarks of AD.

These novel antibodies join a pipeline of antibody candidates including lead product candidate PMN310 that selectively targets the toxic form of the amyloid beta protein. “The ProMIS platform addresses a problem that has plagued the Alzheimer’s drug development community: the inability to selectively target the neurotoxic form of Tau and amyloid beta,” said Dr Neil Cashman, Chief Science Officer of ProMIS Neurosciences.

30 May: Alzheimer’s Drug Discovery Foundation announces inaugural Diagnostics Accelerator funding awards

The Alzheimer’s Drug Discovery Foundation (ADDF), a US-based venture philanthropy organisation that solely funds research on Alzheimer’s disease (AD) and dementia, recently launched the Diagnostics Accelerator in partnership with Bill Gates. The Diagnostics Accelerator aims to fast-track research that could result in easier and earlier diagnosis of AD and related dementias.

On 30 May, the ADDF announced the four inaugural award recipients of Diagnostics Accelerator funding. Two of the funded projects aim to develop diagnostic blood tests, while the other two involve non-invasive retinal imaging approaches.

Dr Saliha Moussaoui, Chief Scientific Officer of Amoneta Diagnostics SAS, was awarded up to USD 2 million, to develop a diagnostic test that measures the presence of two RNAs in small-volume blood samples. Amoneta Diagnostics hopes that this approach will be able to diagnose AD very early in the disease development process, before symptoms are obvious.

Building on previous work showing that tau protein fragments could be detected in the blood of people with AD, Prof. Kaj Blennow from the University of Gothenburg was awarded USD 500,000 to develop a highly-sensitive test able to detect and measure these brain-derived tau fragments in blood samples. Studies indicate that brain neurodegeneration can be connected to retinal changes, such as the structural alterations observed in retinal blood vessels from people with AD. Dr Tom MacGillivray from the University of Edinburgh was awarded over USD 488,000, for a project evaluating the utility of imaging tests that assess retinal blood vessels and ocular markers of neurodegeneration. Dr MacGillivray’s project will use advanced computer algorithms to enhance the diagnostic capability of retinal imaging scans for AD.

With a similar focus on the retina, Dr Peter van Wijngaarden from the Centre for Eye Research in Australia was awarded over USD 420,000, to develop and test a camera that uses specific wavelengths of light to detect the abnormal build-up of tau proteins in the retina. The Diagnostics Accelerator funding will fast-track this technology into clinical trials designed to evaluate the sensitivity of this diagnostic for very early stage AD.

1 June: The Alzheimer’s Clinical Trials Consortium selects Elenbecestat and BAN2401 for upcoming clinical trials on AD prevention

The Alzheimer’s Clinical Trials Consortium (ACTC), established by the National Institute on Aging at the National Institutes of Health, is a clinical trials infrastructure launched in December 2017. This
Studies reveal the influence of Tau proteins and prevent neuronal cell death. US researchers from the University of New Mexico reported the development of a vaccine that may prevent the formation of Tau accumulation in the brain. Results were published in the journal NPJ Vaccines.

In the published study, scientists developed a vaccine with virus-like particles and tested it one of the most pathologically aggressive mouse models of tauopathy. Tauopathies including frontotemporal dementia and Alzheimer’s disease are progressive neurodegenerative diseases associated with the aggregation of Tau protein in the brain.

Researchers found that when the vaccine was given to animals, they developed antibodies that reduce levels of the Tau proteins and prevent neuronal cell death. Using learning and spatial memory tests, they also showed that vaccination could improve cognitive functions.

Looking at the overall disease span by stage-duration, estimates showed that people with signs of amyloid pathology, but without mild cognitive impairment (preclinical AD), would take overall 10 years until they developed a form of mild cognitive impairment (prodromal AD). The potential subsequent “prodromal AD” (marked by amyloid pathology and mild cognitive impairment) phase, was estimated to continue for about 4 years until the beginning of dementia, which would continue for about 6 years until death.

The researchers also reported that from their analysis, the male sex, clinical setting APOE 4 e4 allele carriership (a gene linked to AD), and abnormal cerebrospinal fluid tau were associated with a shorter disease duration until the point of death.

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On 1 June, a team of researchers published a statistical investigation on the estimated duration of stages in Alzheimer’s disease (AD) as a research article in the journal Alzheimer’s & Dementia.

The study applied a multistate modelling approach on data from six cohorts that encompassed 3268 participants. The results showed that participants who received a diagnosis at 60 years of age had an overall disease duration of 24 years until death, while people diagnosed at the age of 80 had an overall disease duration of approximately 15 years.

The model further estimated that participants who showed evidence of amyloid pathology (a biomarker for AD) but who did not show signs of cognitive impairment at the age of 70 would have an approximate disease duration of about 20 years.

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nine changepoints in a range of biomarkers during the preclinical phase of AD based on cognitive assessments, cerebrospinal fluid (CSF) values and magnetic resonance imaging (MRI) measures.

Of the 290 participants included at the start of the study, 209 remained cognitively normal at the end of the study period and 81 were diagnosed with mild cognitive impairment or dementia due to AD. All nine measures had significant changepoints, all preceded symptom onset. Scientists detected higher levels of the Tau protein 34 years prior to symptom onset. The levels of a modified version of the Tau protein called "p-Tau" increased 13 years prior to the onset of clinical symptoms. They also found signs of cognitive impairment 11–15 years before the onset of any symptoms. Furthermore, higher levels of Abeta were identified 10 years prior to symptom onset.


14 June: French scientists publish an investigation into a new tool to help differentiate between frontotemporal dementia and AD

On 14 June, French scientists published an article on a potential new diagnostic tool for the differentiation between the behavioural variant of frontotemporal dementia and typical Alzheimer’s disease (AD) in the Journal of Alzheimer’s Disease.

The team involved 22 people with the behavioural variant of frontotemporal dementia (the most common form of frontotemporal neurodegeneration, often connected to changes in complex thinking, the personality and behaviour - all of which may reflect impairment in moral sentiment processing). In addition, they also included 15 participants with AD (that had positive markers for the condition within the liquid in their spinal cord) as well as 45 healthy individuals.

The researchers then explored the participants’ moral emotions with the “The Moral Emotions Assessment” – a list of short moral scenarios as well as “control” scenarios that don’t elicit a particular emotion. The participants were asked to read those scenarios aloud and to choose one of four answer choices to describe the emotion they would feel in the described situation (or indicate that the scenario was neutral).

The researchers reported that they found the assessment effective to differentiate between people with AD and people with the behavioural variant of frontotemporal dementia, noting that the latter were more impaired in emotion processing than people with AD and healthy controls.

https://content.iospress.com/articles/journal-of-alzheimers-disease/jad180991

20 June: Large-scale MindCrowd study shows early cognitive deficits in participants with a family history of AD

On 20 June, Dr Joshua Talbloom and collaborators published a paper in the journal eLife, showing that individuals with a family history of AD performed less well in online learning tasks than peers with no AD family history.

Although it is well-established that people with a first-degree family history of AD are at higher risk of developing the disease, the influence of family history on cognition across the adult lifespan has not yet been fully characterised. The researchers also aimed to identify any lifestyle, medical or demographic factors that might affect cognition in persons with or without a family history of AD. To achieve this, the MindCrowd study recruited over 59,000 participants aged between 18-85, assessing cognition using an online learning and memory task called PAL (paired-associates learning). The PAL task was chosen as it is known to be affected early in the development of AD.

Statistical analysis of the study results showed that reduced performance in PAL tasks was evident in persons with a family history of AD (FH+) many decades before disease onset. This reduced PAL performance in FH+ participants was observed irrespective of gender, although female participants generally had higher PAL results compared to their male counterparts. Diabetes and educational attainment were also identified as modifiers for PAL performance in FH+ individuals, with diabetic participants and those with fewer years in education achieving lower PAL results overall.

https://elifesciences.org/articles/46179

26 June 2019: AB Science reports interim analysis for Phase III trial of masitinib for mild to moderate AD

On 26 June, AB Science reported interim analysis results for its Phase III trial of masitinib, a drug that is classed as a tyrosine kinase inhibitor. Masitinib is thought to act by inhibiting tyrosine kinases that promote neuroinflammation, amyloid beta signalling and Tau phosphorylation.

Following on from a successful Phase II clinical trial of masitinib in 2011, AB Science completed Phase III trial recruitment in mid-2018. This trial (AB09004) was an international, randomised, placebo-controlled study that evaluated the efficacy and safety of masitinib as an add-on therapy to cholinesterase inhibitors and/or memantine. 720 participants with confirmed mild to moderate AD were enrolled and randomised to placebo or one of two doses of masitinib.

AB Science reported that its pre-planned interim analysis of the study data had detected a positive trend of efficacy in one of the masitinib doses tested. Final analysis will be completed by the end of 2019.


27 June 2019: vTv Therapeutics announces Phase II clinical trial evaluating azeliragon in patients with mild AD and type 2 diabetes

On 27 June, vTv Therapeutics announced that it had initiated recruitment of participants with mild Alzheimer’s disease (AD)
and type 2 diabetes to a new Phase II proof-of-concept trial of azeliragon.

Azeliragon is an oral small molecule inhibitor of RAGE (receptor for advanced glycation end products), which is thought to promote inflammation and amyloid beta deposition in the brain. Although the recent STEADFAST Phase III trial of azeliragon in AD failed to reach its co-primary endpoints, a post-hoc subgroup analysis of cognitive and functional measures showed positive effects in patients with type 2 diabetes and AD.

Based on these encouraging results, vTv Therapeutics is aiming to recruit around 100 participants with AD and type 2 diabetes (defined as an HbA1c level of 6.5 – 9.5%) to its Phase II placebo-controlled study of azeliragon. If safety and efficacy endpoints are met within the 6-month timeframe of this study, vTv Therapeutics will progress to a larger-scale Phase III trial. Top-line results from the Phase II proof-of-concept trial are expected towards the end of 2020.


DEMENTIA IN SOCIETY

27 May: 4th annual “Living with Dementia in Rural Ireland” conference held

The 4th annual “Living with Dementia in Rural Ireland” conference was held in Boyle, Co. Roscommon, Ireland on 27 May 2019. It sought to address the need for more awareness of dementia; to help people feel more comfortable talking about it, openly; and to examine what needs to be changed at local, national, European and global levels. It also looked at barriers, such as stigma, lack of access to care, and difficulty obtaining a timely diagnosis.

People of all ages (some, even, in their early thirties) and from all walks of life are being diagnosed with dementia – a fact that was highlighted at the day-long conference. The main theme of this year’s edition was enabling people with dementia to live in their communities for as long as possible, and ensuring they are afforded the same rights and opportunities as everyone else. Access to a range of live-in, residential and other community supports is vital, for this to be possible.

Participants included a number of people diagnosed with dementia, and the event was an opportunity to listen to them, to hear their experiences and their concerns. The importance of their voices being heard, without the presence of “gate keepers” to “filter their views” was raised, throughout the day. The conference heard from Helen Rochford-Brennan from Tubbercurry, Co Sligo, Ireland. Almost 7 years ago, at the age of 62, Ms Rochford-Brennan was diagnosed, after having already spent 5 years struggling with early-onset Alzheimer’s disease. She has since written very personally about living with Alzheimer’s dementia and hopes her participation in research will, one day, help find a cure. Her advocacy work, at national level with the Irish Dementia Working Group and at European level, as Chairperson of the European Working Group of People with Dementia (EWGPWD) allows her to share her experience with the widest possible audience, which she also hopes will help highlight the importance of research into dementia care and cure, leading to more funding and more results.

Professor Eamon O’Shea of National University of Ireland Galway (NUI Galway) and Ms Rochford Brennan spoke about the need, in Ireland, for a continuum of care. Currently, there is nothing available between home care and nursing home care. They both stressed the importance of looking at other models of care, such as independent living and assisted living units, which allow people to move to a more manageable home, if needed.

Carol Hargreaves, a member of the Scottish Dementia Working Group (SDWG) and of the EWGPWD, shared some examples of good practice from Scotland. Delegates were told that, in Scotland, people diagnosed with dementia are entitled to one year of post-diagnostic support, provided by the NHS, often via Alzheimer Scotland “Dementia Link Workers”. These specialists help highlight the supports and services available to the person diagnosed, to help them adapt and live as well as possible with dementia. Appropriate and relevant services are not available, however, in many parts of Ireland.

Seán Canney, Minister of State at the Department of Rural and Community Development and the Department of Communications, Climate Action and Environment with special responsibility for natural resources, community affairs and digital development attended the conference.

“Events like the conference offer a forum for stakeholders and all those interested in dementia to come together and share their knowledge and experience. It was an extremely informative afternoon”, he commented.

Pictured: Speakers and partners, including Roscommon LEADER Partnership, Citizens Information Services, Brothers of Charity Services and Older People Council, with Minister Seán Canney in the centre

The Living with Dementia in Rural Ireland conference is organised by Dementia Ireland, set up by Carmel Geoghegan. Ms Geoghegan was a primary carer for her late mother. She is
now an advocate for, and supporter of, campaigns that focus on dementia and end-of-life care, and works on the development of practice and policies that respect people living with a dementia diagnosis.

10 June: Family carers in Ireland are turning to the internet for support and social connections, due to lack of availability of home care

Research, published on 10 June, indicates that many family carers in Ireland depend heavily on the internet for information, support and social connections, as they are unable to leave their homes. Care Alliance Ireland, in partnership with the eleven other National Carers Week partner groups, recently undertook a survey of 300 family carers across Ireland. The resulting report, published as part of Carers Week 2019 (10-14 June), aims to highlight how family carers are using the internet to connect with others, to get supports and information from not-for-profit and statutory agencies, and to manage their day-to-day lives, but also to emphasise that internet supports are not a suitable substitute for one-to-one supports, such as home care:

- 59% of respondents said they felt lonely or isolated.
- Only 3% of respondents said they could “always” make it to social and support events that they would like to get to - with almost a quarter (23%) saying they can “never” get to those kinds of events.
- Over 50% of respondents are members of online support groups and 76% have looked up information regarding the health of their loved one online.

Speaking about the research, Zoe Hughes, Policy & Research Officer with Care Alliance Ireland said: “It’s clear that the lack of on-the-ground supports like respite and home care is having a huge impact on family carers being able to take a break and seek supports - meaning that online supports are increasingly become vital for many of those who are isolated and lonely in their role.” Care Alliance Ireland is an alliance of NGOs that support family carers in Ireland. Read the full report here: https://bit.ly/31gfYuD

LIVING WITH DEMENTIA

7 June: Petri Lampinen shares his experiences of dementia diagnosis and treatment, hoping to encourage change where needed

The two years before my diagnosis were challenging for me and my loved ones. I was examined by a number of doctors with various specialisms and took part in different studies. During that time, I noticed that patient data was not always well transmitted between different treatment units and after my diagnosis, I decided I wanted to share these experiences. I got the opportunity to do so when I received an invitation to a panel discussion at the University of Tampere (Finland), organised by the Finnish Social and Health Informatics Association (FinnSHIA). The focus was on how to ensure better data management in the upcoming social welfare and health care reform.

They wanted to hear about my experiences of cooperating with doctors, nurses, physiotherapists, occupational therapists and social workers. I had a lot to tell them. I told them how the appointments themselves worked very well for me, as they were nearly always on time, but that the administration around them was quite challenging. I had about a hundred medical appointments, during that period, in many different treatment units. This meant sending applications off to many different places in order to get support, both for myself and for my family. Getting decisions on support was often slow, apparently due to an overload of work for the staff involved.

I also noticed how rushed things often were, at the different outpatient clinics I attended. I told the panel at the panel event in Tampere that I noticed doctors often read my patient information for the first time, when I was already sitting in their office. Appointments were often short, too, so doctors didn’t have time to get a proper update. When information came from many different treatment units, I found I sometimes had to instruct the doctor to get my patient information. I decided I would always bring my own patient files (pictured) with me, which was often useful for the doctors.

Overall, the biggest problem was that the information did not pass between different units properly. The worst example of this, for me, was when I was completely excluded from medical examinations. Two different units decided, at the same time, that I did not belong to their clientele, at which time I was left adrift, with no care. Luckily, I got help and was able to return to
16 June: Dementia has dramatically changed Wendy Mitchell’s relationship with cooking and eating

Wendy Mitchell, an ambassador for the Alzheimer’s Society (UK) and author of bestselling book “Somebody I Used to Know” (2018), was diagnosed with Early-onset Alzheimer’s dementia in 2014. She has kindly allowed us to share an article (redacted) she recently published in UK newspaper The Guardian, about how her relationship with food and cooking have changed, since developing dementia and how she has tried to adapt:

Some days there is not much that I remember. When the fog comes down, I don’t know what day it is. I don’t know the time, or even the year. Those are the very worst days and, thankfully, they are still relatively few. But one thing I never forget is that food used to mean so much more to me than it does now.

We think of food as fuel. At its heart, that is all it is. That is all it is to me now. These days I even have to set alarms on my iPad to remind me to eat. Yet, when you no longer get pleasure from food, you realise it is so much more than that. It’s how we show love as a parent, it’s how we bond with friends, it’s an apology for saying the wrong thing, it’s a welcome to the neighbourhood.

I remember how busy my kitchen used to be: the windows hazy with steam, several hob rings bubbling away on the stove, my lemon drizzle cake rising in the oven. Even as adults, my two daughters used to come in and sniff at a cake on the cooling rack, eager for me to cut the first slice. When they were tiny, I’d cheer them up by baking an afternoon tea, setting up a little picnic outside with their mini camping chairs around a little table. As a single mother, run ragged between home and work, I cherished moments like those.

Even when I was diagnosed with young-onset Alzheimer’s in 2014, aged 58, I used food in a way to sweeten the bitter moments that followed. There was grieving, but it also opened up many conversations we never thought we would have. One of those conversations was when it came to writing my lasting power of attorney. I knew it would be a difficult afternoon for us, sat around my small kitchen table, and so I baked an afternoon tea just like I had when the girls were little. It was a welcome relief from an afternoon discussing difficult topics, such as whether or not I wanted to be resuscitated in the event that my heart failed.

There came a time, though, when it was impossible for me to bake any more. A few months after the diagnosis, when I was still adamant I would feel relevant despite this disease inside my brain and my bosses in the NHS retiring me due to ill health, I started baking for a homeless shelter. But then I got confused. I added too much salt, double the flour, and my cakes stopped rising, most ended up in the bin. Admitting defeat and giving up my beloved baking was another loss. But what kept me going in those early days – and it turns out since – was focusing on what I could still do.

The full article, can be viewed, here: https://www.theguardian.com/society/2019/jun/16/how-dementia-robbed-me-of-my-love-of-cooking-wendy-mitchell-alzheimers

18 June: Idalina Aguiar shares details about a new book, based on a project she participated in with Alzheimer Portugal in Madeira

On 18 June, a book called “Com Aromaticas Me Conquisatas” (with aromatics, you win me over) was published in Portugal. It represents the culmination of a project with the same name, promoted by Alzheimer Portugal’s Madeiran branch and the Continent Mission, which took place between April and December 2018. This project, which involved a number of partners and aimed at promoting / strengthening intergenerational relations, included people with dementia who attend our association and children at the nursery "The Carrocel", as well as children from other institutions.

By creating intergenerational links, the aim was to avoid segregation and isolation of people with dementia; to promote social inclusion; to promote the sharing of experiences and wisdom with the young; to provide meaningful activities for people; to combat negative stereotypes in society; and to promote the well-being of people living with dementia. This project also intended to inform children that dementia is not just part of normal ageing.
During the project, we carried out several activities related to gardening and horticulture, namely planting and watering herbs. The opportunity for the stimulation of the senses was very positive. There were also many moments of sharing. Participants, together with the Alzheimer Portugal psychologists and a nutritionist, organised monthly workshops with the children, on herbs and their importance in healthy eating.

The project dedicated some sessions to cooking - an opportunity for the people with dementia who attend our association to prepare some dishes. These sessions resulted in 8 recipes that are available in the book.

We wanted to involve the community in this project, and we promoted herbs and their importance in food. Several workshops were held, and at each one, a guest presented a dish using a certain aromatic herb. Some people with dementia participated in these workshops. The result was 11 recipes, all of which are also in the book.

A workshop on the MIND Diet (Mediterranean-DASH Intervention for Neurodegenerative Delay) and another on Organic Farming were also held and people with dementia, as well as other members of the community, attended.

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

Pictured: Dr Isabel Fragoeiro (president of Alzheimer Portugal in Madeira), Dr Bruno (nutritionist and author), Idalina Aguiar (member of the EWGPWD), Dr Pedro Ramos (Secretary for Health), Dr Gonçalo (psychologist and author) and Dr Vânia Jesus (president of IHM)

NEW PUBLICATIONS AND RESOURCES

21 May: New report from Alzheimer’s Disease International is an urgent call to action for countries without dementia strategies

A new report from Alzheimer’s Disease International (ADI), “From Plan to impact II: The urgent need for action” reveals that two years on from the publication of the World Health Organization (WHO)’s Global Action Plan on the Public Health Response to Dementia 2017-2025, the primary target to have 146 of the 194 WHO Member States develop a national response plan to dementia, is falling far behind schedule.

The recommendations come from a report by ADI, which was released at its official side event to the 72nd World Health Assembly (WHA), “Why we all need to do more: Examining the seven action areas of the Global action plan on dementia”, on 21 May in Geneva, Switzerland.

Read the media release: https://www.alz.co.uk/media/190521


In preparation for its World Alzheimer’s Month (WAM) campaign, Alzheimer’s Disease International (ADI) is developing materials and a programme of training and support for its 94 member associations across the world. The theme for 2019 – “Let’s talk about dementia: end the stigma” - is something which speaks to a huge challenge in the global dementia community. The campaign aims to encourage those often difficult first conversations about dementia, and to stimulate people to seek out information, advice and support. ADI has prepared a “Guide to planning a successful World Alzheimer’s Month Campaign”, which contains guidance on organising events, engaging with the government, tips for media and social media, and how to measure the success of a campaign. The guide is available to download on the World Alzheimer’s Month campaign website, where new materials will be added in the coming months, including posters, flyers and social media assets, made available in multiple languages.

During the month, ADI will launch the World Alzheimer Report 2019 on the topic of stigma. This important report will be based on the findings of the biggest global survey on attitudes
around dementia, and will be supported by case studies, expert essays and evaluation of programmes to tackle stigma. 

For more information and to see how you can raise awareness of dementia during WAM: https://www.worldalzmonth.org/

**JOB OPPORTUNITIES**

1 July: EFPIA seeks Manager Regulatory Law and Policy

The European Federation of Pharmaceutical Industries and Associations (EFPIA) represents the pharmaceutical industry operating in Europe. Through its direct membership of 36 national associations and 40 leading pharmaceutical companies, and in collaboration with health and research players, EFPIA’s mission is to create an environment that enables its members to innovate, discover, develop and deliver new therapies and vaccines for people across Europe, as well as contribute to the European economy.

The regulatory landscape in Europe for medicines and medical products is rapidly evolving with a trend to greater complexity.

This reflects scientific developments as well as political and budgetary pressures.

EFPIA wants to strengthen its legal capacity and is looking for a Manager Regulatory Law and Policy who will ensure that EFPIA’s regulatory policy work focuses on delivering on its priorities. The successful candidate will be responsible for interpreting, advising and communicating about European regulatory requirements and systems. Within EFPIA’s Legal Team, they will develop and coordinate EFPIA’s regulatory law strategy.

Read more about the role and how to apply, here: https://efpia.eu/about-us/job-vacancies/

Applications close on 5 July 2019.

Contact Alzheimer Europe:

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

Alzheimer Europe Board:

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

Alzheimer Europe Staff:

**Executive Director:** Jean Georges; **Communications Officer:** Kate Boor Ellis; **Conference and Event Coordinator:** Gwladys Guillory; **Director for Projects:** Dianne Gove; **Project Officers:** Christophe Bintener, Cindy Birck, Angela Bradshaw, Ana Diaz; **Policy Officer:** Owen Miller; **Finance Officer:** Stefanie Peulen; **Administrative Assistants:** Aideen O’Brien; Grazia Tomasini.
### AE CALENDAR

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<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>2-3 July</td>
<td>NEURONET Scientific Advisory Board and Consortium Meeting (Madrid, Spain)</td>
<td>Jean, Chris and Angela</td>
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<tr>
<td>3 July</td>
<td>Project proposal preparation (London, UK)</td>
<td>Ana and Dianne</td>
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<tr>
<td>4 July</td>
<td>EPAD Review Board (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>5 July</td>
<td>GSK Health Advisory Board (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>8 July</td>
<td>Meeting with WYLD representative (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<td>8-9 July</td>
<td>29AEC conference suppliers meeting (The Hague, Netherlands)</td>
<td>Gwladys and Aideen</td>
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<td>9 July</td>
<td>Workshop organised by Roche (Basel, Switzerland)</td>
<td>Ana</td>
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<tr>
<td>11-12 July</td>
<td>Patient Access Partnership conference on the Future of Health Annual – Advancing the UN 2030 Sustainable Development Agenda (Brussels, Belgium)</td>
<td>Owen</td>
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<td>13 July</td>
<td>WW-FINGERS face-to-face meeting (Los Angeles, USA)</td>
<td>Jean</td>
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<td>14 July</td>
<td>Eisai Advocacy Meeting (Los Angeles, USA)</td>
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<td>14-19 July</td>
<td>Alzheimer’s Association International Conference AAIC (Los Angeles, USA)</td>
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<td>18 July</td>
<td>Meeting with Biogen (Los Angeles, USA)</td>
<td>Jean</td>
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<td>26 July</td>
<td>ADDIA Meeting (Paris, France)</td>
<td>Jean</td>
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<td>28-29 August</td>
<td>EWGPWD meeting (Brussels, Belgium)</td>
<td>Ana and Dianne</td>
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### CONFERENCES 2019

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<tr>
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<tr>
<td>1-4 July</td>
<td>Royal College of Psychiatrists’ International Conference, <a href="https://www.rcpsych.ac.uk">https://www.rcpsych.ac.uk</a></td>
<td>London, UK</td>
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<td>2-3 September</td>
<td>Euro Congress on Dementia and Alzheimer’s Diseases (ECDA-Rome), <a href="https://www.dementiameet.com/">https://www.dementiameet.com/</a></td>
<td>Rome, Italy</td>
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<td>5-7 November</td>
<td>14th UK Dementia Congress, <a href="https://careinfo.org/event/uk-dementia-congress/">https://careinfo.org/event/uk-dementia-congress/</a></td>
<td>Doncaster, UK</td>
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<td>5-7 November</td>
<td>First dementia conference Krems, “Timely Detection of Dementia”, <a href="http://www.donau-uni.ac.at">www.donau-uni.ac.at</a></td>
<td>Krems, Austria</td>
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29th Alzheimer Europe Conference
Making valuable connections
The Hague, Netherlands
23–25 October 2019
www.alzheimer-europe.org/conferences  #29AEC