Let me start this editorial by warmly congratulating Sweden on the announcement of their new dementia strategy. This is very encouraging news as we are seeing more European countries begin to recognise dementia as a priority and start the development or implementation of national dementia strategies. We also look at the report on the mid-term evaluation of the Irish Dementia Strategy.

On a global level we look at the publication of a new report by Alzheimer’s Disease International (ADI) on national responses to dementia, which marks the one-year anniversary of WHO’s adoption of the Global Action Plan on the Public Health Response to Dementia 2017-2025. The projects in which we are involved have had a busy month with several project meetings taking place in Europe, including a General Assembly for EPAD in Amsterdam, ROADMAP in Barcelona and SyDAD in Milan. MOPEAD has started screening research participants in Cologne, Germany and Barcelona, Spain. The AMYPAD diagnostic and patient management study has also enrolled its first research participant in Geneva and EPAD hit the 700 mark in screened participants.

Last but not least, the INDUCT FindMyApps project launched its website with a special thanks to the members of the European Working Group of People With Dementia (EWGPWD) and staff members from Alzheimer Europe who provided insights on how to enhance the website content and design.

On the research front, we have to report on another phase III failure. On a similar negative note, we are disappointed to report the news that the French Government will no longer reimburse the four drugs used to treat the symptoms of Alzheimer’s disease. By becoming the only European country not to reimburse these drugs, France could also be jeopardising its national competitiveness in research.

As usual we also keep you updated with news from our members. The Turkish Alzheimer Association is one of the partners of the AD-AUTONOMY project and reports on the first working session. The project will raise awareness on the autonomy of people with dementia for decision making. From Finland we hear about new legislation which specifies the right to self-determination, especially for people with dementia and we look at a report from the Alzheimer’s Society UK on proving and improving the value of involving people affected by dementia in research.

Finally we have been very busy this month evaluating the abstracts for our conference. In the coming days, we will be reaching out to all authors.

Don’t forget that the early bird registration fees for the conference are available until the end of June.

Jean Georges
Executive Director
ALZHEIMER EUROPE

23 April: Alzheimer Europe’s right to lodge complaints before the European Committee of Social Rights has been renewed

Alzheimer Europe is pleased to announce that its entitlement to lodge complaints under the collective complaints procedure of the European Social Charter was approved by the Governmental Committee of the Council of Europe at its meeting on 23-27 April 2018. We hereby thank the Governmental Committee for having renewed this right which will be valid from July 2018 to June 2022.

30 May: Alzheimer Europe finalises abstract selection for 28AEC

Alzheimer Europe would like to thank everyone who submitted abstracts for its 28th Annual Conference (28AEC) in Barcelona from 29 to 31 October 2018. The Scientific Committee reviewed a record 427 abstracts and approved 144 oral presentations and an additional 220 poster presentations. Notifications are currently being sent out to all applicants. Selected presenters for poster and oral presentations must register by 30 June, when Early Bird registration closes.

https://www.alzheimer-europe.org/Conferences/Barcelona-2018

Alzheimer Europe Networking

On 3 May (London, United Kingdom), Jean attended a meeting with GSK.

On 4 May, Dianne attended the Covenant on Demographic Change Board Meeting by Skype.

On 7-8 May (Manchester, United Kingdom), Jean attended the Scientific Advisory Committee meeting of the Neighbourhoods and Dementia Study.

On 7-8 May (Milan, Italy), Cindy attended the SyDAD annual meeting.

On 9-11 May (Geneva, Switzerland), Jean attended a workshop “Harmonising Neuropsychological Assessment for Dementia in Europe”.

On 12-14 May (Frankfurt, Germany), Gwladys attended the ICCA AES 2018.

On 14-16 May (Frankfurt, Germany), Gwladys attended the international fair IMEX 2018.

On 18 May (Bradford, UK), Dianne and Jean attended the AE ethics meeting on intercultural care and support for minority ethnic groups.

On 23-25 May (Amsterdam, Netherlands), Jean, Dianne and Cindy attended the EPAD General Assembly meeting.

On 28 May (Luxembourg, Luxembourg), Jean met with CHAFEA representatives to discuss the 2018 operating grant of Alzheimer Europe.

On 29-30 May (Utrecht, Netherlands), Jean attended the Joint Action Programme Board.

EU PROJECTS

18 April: European Medical Information Framework project holds Symposium on “Liberating Evidence from European Health Data”

On April 18 (Brussels, Belgium), the European Medical Information Framework project (EMIF) attracted over 110 participants who attended the public symposium ‘Liberating Evidence from European Health Data’.

The day started with an introduction to EMIF by Bart Vannieuwenhuyse and Professor Sir Simon Lovestone. Thereafter, the respective topic leads gave a high-level overview of the tools and technologies which were developed in EMIF (Nigel Hughes), including the new disease insights that were gained in the field of Alzheimer’s disease (AD) by Johannes Streffer as well as the metabolic complications of obesity by Dawn Waterworth.

The next session focused on other projects and how these are currently impacting the European health data ecosystem. Peter Rijnbeek discussed how the OMOP Common Data Model (CDM) will revolutionise the way healthcare data is being used in Europe. “We are in a perfect storm” said Peter, and the upcoming Innovative Medicines Initiative (IMI) project EHDEN (European Health Data and Evidence Network) will help tremendously in the wide-spread adoption of the OMOP CDM throughout Europe. After that, Nemanja Vaci presented an overview, activities and developments of the IMI ROADMAP project in its endeavour to provide the foundation for an integrated data environment and framework for real-world evidence in AD for the benefit of patients. Adil Mardinoglu, showed the audience an example of how large biological databases can help in solving fundamental research questions to better understand disease pathologies. Gerald Luscan, then gave an overview of how the IMI European Prevention of Alzheimer’s Dementia (EPAD) project is building a platform to
accelerate clinical trials, and how the project recruits participants.

After lunch, Valentina Strammiello gave a patient’s perspective about the re-use of healthcare data. During her speech she stressed that, while patients are genuinely concerned about data security and privacy issues, they support the idea of bona fide researchers accessing their data.

Thereafter, Nikolaus Forgo gave the audience a crash course on the upcoming General data protection regulation (GDPR), effective from the 25 May 2018. He explained that the GDPR might not be the hoped-for revolution to simplify the European legislation on data protection. At the same time he pointed out that the GDPR also offers reliefs and opportunities to allow the use of real-world data for research purposes.

Next, there was a panel discussion on the “Past, present and future of the European Health Data ecosystem” (Valentina Strammiello, Nikolaus Forgo, Isabelle Bos, Adil Mardinoglu, Thomas Allvin, Daniel Prieto-Alhambra).

The last session projected forward, looking at the future of the health data ecosystem. Bo Saxberg gave a lecture about the evolution in value of real-world data. He explained that by the augmentation of currently available real-world datasets, e.g. via the inclusion of longitudinal trajectories, the value proposal of the dataset for all stakeholders could be tremendously increased.

Finally, IMI Executive Director Pierre Meulien talked about the current challenges when working with healthcare data as well as how IMI aims to address these in the future by the inclusion of all stakeholders, being agile, scalable but also sustainable and by collaborating with IMI’s associated partners and other key initiatives.

18 April: AMYPAD holds an open lecture on biomarkers and disease modelling in Alzheimer’s disease

The disease modeling group (WP5) of the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project took the opportunity to invite two prestigious guest speakers and host an open lecture to present and discuss disease modeling efforts in Alzheimer’s disease, which took place in London on 18 April.

The evening lectures began with an inspiring and thought provoking introductory presentation by Prof. William Jagust from UC Berkeley, where he walked the audience through the neuroimaging evidence behind the theoretical model of the cascade of biomarker changes leading to Alzheimer’s disease. Several recent studies were highlighted where the focus shifts towards earlier stages of the disease course, observing relevant signals of PET biomarker changes in cognitively healthy subjects – a topic of strong interest within AMYPAD.

Following this introduction, the second guest speaker Roger Gunn (pictured) showed in detail his recent work on a novel quantitative method for amyloid PET imaging. The method (Amyloid Load) has promising results showing great performance in distinguishing diagnostic groups, estimating longitudinal changes and automated image classification.

In a second part of the event, two AMYPAD researchers presented the goals and plans of WP5, as well as preliminary results of the VUmc group and one of the key aspects of this WP, namely the great effort put into generating high quality data for modeling activities. These were received with great interest by the attendees, which engaged in fruitful discussions and also provided suggestions for future directions.

As a first of its kind, the Open Lecture event was a great success. The quality of the lectures and, perhaps more importantly, of the scientific discussions following each presentation was exceptional.

For further information, visit www.amypad.eu.

23-24 April: PACE General Assembly and Consortium Meeting took place in Antwerp

Members of the PACE project met over two days in Antwerp and discussed different issues such as the publications that researchers in PACE are currently working on and will be published in various scientific journals, other publications planned for publication before the end of the year, and other dissemination opportunities before and after the end of the project.

There were also some discussions and further information regarding the analysis plan for the cost-effectiveness evaluation of the intervention ‘Steps to Success’ on palliative care that PACE has implemented in long-term care facilities in 7 different countries (Study II). Delegates also discussed about the preliminary results of the findings of study II and of the process evaluation and the White Paper that will be produced later this year.

During the second day of the meeting, AGE platform and AE presented the consultations that both organisations had conducted in 2017 with different groups (in the case of AE with representatives of its member organisations and with the EWGPWD). The results from these consultations, together with the findings of the project, will be used in the development of the PACE Policy Recommendations. Dianne Gove and Ana Diaz attended the meetings.

26 April: ROADMAP project holds 5th General Assembly Meeting in Barcelona

On 25 and 26 April (Barcelona, Spain), Jean, Dianne and Christophe attended the 5th General Assembly Meeting (GAM)
of the Real World Outcomes across the AD spectrum for better care: Multi-modal data Access Platform (ROADMAP) project. The meeting was chaired by Project Coordinator John Gallacher (University of Oxford), Project Leader Frédéric Reydet de Vulpillieres (Novartis) as well as Project Manager Carlos Diaz (Synapse). The aim of the meeting was to provide updates on the different Work Packages (WPs), to discuss WP-specific progress as well as to identify activities that need further cross-WP collaboration.

During the first day of the meeting, the Consortium members discussed WP-specific activities in workshops. These encompassed a visualization of available data sources for outcomes called the “data cube”, progress of the health economics team with regard to their health economic modelling activities, the validation of disease progression models, a systematic literature review on the ethics of predictive modelling for Alzheimer’s disease (AD) secondary prevention as well as the potential data sources with real-world evidence in Europe.

During the second day, presentations followed with updates on the activities of the project’s work streams. During the first session Carlos Diaz and Sandra Pla reported on the current status of the project and gave an update on the financials as well as the reporting to the Innovative Medicines Initiative (IMI). This was succeeded by key topics for the next phase which encompassed; the project’s data cube, updates on the outcome prioritisation progress and model validation results.

After that, the health economics team provided an overview of the recent developments with regard to the proof of concept models. Then, the attendees obtained updates on the regulatory and health technology assessment (HTA) engagement, communication as well as the ethics activities. At the end of the meeting, the chairs provided an overview of the action items that need to be tackled and outlook towards the next meetings. Read more about the project here, a video with an update on the meeting by the Project Coordinator is available here.

1 May: EPAD publishes details on its registry to facilitate Alzheimer’s disease prevention trial recruitment

A paper authored by a dedicated workgroup (WP3) within the European Prevention of Alzheimer's Dementia (EPAD) project was recently published in the Journal Alzheimer’s & Dementia. The paper was led by the EPAD fellow Lisa Vermunt from VU University Medical Center, Amsterdam, Netherlands.

The publication entitled “European Prevention of Alzheimer’s Dementia Registry: Recruitment and prescreening approach for a longitudinal cohort and prevention trials” highlights that 1) the EPAD registry facilitates Alzheimer’s disease prevention trial recruitment, 2) data of existing cohorts could be reused for prescreening purposes and 3) recording the process can help to improve recruitment strategy in the future. https://doi.org/10.1016/j.jalz.2018.02.010

4 May: AMYPAD diagnostic and patient management study enrols its first research participant

The members of the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) initiative proudly announced the recruitment of its first research participant. The first participant was recruited in Geneva, Switzerland, within the diagnostic and patient management sub-study (DMPS) of the AMYPAD project. In this clinical study, researchers aim to include subjects suspected of possible Alzheimer’s disease and determine the usefulness of β-amyloid imaging as a diagnostic marker for Alzheimer’s disease. The study will involve people with dementia, but also subjects with mild cognitive impairment (MCI) or subjective cognitive decline (SCD), and will study the impact of β-amyloid PET on both diagnostic confidence, patient management and resource utilisation. According to Prof. Giovanni Frisoni (pictured), group leader of the laboratory of neuroimaging of aging at the University of Geneva, “Anyone would agree that amyloid PET accurately reflects brain amyloidosis, but to what extent this information addresses patients’ needs and expectations rather than physicians’ and industry’s is a contentious subject that AMYPAD DPMS will provide an answer to”.

For further information, visit www.amypad.eu.

7-8 May: SyDAD Annual meeting held in Milan

The SyDAD (Synaptic Dysfunction in Alzheimer Disease) Annual meeting was hosted by University of Milan on 7 and 8 May. It gathered all Early Stage Researchers (ESRs), their supervisors and partner organisations, to discuss research projects and the project’s training programme.
SyDAD is a European Training Network (ETN), sponsored by Marie Skłodowska Curie Actions. The project, supporting 15 ESRs, is a collaborative research program to reveal the mechanisms behind synaptic dysfunction in Alzheimer’s disease (AD). The project is led by Professor Bengt Winblad (Porject Coordinator) and researcher Susanne Frykman (Project Manager), at the Department of Neurobiology, Care Sciences and Society (NVS) of the Karolinska Institutet, Sweden. Alzheimer Europe is a Partner Organisation in this project. Cindy Birck, AE Project Officer attended the meeting.

10 May: Study centres University Hospital Cologne and Fundació ACE start screenings for the MOPEAD project

At the beginning of May, two study centres that collaborate with the Models of Patient Engagement for Alzheimer’s Disease (MOPEAD) project started screenings. The aim of the project is to compare and contrast four patient engagement strategies to identify ways to improve the early detection and diagnosis of Alzheimer’s disease (AD).

Pre-screenings help identify people with mild Alzheimer’s disease (AD) dementia or prodromal AD (a stage of AD where people have mild cognitive impairment). They can take place in a memory clinic (Open House), during an endocrinologist (tertiary care) or GP (primary care) routine visit, or on-line (Citizen Science). If it is suspected that someone has AD, then they are invited to undergo more complete tests.

Fundacio ACE (Spain) has started for the “Open House” and “tertiary care” strategies with 12 and 23 pre-screenings respectively. Subsequently, seven patients have been referred to the Fundacio ACE clinic where they are invited to more elaborate tests and receive support.

The University Hospital Cologne (Germany) also started the “Open House” where they screened 34 patients. The “primary care” and “Citizen Science” recruitments are due to start within the next few weeks.

Alzheimer Europe is collaborating in the project both through the support in communication activities as well as by promoting reflection about ethical and social issues related to the project. Read more about the project here.

17 May: Reviewers rate progress in the final year of PredictND as excellent

On 20 March, the research project “From Patient Data to Clinical Diagnosis in Neurodegenerative Diseases” (PredictND) held the 4th Annual Technical Review (ATR) meeting at VUmc in Amsterdam (the Netherlands). The reviewers assessed in their report that “Excellent Progress” has been made towards the project objectives also in this final year.

The key objective of PredictND was to develop and validate a clinical decision support system (CDSS) for differential diagnostics of dementias and for predicting disease progression. The tool compares patient data (neuropsychological and clinical test results, imaging as well as other biomarkers) to data from a high number of previously diagnosed patients, and computes a quantitative index capturing the similarity. The tool was validated in a carefully collected prospective study containing approximately 800 patients from 4 European memory clinics.

The results showed that the use of the CDSS supported clinicians in their decision-making and increased their confidence potentially enabling earlier diagnoses in future. Another key objective was to define a battery of so called low-cost tests, including web-based cognitive testing, web-based games and gait data for screening of early indicators of dementia. Promising results were obtained showing the potential of such low-cost tests. In addition, multiple sub-studies were implemented, demonstrating the use of machine learning in dementia diagnostics. Tools for computing novel imaging biomarkers from MRI and CT were developed, e.g., for vascular burden and frontotemporal dementia. Further, the use of amyloid PET imaging biomarkers in the CDSS was evaluated. Regarding prediction of disease progression, promising results were also obtained in predicting progression at a very early phase by studying data on people that reported subjective memory complaints.

The PredictND project received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under Grant Agreement no 611005. The project team consisted of nine European institutes: VTT Technical Research Centre of Finland Ltd. (Finland, co-ordinator), GE Healthcare Ltd (UK), Imperial College London (UK), University of Eastern Finland (Finland), Rigshospitalet/Region Hovestaden (Denmark), VUmc (The Netherlands), University of Perugia (Italy), Alzheimer Europe (Luxembourg), and Combinotics Ltd. (Finland).

Read more about the project here.

17 May: The INDUCT FindMyApps project launches website

On 17 May, VU University Medical Center Amsterdam (VUmc) proudly announced the launch of the FindMyApps project website. FindMyApps aims to make the use of touchscreen devices and applications for people with dementia better accessible helping them to find dementia-friendly and appropriate apps.

Touchscreen devices can potentially provide a great help to people with dementia especially to maintain social contact, to help tackle the daily challenges and to find meaningful activities. However, in practice, touchscreen devices are not always easy to use for people with dementia and in the fast-
paced growing application market, it is often difficult to find the appropriate application(s), i.e. fitting the persons’ needs, abilities and preferences.

Saxion University of Applied Sciences in Deventer, in collaboration with VUmc in Amsterdam, Radboudumc in Nijmegen, people with dementia and the Media Company EUmedianet, created the website and platform.

The project team at VUmc especially thanked the members of the European Working Group of People With Dementia (EWGPWD) and staff members from Alzheimer Europe who provided insights on how to enhance the website content and design.

If you would like to pose a question or just would like to share your thoughts you are invited to contact Floriana Mangiaracina (pictured), Early Stage Researcher of the FindMyApps project, at f.mangiaracina@vumc.nl

Check out the website here: here.

21 May: People with dementia, carers and MinD project members meet for the third time to work together

May 2018 has seen another MinD secondment in the UK. The University of Wolverhampton and Nottinghamshire Healthcare NHS Foundation Trust, UK, jointly hosted visiting researchers from Germany, Luxembourg, the Netherlands, Spain and Russia to work on the two MinD design ideas.

During the two weeks, the designers and a psychologist worked in two teams on design development of the ‘Good Life Kit’ and the ‘We Connect - Social Engagement Map’. The Social Engagement Map aims to support people with dementia to stay socially connected and engaged, and in control of their social life. The Good Life Kit aims to support people with dementia in managing everyday life confidently. The design concepts had been selected in October 2017 from a shortlist with the help of people with dementia, caregivers and healthcare experts in Germany, Spain and the UK.

To ensure that the designs meet the needs and expectations of people with dementia, once again, a shared co-design session was held with people with dementia and carers from the Nottinghamshire Public and Patient Involvement Group (PPI). The workshop on May 14th brought 16 people with lived experience together with the psychologist, designers and programmers, to explore the functions and aesthetics of the screen technology of the Social Engagement Map from a user perspective.

The morning began with coffee in a sociable outdoor cafe to allow everyone to meet and re-acquainted themselves with one another and welcome new participants. Moving indoors, a number of inclusive exercises allowed to people to connect through shared life experience and common interests, enriched by those experiences.

The afternoon offered an opportunity to test out a replica of the screen, which enabled participants to comment on ease of use, aesthetics and suggestions for improvement. Users were delighted when they were able to identify their own faces and interests floating across the screen and imagine how this would enable future potential connections and shared activities. Many useful comments and suggestions were recorded through a brief questionnaire that demonstrated a vibrant interface between the technology and its PPI testers. As with the previous PPI event in March, there was a good balance between purpose and process that enabled both the project and all its participants to grow in capacity and confidence and create dementia friendly technology together within a positive, mindful and empowered partnership centered on authentic lived experience.

23 May: The EPAD project holds its General Assembly Meeting in Amsterdam

This year, the European Prevention of Alzheimer’s Dementia (EPAD) General Assembly meeting was held in Amsterdam (Netherlands), under the banner “How to assure sustainability”. It was hosted by VUmc and kindly sponsored by VUmc, Amgen, Novartis and Janssen. The meeting gathered more than 180 attendees and provided an excellent opportunity to discuss the results obtained so far and what the project wants to achieve by the end of this year and beyond.

On 23 May, Serge Van der Geyten, Craig Ritchie, and Philip Scheltens welcomed the attendees, gave a general overview of the project and introduced the agenda for the coming days.

Neil Mitchell, Joe Milne and Kristy Draper explained then the role of the University of Edinburgh (UEDIN) in the EPAD Longitudinal Cohort Study (LCS) and the Proof of Concept (PoC) as well. The enhanced role of IQVIA within the study management under the leadership of UEDIN was also reported.

During the second day of the meeting, the emphasis was squarely on the EPAD Longitudinal Cohort Study (LCS).

During the first session, Joe Milne reported the current LCS status and the progress done so far. Katrin Haeverans, Emma Law and Craig Ritchie presented then the LCS recruitment taskforce and the PrePAD Velocity.
The next session was hosted by Craig Ritchie, who invited five national principal investigators to present their Trial Delivery Centers (TDCs) and report their lessons learned and future plans (pictured). There was also a presentation on the EPAD Academy by Iva Knezevic and on the EPAD research access process by Judith Syson and James Bonner. During the afternoon of the second day, the consortium members discuss WP-specific activities through the organisation of an interactive poster session. This was succeeded by breakout sessions for three WPs. On the third and final day, presentations were delivered on the PoC Protocol, virtual pipeline and EPAD branding. There was also a session on the EPAD academy where nine young researchers had the opportunity to present their work within the EPAD and AMYPAD projects. Craig Ritchie and Serge Van der Geyten closed them the meeting by presenting what the project wants to achieve in 2019 and beyond. Executive Director Jean Georges, Director of Projects Dianne Gove and Project Officer Cindy Birck attended the General Assembly Meeting.

28 May: Span+ project launches European survey of current interventions and projects aimed at the empowerment of people with dementia

The Dutch Radboudumc Alzheimer Centre, with support from Alzheimer Europe, is conducting a European survey to gather information about as many interventions and projects as possible in Europe aimed at empowering people with dementia. We are interested in finding out which interventions and projects people consider empowering and why. Examples of interventions or projects considered empowering are interventions or projects that:
- aim to support people with dementia to stay active and involved for as long as possible
- aim to enhance their ability to live well with dementia
- address individual needs and preferences.

What do you need to do if you want to help us out?
- If you are currently involved or know about interventions or projects in your country that are either described as empowering, or that you would consider as being empowering to people with dementia, please follow the link below and complete the survey. The survey is in English and we would be grateful if you provide the information in English. The survey will be live until the end of June.
- If you are aware of other people or organisations in your country who are conducting this type of interventions or projects, please feel free to share this link with them.

With your contribution, we hope to be able to gain a broad overview of empowering interventions and projects in Europe. In this way, important knowledge about empowering people with dementia will become available.

To go to the survey, click here: https://www.radboudumc-surveys.nl/elg/v206/index.php/343425?lang=en

Our survey is part of a project called ‘SPAN+: Empowering people with dementia’. For more information, see: http://www.ukonnetwerk.nl/spanplus/en

EU project acknowledgement

A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter with EU funding are:
- AMYPAD – grant agreement 115952
- EMIF – grant agreement 115372
- EPAD - grant agreement 115736
- MOPEAD - grant agreement 115985
- PredictND - grant agreement 611005
- ROADMAP - grant agreement 116020

Members of the European Alzheimer’s Alliance

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

Austria: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP).
Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).
Bulgaria: Andrey Kovatchev (EPP).
Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR).
Cyprus:
25 April: European Commission presents its Communication on Digital Transformation of Health and Care in the Digital Single Market

The Commission has adopted a communication setting out a plan of action that puts citizens at the centre of the healthcare system in three ways:

• by enabling citizens’ secure, cross-border access to their electronic health records and the possibility of sharing their records across borders;

• by facilitating the use of larger data sets through a shared European data infrastructure to prevent diseases, determine personalised medical treatment and better anticipate epidemics;

• and by providing digital tools that enable citizens to manage their health more actively within integrated care systems.

This approach will provide the basis for EU action in digital health over the next years, such as support for the exchange of e-prescriptions and electronic patient summaries, enabling the cross-border exchange of full electronic health records, voluntary coordination in sharing data and resources for disease prevention and research, and capacity building and the exchange of innovation and best practices for healthcare authorities. The full press release can be read here.

EU DEVELOPMENTS

Costas Mavrides (S&D); Eleni Theocarous (EPP). Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). Estonia: Urmas Paet (ALDE); Finland: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Mapieta Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). France: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Francoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). Germany: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Costas Chrysogonos (GUE/NGL); Kostadinka Kuneva (GUE/NGL); Kyriks Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP);Eleftherios Synadinos (NI); Elissavet Vozemberg-Vroni (EPP). Hungary: Ádám Kósa (EPP). Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuiness (EPP); Liadh Ni Riada (GUE/NGL).

Italy: Brando Benifei (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D). Lithuania: Vilija Blinkeviciute (S&D). Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). Malta: Roberta Metsola (EPP); Alfred Sant (S&D). Netherlands: Gerber-Jan Gerbrandy (ALDE); Esther de Lange (EPP); Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP); Lambert van Nistelrooij (EPP). Poland: Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). Romania: Cristian-Silviu Busoi, MEP (EPP); Marian- Jean Marinescu (EPP); Daciana Octavia Draghici (S&D); Costas Mavrides (S&D); Eleni Theocharous (EPP). Sweden: Angelika Diekmann, MEP (EPP); Costas Mavrides (S&D); Eleni Theocharous (EPP). Slovakia: Miroslav Mikolásik (EPP); Ian Stefanec (EPP); Anna Záborská (EPP); Jana Žitnanská (ECR). Slovenia: Franc Bogovič (EPP); Marek Štefanič (ALDE); Tomaž Kavčič (S&D); Žiga Zupančič (S&D). Spain: Jouko Reponen (EPP); Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). United Kingdom: Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Rory Palmer (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D).


In response the Commissions announcement of the proposal for a Multi-Annual Financial Framework post-2020 on 2 May the European Patients Foundation (EPF) and the European Public Health Alliance (EPHA) have issued a joint statement—Health deserves more, not less spending!

EPF and EPHA are pleased to see that the Commission is planning for continued investment in health. This acknowledges the unprecedented common challenges in this area that no single country can tackle alone. They welcome the fact that health is placed under the “Investing in People, Social Cohesion & Values” heading, however, they note with concern that the ESF+ instrument is being asked to do much more, with the inclusion of health, but with diminished resources health is hit with significant cuts in the MFF proposal. EPF and EPHA state that any funding decrease is unacceptable. In the joint statement they call for the budget allocated to health to be significantly increased to be commensurate with the magnitude of the challenges needed to be taken up in these areas – not least epidemic levels of largely preventable chronic diseases, the threat of antimicrobial resistance and increasing health inequalities - in light of the State of Health in the EU report, recently released by the European Commission. In the statement EPF and EPHA renew their call for visible, autonomous leadership in health, embodied by a Vice-President of the Commission for Health. The final call is for all policies and instruments within the new
Multi-Annual Financial Framework to explicitly contribute to enhancing human health prevention and protection. The full statement can be read here:

http://www.eu-patient.eu/News/News/health-mff/

2 May: European Commission proposes 100 billion for research programme in new MFF seven year budget

The European Commission outlined a EUR 97.6 billion budget for Horizon Europe, its new research programme, running between 2021 and 2027, which is an increase of almost 30%.

EU research officials say they are very satisfied with the Horizon Europe increase, even if it is less than the €120 billion asked for by the European Parliament, and the €160 billion hoped for by lobbyists.

The new research programme is one of the few EU budget lines to go up in the Commission’s seven-year proposal. “Everyone said we want more for research – it’s happening,” the Commission’s President Jean-Claude Juncker told reporters at the unveiling of the blueprint.

Like all EU decisions, the proposal will require many rounds of scrutiny before final adoption. It will need unanimous agreement from the EU’s member countries and consent from the Parliament – a process expected to last more than a year.

https://sciencebusiness.net/framework-programmes/news/european-commission-proposes-eu100b-research-programme

23 May: European Commission publishes recommendations to 12 Member States to make improvements to their national health systems

On May 23, the European Commission (EC) adopted proposals for country-specific recommendations. The Commission recommends that the governments of 12 Member States make improvements to their national health systems to improve their effectiveness, increase accessibility and strengthen their resilience, with the following specific recommendations:

Each May the EC adopts proposals for country specific recommendations which are a key step in the European Semester process, the EU’s yearly cycle of economic and social policy coordination. The 12 countries include Austria, Bulgaria, Cyprus, Finland Ireland, Latvia, Lithuania, Malta, Portugal, Romania, Slovenia, and Slovakia.

Although Member States are responsible for their own health policy and the organisation and delivery of care, in the context of the European Semester, the EU can give recommendations on certain aspects of its health system to an EU country. The rationale is that EU governments spend an average of 15% of their budgets on health, making it one of the largest and fastest growing areas of expenditure. However, health is also an investment. The health sector is a major source of employment, and timely access to high quality healthcare contributes to social inclusion.

More information can be read here.

28 May: European Commission publishes report on Pharmaceutical incentives

A study on the economic impact of pharmaceutical incentives and rewards in Europe, requested and funded by the European Commission and carried out by Copenhagen Economics has recently been published.

This study has been conducted in response to the invitation of Member States in the Council Conclusions of June 2016 to conduct an analysis on the functioning and actual use of the various pharmaceutical incentives.

The Commission intends to use the study as an external input in the ongoing analysis. This reflection will also be based on the findings of the previous study on the economic impact of the Paediatric Regulation and the ongoing study on the functioning of the EU regulation for medicines for rare diseases (orphans). All these elements will in the end contribute to the evaluation of the orphan and paediatric Regulations.

The study provides an overview of pharmaceutical incentives and economic evidence on how Supplementary Protection Certificates and regulatory data protection are used in practice and their overall effects on innovation, availability and accessibility of medicinal products.

More specifically, the factual and evidence-based report presented by Copenhagen Economics gives insights into the following 5 types of pharmaceutical incentives:

- The supplementary protection certificate (SPC) which extends the standard duration of patent protection to a medicinal product;
- Data protection which prevents marketing authorisation applications for generics to refer to the results of pre-clinical tests and clinical trials of authorised medicinal products;
- Market protection which ensures that generic copies of authorised medicinal products are not marketed;
• Market exclusivity for orphan medicinal products; and
• Rewards for paediatric medicinal products (i.e. used for treating children aged 0 to 18), which can benefit from a 6 month extension of the SPC or additional 2 years of market exclusivity in the case of orphan medicinal products.

The Commission will continue to discuss with all interested parties during the whole process with the aim to provide results by 2019 to allow the next Commission to take informed decision about possible policy options.

The full report can be read here.

29 May: EU ministers endorse Commission plans for research cloud

At a meeting of the EU Competitiveness Council on 29 March, EU research ministers endorsed the roadmap for the creation of the European Open Science Cloud (EOSC) which will support EU science in its global leading by creating a trusted environment for hosting and processing research data. The conclusions of the Competitiveness Council, proposed by the current Bulgarian Presidency of the Council of the EU, are the result of two years of intense negotiations.

Carlos Moedas, Commissioner for Research, Science and Innovation, said: “The Cloud will be a game changer for science in Europe. These conclusions show that we are delivering on our Open Science priority, bringing an idea to fruition in just two years. Such quick progress in such a short time would not be possible without the support of national governments, industry and the scientific community.”

On 23 November 2018, the incoming Austrian Presidency of the Council plans to gather research and innovation ministers to sign off the governance structure, which will steer and coordinate the work of several projects under Horizon 2020, and to launch the first version of the EOSC portal.

More can be read here.

30 May: European Commission adopts legislative proposal for a new European Social Fund Plus (ESF+)

Following the adoption of the new Multiannual Financial Framework for the period 2021-2027 on 2 May, the European Commission (EC) has adopted a legislative proposal for a new European Social Fund Plus (ESF+).

The European Social Fund Plus will focus on investment in people and support the delivery of the European Pillar of Social Rights. The EC said that this will help to respond to global challenges, maintain social fairness but also to drive Europe’s competitiveness forward. The European Social Fund Plus will be a more flexible and simpler version of the current European Social Fund by merging a number of existing funds and programmes. Pooling resources will allow the EU and Member States to provide more integrated and targeted support in response to the social and labour market challenges that people in Europe face today. For instance, integrating support to the most deprived into the ESF+ will benefit eligible persons through a better mix of material assistance and comprehensive social support.

Specifically, the European Social Fund Plus will merge:

• the European Social Fund (ESF) and the Youth Employment Initiative (YEI);
• the Fund for European Aid to the Most Deprived (FEAD);
• the EU Programme for Employment and Social Innovation and
• the EU Health Programme.

The health strand of the ESF+ Programme will support public health policies and access to medical products.

Vytenis Andriukaitis, Commissioner for Health and Food Safety, stressed that: "Health is a fundamental value therefore it makes sense that the future EU budget envisions integrating the Health programme in ESF+ under the cluster of "values". This will lead to new and stronger synergies with the other building blocks of the European Pillar of Social Rights and will allow better coordination of health related investments. It will also support health promotion and disease prevention, improving effectiveness, accessibility and resilience of health systems as well as reducing health inequalities and making healthcare better and safer for the benefit of patients and society at large."

Building on achievements and lessons learned from the previous health programmes, the new strand of the ESF+ programme will:

1. Improve crisis-preparedness, management and response in the EU to protect citizens from cross-border health threats,
2. Strengthen health systems, by supporting the digital transformation of health and care, developing a sustainable EU health information system, and supporting national reform processes for more effective, accessible and resilient health systems addressing, in particular, the challenges identified in the European Semester,
3. Support EU health legislation and
4. Support integrated work, (e.g. ERNs, HTA and implementation of best practices for the promotion of health, prevention and management of diseases).

More can be read here.

MEMBERS’ NEWS

19 March: Alzheimer’s Society UK publishes report on proving and improving the value of involving people affected by dementia in research

Patient and public involvement (PPI) in research is the philosophy where research is done ‘with’ or ‘by’ people
affected by the condition rather than ‘about’, ‘for’ or ‘to’ people.

Alzheimer’s Society’s first PPI Impact Report found that there are 5 important areas that have been impacted by contributions from our Research Network:

- Impact on volunteers
- Impact on researchers
- Impact on research
- Impact on Alzheimer’s Society
- Impact on wider Society.

The evidence tells us that PPI is not only the ‘right thing to do’ but allows us to confidently say where and how the Research Network is having an impact. Our next challenge is to move from a state of ‘proving’ why people affected by dementia should be involved to one which focuses on ‘improving’ people’s involvement. We are particularly committed to increasing the involvement of people with a diagnosis of dementia given the unique perspective they bring to challenges in dementia research.

Across health research an increasing value has been given to lived experiences of health conditions in the research process, often placing it on an equal footing with academic expertise. More researchers are now doing PPI, not just because funders tell them to but because they believe that it’s the ‘right thing to do’. They see the benefits to recruitment in their studies, unique contributions to data analysis and dissemination and an increased confidence that the outcomes they are measuring are meaningful to people affected by the condition.

Since 1999 Alzheimer’s Society in the UK has pioneered the active involvement of people affected by dementia through our award winning Research Network. We were, and continue to be, leaders in facilitating PPI, not just for our own funded research but also across dementia research in the UK and Europe.

This philosophy of conducting research in partnership with people affected by dementia is gathering increasing support across Europe, with Alzheimer Europe’s position paper released in 2017 adding further support. The need to improve PPI across Europe is being strengthened by increasing numbers of journal articles being published either acknowledging PPI input or describing innovations in PPI.

Read the report or watch the short video here to find out more.

4 May: Alzheimer Bulgaria announces the opening of the first day care centre for people with dementia in Plovdiv

On 4 May, members from Alzheimer Bulgaria (Sani, Annie, Ivana, Irina and Kolju) attended the opening of the first day care centre for people with dementia in Plovdiv (Bulgaria). The centre is part of the Centre for Social Services for the Elderly with Disabilities.

The organisation expressed its gratitude to the Municipality of Plovdiv and Mrs. Veselina Boteva in particular. She is Director of the Social Policy Directorate of the Municipality of Plovdiv, and her efforts have made it possible to turn the country's first day care centre for people with dementia into reality.

Alzheimer Bulgaria stated that they strongly hope that this good practice of the municipality of Plovdiv will give rise to further work on elaboration and adoption of national standards for dementia care. And in addition, that it will support training of professionals in health and social systems relevant to the good European practices which are already put in place.

More information (article in Bulgarian) about the opening of the day care centre in Plovdiv can be found on the Alzheimer Bulgaria’s website:

https://alzheimer-bg.org/novini/novini-za-dnevniqa-centar-v-plovdiv/

8 May: Alzheimer Society of Finland launches project “My Choice” to develop new tools for decision-making supporting people with memory-related diseases

There is a large-scale social and health care reform going on in Finland. The new social and healthcare system gives citizens more options to choose the care they need. At the same time, it calls for new knowledge to enable people to make thoughtful choices: what to choose, wherefrom and why.

The new project of the Alzheimer Society of Finland “My choice” aims to strengthen the ability of people with memory-related diseases to make good choices in the new social and health care system. Therefore, the project will develop and provide tools for people with memory-related diseases.

The project also encourages to listen to people with memory-related diseases as experts of their own life, strengthening the participation of families of people with memory-related diseases when the services are developed. “The steering group of the project not only consists of experts, but also of people with memory-related diseases and their family members. Their
Involvement is already visible from the planning stage of the project on and reaches through the monitoring stage too”, describes Mia Haapanen, Specialist of the project in Alzheimer Society of Finland.

The local associations can get financial support to provide counselling and guidance to families of people with memory related diseases. “The role of the assisting persons is central in guidance”, says Mia Haapanen.

The project consists of three phases that are carried out from 2018 to 2020. At the beginning, the project sorts out the condition of social and health care services from the point of view of families of people with memory-related diseases. The information of good practices as well as challenges are then gathered and listed. The first-stage research is followed by the creation of supported decision-making models. These models will then be implemented in pilot regions which can be a whole county or smaller areas.

9 May: Alzheimer Iceland re-elects board

On 9 May, Alzheimer Iceland re-elected its board and the association has hired a new General Manager, Vilborg Gunnarsdóttir. This year’s annual report showed that the organisation has increased all kinds of educational meetings around the country including 18 open meetings and 11 meetings especially for professional caretakers. Interview meetings were held with relatives advising them about whatever comes up regarding dementia and problems on daily bases. The association also held 4 forums under the name of “What is it with the Brain”. On top of that the working group have been preparing an education in cooperation with the department of Continuing education at the University of Iceland. The plan is that this will formally start next September.

The concept of Alzheimer cafés which have only been in Reykjavik up until now have been rolled out to 5 different places in Iceland and they are now under the umbrella of the organisation. The association is still waiting for the Health minister to formally start a working group to draw up a text for the strategy for people with dementia and has had one meeting with her and she confirmed that the association would have a representative in that working group.

11 May: People with Dementia, their families and professionals meet to discuss autonomy

The main objective of AD-AUTONOMY is to improve the quality of life of persons with dementia, their families and professionals through an innovative training program. The project aims to raise awareness on and motivate maintaining autonomy, to increase the autonomy of people with dementia (PwD) for decision making and independent living, to promote autonomy through training, to support empowerment through introducing technology and techniques for emotional management, to include professionals in the process, and to develop training methodology with tools.

AD-AUTONOMY is a unique and innovative training program, which is based on direct involvement, training and practical activities of persons with AD, their families and professionals and also it addresses families and professionals as “supports”, not only as caregivers. The involvement of these parties is achieved by organising Working Sessions with 10 PwD, their families and 3 professionals, within the supervision of a facilitator and an observer, in order to explore different perspectives and ideas about Autonomy of PwD.

The first working session in Turkey was held on April 16, 2018 and after the introduction of the main available and recommendable autonomy approaches, participants were invited to discuss and define autonomy, its main dimensions, daily activities and barriers for their implementation, main emotional skills for managing the impairment related to dementia and key techniques for emotional management.

The outcomes of the working session will be published after the completion of the project, but it may be interesting to mention a few intriguing facts in advance. While discussing autonomy and the most important dimensions, we understand that the main concern is “mobility”. Both people with dementia and their families worry about PwD getting lost outdoors. When we limit the subject to indoors, the anticipation comes down to personal hygiene and eating.

The most striking interpretation to derive from the session was that, when autonomy is discussed, the person with dementia is not the only one whose autonomy is at stake; families also dread losing their own identities.
**POLICY WATCH**

7 May: New legislation specifies the right to self-determination in Finland

During the month of April, a draft for the Self-Determination Act was handed to Annika Saarikko, Minister of Family Affairs and Social Services (Finland).

The forthcoming legislation aims to better define the right to self-determination of people with memory-related diseases in social and health care. The upcoming law will have a key role in securing good care and treatment. In addition, circumstances when the self-determination right can be restricted in social and health care are exactly defined.

“This is a question of human and fundamental rights of people with memory-related diseases”, emphasises Mari Luonsinen, specialist staff member at the Alzheimer Society of Finland. The Alzheimer Society of Finland has participated actively in the preparation of a working group of The Ministry of Social Affairs and Health. During the working group they stressed that restriction measures can only be used when all other measures don’t work out; they may only be an exception.

“Our opinion is that restriction measures are the very last option. For example, they cannot be justified by a lack of personnel or by stress in care settings”, says Jasminda Jokinen, Legal Officer at the Alzheimer Society of Finland.

Commenting on the Act, the Alzheimer Society of Finland stated that; “People with memory-related diseases represent the largest group of people that the Act applies to. The good thing in the law is that the person must be assisted in using self-determination if the person is not able to express one’s own will.”

The draft is going to proceed to the Finnish Parliament in autumn and the legislation comes into force in 2020. The forthcoming law is unique world-wide.

“I believe that this Act respects all people, protects patients and gives clear rules to professionals in social and health care”, said Minister of Social and Health Care Services, Annika Saarikko.

23 May: Alzheimer’s Disease International (ADI) launches new report on 1st anniversary of the World Health Organization’s (WHO) global plan on dementia

A new report by Alzheimer’s Disease International (ADI) on national responses to dementia marks the one-year anniversary of WHO’s adoption of Global Action Plan on the Public health Response to Dementia 2017-2025.

The report entitled “From plan to impact; Progress towards targets of the Global plan on dementia” shows that world governments are still too slow at tackling the dementia epidemic and recommends that greater progress is needed by countries to implement national plans to respond to dementia. ADI is calling on world governments to commit to developing national plans and to devote funding to plans to tackle dementia, with it set to become a trillion-dollar disease this year. Dementia is the 7th leading cause of death globally.

The first target in the Global action plan is for 75% of WHO’s 194 Member States to have developed or updated national policies, strategies, plans or frameworks for dementia by 2025. As it stands, 27 Member States have a national plan, while 28 Member States have a plan in development.

- Every 3 Seconds someone develops dementia - but most people with dementia do not receive a diagnosis or support
- Progress too slow from governments in generating national dementia plans: Global action plan sets goal for 146 states to develop a national response to dementia by 2025
- Scale of challenge is huge, over 15 new plans needed each year to hit 2025 target, only 1 plan since 2017
- ADI calls for greater funding to be devoted by governments towards plans

Paola Barbarino, CEO of ADI, said: “Governments must act now as national plans take time to develop and set in place and are essential in achieving tangible actions for the benefit of people with dementia and their families and care partners who don’t have time to wait. Some states such as Japan, UK and Costa Rica, have been very proactive in developing and implementing national plans and policies to combat this global epidemic. However, we have a huge challenge ahead of us, which would see us need at least 15 new plans a year to hit the 2025 target.”

The report from ADI, was released at its official side event to the World Health Organisation’s (WHO) 71st World Health Assembly, “Mobilising Society: Inspiration for developing national responses to dementia” on May 23 in Geneva.

The full report can be read here.

23 May: National Dementia Office and the Department of Health publish mid-term review of implementation of the Irish national dementia strategy (NDS)

A new report by Alzheimer’s Disease International (ADI) on national responses to dementia marks the one-year anniversary of WHO’s adoption of Global Action Plan on the Public health Response to Dementia 2017-2025.

The mid-term review of the implementation of the Irish national dementia strategy (NDS), which has been prepared by the National Dementia Office and the Department of Health, has been published.
The Minister with Special Responsibility for Mental Health and Older People, Jim Daly, TD noted that good progress has been made in implementing the strategy, which remains a work in progress with challenges still to be overcome. Reaffirming the commitment of the Department of Health and the Government to fully implementing the strategy, the Minister said:

“This is an area that I am very conscious of and recognise that it needs more focus to deliver on the full strategy. I am also conscious that dementia is becoming a condition that affects more and more families across the country. I have already had high level meetings with my officials and the HSE to discuss further deliverables in the context of the estimates for budget 2019 and I hope to be able progress new measures at this time.”

The National Dementia Strategy was launched in December 2014, as a response to the increasing number of people with dementia in Ireland. The Strategy emphasises that most people with dementia live in their own communities and can continue to live well and participate in those communities. The strategy contains 14 priority and 21 additional actions under the headings of leadership; better awareness and understanding; timely diagnosis and intervention; integrated services; supports and care for people with dementia and their carers; training and education; and research and information systems.

Chairperson of the European Working Group of People with Dementia and Member of the NDS Monitoring Group Helen Rochford-Brennan said: “While acknowledging that progress has been made in implementing the National Dementia Strategy so far, it is clear that significant challenges remain in ensuring that all people with dementia and their carers get the support they need to live as well as possible in their communities. This is also my personal experience as someone who has been diagnosed with dementia. It is very obvious that more funding is now required to take the next steps in the implementation of this Strategy.”


24 May: Swedish Minister for Children, the Elderly and Gender Equality announces national dementia strategy for Sweden

On 24 May in Stockholm Lena Hallengren, the Swedish Minister for Children, the Elderly and Gender Equality, announced the Swedish Government’s decision to launch a national dementia strategy for Sweden with the overall ambition of equality in care for persons with dementia.

The plan is built on the notion of a national standardised care-process, equal for all Swedish persons with dementia no matter where they enter the health-care system. This is most often with the primary physician in the 290 Swedish communities. The main concern is to “find and help the patient with Dementia from first diagnosis to care and treatment”, however with the care-system that exists today it is fragmented around neuro-degenerative diseases.

Firstly, the accrued competence in the Swedish health-care system about neuro-degenerative diseases and of the progressive nature of symptoms of cognitive decline is low. Secondly, most care of persons with dementia takes place in the social services sector targeted at the elderly, in the severe stages of the disease, where assisted care-home staff are not trained to meet the needs of the person with dementia or the needs of care-givers.

The minister declared that competence-building efforts are the key to proceed with this plan. Sweden has opened up to learn from the other Nordic countries that are now entering the second and third stages of national dementia strategy-work.

The Swedish National Dementia Strategy consists of key areas:

- cooperation between health-care and social services
- staff-quality, competence building
- evaluation and follow ups
- care-givers
- the civil society
- digitalisation and technique as part of the care-process for persons with dementia.

As from the launch, Olivia Wigzell, Director-General of the Swedish National Board of Health and Welfare, has received a new assignment from the Swedish Government to create, evolve and spread a national standardised care-process equal for all Swedish patients with dementia. A Swedish person with dementia becomes a patient after he or she receives a diagnosis of dementia by a physician.

The Swedish National Board of Health and Welfare shall according to the appropriate directions also follow up and handle the long-term strategic issues that may arise in the finalised Swedish dementia strategy. A first outline of the work...
plan is to be presented to the Swedish Government on 10 October, 2018. However, the Swedish national elections will be on 9 September, but a finalised presentation shall be presented to the Swedish Government by 1 June 2022.

“Working for Alzheimer Sweden, part of the Swedish dementia society specialised in Alzheimer’s disease and the care-giver perspective since the 1980s, I feel relieved and re-energised by this positive announcement from the Government! In what Lena Hallengren is saying, I hear that the government understands that long-term competence-building about neuro-degenerative diseases in all-sectors of the health-system is the cornerstone of a dementia strategy for this country. I very much hope that they will safe-guard the promise to roll out the plan in a substantial equality - country. I very much hope that they will safe-guard the system is the cornerstone of a dementia strategy for this country. I very much hope that they will safe-guard the promise to roll out the plan in a substantial equality - country. I very much hope that they will safe-guard the promise to roll out the plan in a substantial equality - country. I very much hope that they will safe-guard the promise to roll out the plan in a substantial equality - country. I very much hope that they will safe-guard the promise to roll out the plan in a substantial equality -

28 May: France moves to stop reimbursement of treatments for Alzheimer’s disease

The French Minister of Health, Agnès Buzyn has announced that the four drugs used to treat the symptoms of Alzheimer’s disease - donepezil, rivastigmine, galantamine, memantine will no longer be reimbursed by the French Government. The Haute Autorité de Santé (HAS) (Health Authorities) made a recommendation in October 2016 that these treatments, which at the end of 2015 represented around 90 million euros of annual expenditure had "medical interest insufficient to justify their costs". At this time, Minister for Health Marisol Touraine, refused to stop reimbursement saying: “doing so would plunge patients and their families into disarray, while the quality of care is still very variable from one place to another”. During a press conference on Friday 25 May, Professor Christian Thuillez, president of the transparency commission of the HAS, argued that the improvement of care advocated by the HAS "will provide much better services than drugs whose benefits exist but are modest and are not sufficient compared to the risks to patients of cardiovascular."

The association France Alzheimer, which brings together families of patients, stated that not reimbursing patients “would result in inequity between the wealthier and the poorest families. Given the extremely high burden on families (more than 1,200 € / month on average), few will be able to pay the monthly 30 € equivalent to the cost of treatment in addition to their current expenses. Beyond the issue of efficiency and cost, prescribing drugs was also important in maintaining a therapeutic relationship between the physician and the patient.”

In an article published in the Libération, March 2017 many French neurology, psychiatry and geriatric societies and the Federation of memory centers recognised the modest effect of these drugs. However, they agreed that if the drugs were not reimbursed this could limit the chances of accessing innovative therapeutic research. By becoming the only European country not to reimburse drugs, France would be jeopardising its national competitiveness in research.

“This decision also calls into question the work of health professionals, neurologists, and doctors who, for several years, prescribed these drugs to their patients, aware of the benefits to them. They did not prescribe these drugs to please or just to be compassionate to the patient or even to avoid the desperation of the patient. Knowing that some medications have potential side effects, a doctor would never take the risk of prescribing them without being certain that there is an expected benefit, even modest”, says Joel Jaouen, president of France Alzheimer and related diseases. Read more at: https://www.lemonde.fr/sante/article/2018/05/28/alzheimer-to-the-funding-of-medicaments_5305562_1651302.html#70RwutFLFrYT85I.99

SCIENCE WATCH

27 April: Researchers investigate the effect of music on the activation of brain regions in people with dementia

On 27 April, the University of Utah Health, announced in a press release, that findings from a study on music-based treatments will be published in the April issue of The Journal of Prevention of Alzheimer’s Disease.

The research team, led by Jeff Anderson, aimed to investigate the mechanism that activates the attentional network of the brain. For their study, 17 people with dementia and their caregivers were supported in selecting songs that are meaningful for the participants as well as on how to use media players.

For their investigation, the scientists used functional MRI to scan brain regions activated when listening to eight 20-second clips of music versus eight 20-second blocks of silence. They then compared the images from each scan. The analysis showed that when participants listened to the personal soundtrack, their visual network, the salience network, the executive network and the cerebellar and corticocerebellar network pairs all showed significantly higher functional connectivity.
While these investigations may help to better understand the underlying mechanisms, the team stated that they are by no means conclusive. On one hand the sample only included a fairly small group of participants. On the other hand, imaging sessions were only organised once for each participant. Therefore, further research needs to be conducted to assess if the effects identified in this study continue beyond the brief period of stimulation as well as whether other areas of memory or mood are enhanced by changes in neural activation and connectivity in the long term.


1 May: Study suggests that a specific region of the brain could predict cognitive impairment in Parkinson’s disease

In a recent study published in the journal Brain, researchers from King’s College London (UK) reported that changes in a specific region of the brain could predict the development of cognitive impairment in people with Parkinson’s disease (PD). Scientists compared MRI data of people with PD with and without cognitive impairment. They also did a 36 months follow-up study of MRI data of people with PD to identify early predictors of cognitive impairment. They showed that the degeneration of the brain region called nucleus basalis of Meynert could predict the clinical onset of cognitive impairment in PD.


1 May: FDA approves Phase 2 trial of TNX-102 SL for AD agitation

On 1 May, the clinical-stage biopharmaceutical company Tonix Pharmaceuticals, which is developing next-generation medicines to help important public health challenges, announced that the US Food and Drug Administration (FDA) approved the start of a Phase 2 trial to investigate TNX-102 SL in people with agitation in Alzheimer’s disease (AD). The experimental drug is currently in Phase 3 development for the treatment of Posttraumatic Stress Disorder.


3 May: Researchers publish findings from the discontinued Phase 3 EPOCH trial

On 3 May, final results of the EPOCH trial investigating verubecestat for the treatment of mild to moderate Alzheimer’s disease (AD) were published in the New England Journal of Medicine. The research study led Michael F. Egan from Merck, concluded that verubecestat did not reduce cognitive or functional decline in people with mild-to-moderate AD. In addition, the experimental drug was associated with treatment-related adverse events. This Phase 2/3 trial was a randomised and double-blind study investigating the efficacy and safety of verubecestat in people with mild to moderate AD. The trial included 1,958 participants assigned to receive once daily oral doses of verubecestat (12 and 40mg) or placebo.


7 May: Cholesterol may play a role in the development of AD

In the study published on 7 May in the journal Nature Chemistry, a European research team led by the University of Cambridge (UK) suggested that cholesterol may play a role in the development of Alzheimer’s disease (AD) by enhancing the onset of amyloid-beta 42 (Aβ42) aggregation in the brain. Researchers investigated the role of cholesterol in modulating Aβ42 aggregation and showed that cholesterol-containing lipid vesicles could accelerate Aβ42 aggregation up to 20 times. The Aβ42 aggregation was significantly enhanced with an increase rate of cholesterol in the vesicles. In addition, they reported that the Aβ42 fibrils formed in the presence of cholesterol had a similar morphology and structure to those formed without cholesterol.

http://www.nature.com/articles/s41557-018-0031-x

7 May: US study assesses association of mild traumatic brain injury and risk of dementia diagnosis

On 7 May, researchers from California (USA) published results from a large-scale retrospective cohort study on data of more than 350,000 US military veterans in the journal JAMA Neurology. Previous research suggested evidence of an association between the event of a moderate to severe traumatic brain injury (TBI) and the risk of developing dementia in later life. Yet, an association between mild TBI and dementia - especially without loss of conscience - has so far not been thoroughly investigated, respectively yielded mixed results.

The team analysed data on individuals who receive care in the Veterans Health Administration health care system, collected between 2001 and 2014. It was comprised of 178,779 patients diagnosed with at least one TBI and 178,779 patients as control.
Their analysis showed, that among those with mild TBI without loss of conscience there was an association with a two-fold increase in the risk of dementia diagnosis. In addition, the team found an association between TBI severity and dementia diagnosis. Although, these results are interesting, the scientists stated that there is a need for further research in order to be able to determine the mechanisms underlying the association observed between TBI and dementia. In addition, there is no indication on how relevant this study is for the general public since it focuses on US war veterans.

You can find the publication here.

8 May: Study assesses mid-life risk factors of dementia using information collected in a large long-term study

On 8 May, an international team of researchers from the USA and China published findings on the assessment of risk factors of dementia in the Journal of Alzheimer’s Disease.

The team assessed data from the Framingham Heart Study Offspring cohort, a long-term study initiated in 1948 with an original group of more than 5,000 participants, following three generations to observe factors contributing to cardiovascular diseases.

The team was the first to use a newly developed machine learning approach to enable a programme to discover unknown patterns and relationships to better understand modifiable risk factors of dementia.

In their findings, the scientists report on information of 2,461 participants of which 226 developed dementia over the course of 30 years. Apart from age, they found that the marital status of being “widowed”, having a lower Body Mass Index and less sleep during midlife were associated with the diagnosis of dementia.

The authors concluded that through the assessment of demographic as well as lifestyle factors, their results and further research may help to enable public health officials to develop targeted public policy programs for dementia care and prevention. You can find the publication here.

9 May: Forma Therapeutics and the University of Oxford launch a collaboration on DUB inhibitors

On 9 May, the company Forma Therapeutics and the University of Oxford announced a research collaboration for the development of deubiquitinating enzyme (DUB) inhibitors for the treatment of neurodegenerative diseases.

DUB inhibitors are a class of compounds that play important roles in protein and cellular homeostasis. Previous findings suggested a link between DUBs and the progression of neurodegenerative diseases including Alzheimer’s and Parkinson’s disease. Under the terms of the agreement, the company will fund a multi-year research program at the University of Oxford to identify and validate the implication of DUBs in neurodegenerative diseases.


14 May: Widespread Australian study helps to reduce inappropriate psychotropic prescribing and use in residential care facilities

On 14 May, a team of scientists from Australia published an article on the impact of an interdisciplinary intervention that aims to reduce antipsychotic and benzodiazepine prescribing in residential aged care facilities (RACFs) in the Medical Journal of Australia. While commonly prescribed to treat both behavioural and psychological symptoms of dementia, the effectiveness of antipsychotic drugs remains modest and is accompanied by severe risks such as falls, stroke and even death.

Addressing these challenges, the intervention entitled “The Reducing Use of Sedatives” (RedUSe) aims to promote an appropriate use of antipsychotics in RACFs.

After an initial controlled trial in 2008-2009, the intervention received federal funding in 2013. Since then an enhanced version of the 6-months programme was expanded to 150 RACFs, encompassing more than 12,000 residents.

The programme is comprised of a medication audit accompanied by feedback, education of staff together with an interdisciplinary case review at baseline and at three months. The final audit is held at six months.

Results showed a reduction of antipsychotics prescriptions by 13% and 21% fewer regularly prescribed benzodiazepines. Remarkably, for 40% of the overall 2195 residents that were prescribed antipsychotics on a regular basis and for 2247 residents that received regularly benzodiazepines - who participated in the whole intervention period - the medications were reduced (15%) or ceased altogether (24%) throughout the 6-month intervention.

You can read the full publication here.

14 May: Oryzon Genomics begins Phase IIa study for AD drug candidate

On 14 May, the biopharmaceutical company Oryzon Genomics, which develops epigenetics-based therapeutics in oncology and neurodegenerative diseases, announced the recruitment of the first three participants in the ETHERAL study in Barcelona (Spain). In addition, the company announced that it has received approval to start the ETHERAL clinical trial in France.
The ETHERAL Phase IIa trial is a randomised, double-blind and placebo-controlled trial to evaluate the efficacy and safety of ORY2001 in 90 participants with mild and moderate Alzheimer’s disease (AD).


16 May: Study suggests a pathway linking AD and Type 2 diabetes

Compelling evidence supports a link between Alzheimer’s disease (AD) and Type 2 diabetes. On 16 May, Fernanda G. De Felice from the Queen’s University in Kingston (Canada) gave an oral presentation on “Molecular connections between Alzheimer’s disease and Type 2 diabetes” at the Canadian Neuroscience Meeting in Vancouver.

She presented her research on mouse AD models and non-human primates that led to the identification of a pathway common to both pathologies. This mechanism causing inflammation in the brain may lead to glucose intolerance, memory impairments and synaptic degeneration.

“We know that the Alzheimer brain responds less to insulin, which is also indicative of some form of cross-talk in the pathways of these diseases. By looking at non memory-related symptoms of Alzheimer’s disease we are getting a better understanding of the complex nature of this disease and of the different pathways it affects”, says Dr De Felice.


16 May: EIP Pharma receives $20.5 million to support its Phase IIb study of neflamapimod

On 16 May, the private EIP Pharma LLC company, which advances CNS-focused therapeutics for improved patient benefit, announced that Access Industries, an US based industrial group with global strategic investments, will finance $20.5 million to support the Reverse-SD phase IIb study of neflamapimod in Alzheimer’s disease (AD).

Neflamapimod is a brain-penetrant oral small molecule that inhibits the intra-cellular enzyme p38 MAP kinase alpha, a kinase suggested to lead to the dysfunction of synapses that underlies memory deficits in AD.

The Phase IIb study is a 6-month randomised double-blind placebo-controlled trial aiming to evaluate neflamapimod in reversing memory deficits in people with early AD. The Reverse-SD study will involve about 150 participants and the company aims to finish enrolling by the end of the year.

The funding will also help the company to investigate the experimental drug in other central nervous system diseases including Huntington and Parkinson’s diseases.


16 May: Study investigates the effect of moderate to high intensity exercise on cognitive impairment in dementia

On 16 May, a team of scientists from the Oxford University published results on the effects of a physiological exercise-training programme in the journal The BMJ.

The randomised controlled trial included data on 494 participants with dementia. Of these, 329 took part in the intervention (a four-month long period of exercise and support for ongoing physical activity) along with usual care and 165 only received usual care.

In order to estimate the effect of the intervention, the team evaluated a variety of outcomes and chose the Alzheimer’s Disease Assessment Scale - Cognitive subscale (ADAS-cog 11 item scale) as primary outcome. Tests and questionnaires were conducted respectively filled out at the beginning of the intervention, after 6 months and after 12 months.

Surprisingly, the analysis of data showed that the intervention groups’ ADAS-cog score had increased more than the control group who only received usual care, representing a worsening in cognition. The authors stated that the observed difference was small and underlined that it is of uncertain importance.

Nevertheless, they concluded that moderate to high intensity aerobic and strength exercise cannot be recommended as a treatment option for cognitive impairment in dementia.

They noted that future trials should explore other forms of exercise, including psychomotor protocols that are commonly used in long-term neurological conditions where the primary intent is improving physical functioning. You can read the full publication here.

17 May: Johnson & Johnson halts the EARLY Phase 2/3 study for the treatment of AD

On 17 May, the pharmaceutical company Johnson & Johnson announced that it has decided to discontinue the Phase 2/3 EARLY study. Serious elevations of liver enzymes have been observed in some research participants who received the experimental drug. The company concluded that the benefit-risk ratio is no longer supported to continue the development of the study and ended thus the clinical development of the EARLY study in late-onset preclinical stage Alzheimer’s disease (AD) and in a Phase 2 long-term safety study.

The EARLY study was a randomized, placebo-controlled and double-blind clinical trial investigating atabecestat (also known as JNJ-54861911) in participants who are asymptomatic and at risk for developing Alzheimer’s dementia. More than 600 people have received the experimental drug or placebo in these clinical trials. Atabecestat was an investigational drug
called BACE inhibitor, which blocks an enzyme involved in the production of amyloid beta.

http://www.janssen.com/update-janssens-bace-inhibitor-program

18 May: Alkahest Phase 2 clinical trial evaluating GRF6019 has enrolled its first research participant with mild to moderate AD

The US clinical-stage biotechnology company Alkahest, which develops innovative therapies to treat age-related diseases, announced the recruitment of the first research participant in the Phase 2 trial investigating GRF6019 in people with mild to moderate Alzheimer’s disease (AD).

The ALK6019-201 Phase 2 study is a randomized, double-blinded dose response trial to evaluate the safety and tolerability of GRF6019, a plasma-derived product, in 40 people with mild to moderate AD. The experimental drug is administered by intravenous infusion to participants, who will participate for a total of 6 months in this study. The details of the study are available at:


22 May: Study discusses that most people with preclinical Alzheimer’s disease (AD) will not develop AD dementia during their lifetimes

On 22 May, researchers from the University of California Los Angeles published a paper on the investigation of lifetime risks of Alzheimer’s disease (AD) dementia in the journal Alzheimer’s and Dementia. The study was supported by a grant from the National Institutes of Health. The team used a multistate model for the progression of AD through preclinical and clinical disease states, based - although with some differences - on the National Institute on Aging-Alzheimer’s Association (NIA-AA) framework.

The data for the model came from two large studies that measured biomarkers, amyloidosis and neurodegeneration including information on over 2000 individuals from Europe and the United States.

The authors found that the risk of developing AD dementia over the whole lifetime were much different considering age, sex and the preclinical disease state. Further, they reported that considering the results of their model, a man with 70 years that exhibits amyloidosis is at a risk of 20% of developing AD dementia during his life.

The team further stated that a next step would be to assess more ethnically diverse populations and to assess if the genetic APOE4 status - which is associated with AD - is able to help refine the lifetime risk estimates.

https://www.medpagetoday.com/neurology/aldzheimer'sdisease/73046

23 May: Study reveals a molecule that may block tau propagation in AD

The accumulation of the brain protein called tau is known to play a key role in the development of Alzheimer’s disease (AD). In the study published on 23 May in the journal Biochemical and Biophysical Research Communications, US researchers from University of California, Los Angeles, reported that a molecule could suppressed tau propagation in cell cultures and mouse models.

Using cell cultures obtained post-mortem from brains of humans who had AD, scientists showed that the compound called cambinol could block tau migration from cell to cell by inhibiting the nSMase2 activity. In addition, they showed that cambinol could reduce the nSMase2 activity in the brains of mouse models after oral administration compared to controls.


23 May: The British Heart Foundation and Alzheimer’s Society launch a Phase2/3 trial to prevent dementia after stroke

On 23 May, the British Heart Foundation and Alzheimer’s Society announced the start of a new clinical trial to prevent cognitive decline and dementia after lacunar stroke, which is a type of stroke affecting smallest blood vessels in the brain.

The LACI-2 Phase 2/3 study is a randomised trial to evaluate the safety and efficacy of cilostazol and isosorbide mononitrate to prevent recurrent lacunar stroke and progression of cerebral small vessel disease. Both drugs used in the study are existing drugs already on the market for another medical condition. Cilostazol is currently used to treat people with peripheral arterial disease and isosorbide mononitrate to treat people with conditions like angina.

The research will be conducted at the University of Edinburgh, where 400 UK participants will receive one of the four treatments: isosorbide mononitrate only; cilostazol only; both isosorbide mononitrate and cilostazol or neither isosorbide mononitrate nor cilostazol (placebo).


DEMENTIA IN SOCIETY

4 May: International “Star Trek” Star Nichelle Nichols’s reportedly has dementia

According to reports, Nichelle Nichols who is known for her role as Lieutenant Uhura in the original series of Star Trek, exhibits short-term memory loss resulting in dementia.

Her son Kyle Johnson commented that his mother’s condition is "impacting her executive functioning" and makes her
"susceptible to undue influence". As stated by TMZ, he therefore filed legal documents to nominate four fiduciaries (legal guardians) to become Nichelle’s representatives for questions and decisions regarding her finances and health to ensure that she is not taken advantage of.


6 May: Student makes directorial film debut to raise money for charity and awareness about Alzheimer’s disease

On 6 May, Katie Low who is an 18-year-old media and communications student at the North East College premiered her very first film “Remember Me” at The Belmont Filmhouse. The short film (15 minutes) is inspired on Katie’s experiences with her grandmother who had Alzheimer’s disease. Its story centres on a 55-year-old man who is beginning to lose his memory and displays how it affects him and his family. All proceeds from the ticket sales went to Alzheimer’s Scotland. You can find the trailer here.

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22 May: Website for the ‘Fighting For Life’ play by Brian Daniels goes live

On 22 May, the website for the “Fighting for Life” play by Brian Daniel went live. The play based on the Findlay family story, aims to create a wider understanding of the complexities of accessing good quality health and social care for older people. The play aired in England, covers a range of issues including Motor Neurone Disease (MND) and dementia. These are accompanied by the challenges facing older carers, attitudes of health and social care professionals towards older people as well as the vulnerability of older people especially those with dementia.

Further, it covers the role of family caregivers and family dynamics, challenges with communications and co-ordination between health and social care, nursing homes and palliative care, grief and bereavement.

The website provides an overview of carry dates and venues of all performances among other information revolving around the play and its background. You can find the website and dates here.

23 May: New tool in development to review the impact of dementia-friendly communities

On 23 May, the Guardian published an article by Claire Goodman who is professor in healthcare research at the University of Hertfordshire conducting research on the impact of dementia-friendly communities.

The University of Hertfordshire currently works in partnership with the University of East Anglia and the University of Cambridge to develop an evaluation tool aiming to review strengths and challenges of dementia friendly-communities. The National Institute for Health Research funds the research leading to the development of the tool since 2017.

Dementia-friendly communities raise awareness of dementia and support engagement with the topic as well as people affected by the condition. Their aim is to support inclusion as well as participation. Currently, the Alzheimer’s Society has listed 263 communities - that exist in the UK alone - on their website.

The team of researchers conducted a couple of activities in order to develop and refine the tool. First, they compared the prevalence of dementia in the different communities. In addition, they reviewed activities and offers. Now the scientists are surveying people affected by dementia to assess their point of view on the impact of living in the community. Apart from that, Claire Goodman also reported, that they organised a recent consultation event on early findings and the proposed tool which she mentioned raised interesting challenges and questions.

Further, she reported that the consultation revealed consensus on indicators of a “successful” dementia-friendly community. Participants agreed that the community should provide available access to activities for people at all stages of living with dementia. There was also agreement that those activities should be designed and organised involving people affected by dementia.

Other aspects of success included:

- strong local political support for dementia friendliness and access to funding
- positive everyday encounters with neighbours and others, for example schoolchildren, postal workers, the police or bus drivers.
• an environment that assures people they would be listened to, valued, given time and opportunities to be involved and not defined by their diagnosis
• local systems and services anticipating what people with dementia might need, so they are able to go to a concert or the cinema, watch sport, eat out, vote, travel, see the general practitioner (and not be penalised if an appointment is forgotten), and access advice about money and care.

At the end of her article she stressed, that there cannot be a one-size-fits-all approach. They are therefore refining and testing the evaluation tool in six very different dementia-friendly communities.


LIVING WITH DEMENTIA

8 May: Helga Rohra reports on her campaigning in Austria: “Champions of dementia unite to raise awareness”

As a member of the EWGPWD and a well-known advocate for raising awareness about the different faces of dementia (my favourite slogan being “See the person not the disease”), I was invited to Vienna (Austria). The founding of a dementia working group was carefully prepared and I was involved in all stages of the process. I would like to express my immense gratitude to Alzheimer Austria as well as to “Caritas Vienna” for having given me an advisory function from the very beginning of this process.

My role and books, especially the one entitled “A good life despite dementia”, was aimed at helping my friends, people touched by dementia, to overcome this stigma and join the Austrian group. Moreover, the media were keen on interviewing me and writing about the group “PROMENZ”. Innovative and of utmost importance is the fact that the state television “Ö1”, the radio and the main high-class newspapers in Vienna wrote about this event.

The highlight, apart from the founding of the group, was a workshop for pharmaceutical and legal staff on how to become dementia friendly. This workshop was run by the expert of Alzheimer Austria, Monika Kripp, myself and people with dementia.

Austria is a country whose example should be followed: People with dementia on stage guided by the EWGPWD.

Many thanks to Alzheimer Europe for their continued support.

11 May: Carol Hargreaves shares her experience of diagnosis and shows that there is hope

I was in my work (managing a chain of book makers) and I started giving the cashiers jobs I should’ve been doing. Somehow I knew I couldn’t cope. Then, the mini strokes started, but I didn’t realise. Other people would notice a slight change in my face and my speech and tell me. Now if I’m tired or stressed my speech will still go funny. It’s a reminder and it hits me, because I feel so well.

My GP wasn’t great. I was referred to a psychologist but at the time she was off sick. Other doctors put it down to bipolar. They wanted me to go into hospital of my own accord, but I knew my body and I knew it wasn’t the bipolar. So I was sectioned. I was in hospital for about 3 months. My psychologist eventually found out and got involved. That’s when they started sending me for scans and things. In between this I was having lots of mini strokes and was always in an ambulance. It was a really dark time. I was put in a ward of four, with much older women who had suffered strokes too. I had to go to court. What a carry on. My psychologist said that she knew it wasn’t bipolar. Then the scans showed it was dementia. A psychologist that I’d never met before was called in and she said “I’m sorry to tell you the scan has shown vascular dementia. We’ll get you information but you’ve probably got a good six months so get your affairs in order”. Nobody should be told they’ve got a serious illness alone.

Then came the big book of information. I still don’t know where it is now. I’ve never read it. No one ever explained or told my family. My mum still doesn’t believe it. That was when Susan (my Alzheimer Scotland outreach worker) came into my life. I had just turned 50. My psychologist got her to talk to me and she asked me if I would take counselling. Me being me, I said no.

My family were told to watch me like a hawk. They wrapped me up in cotton wool. I would say I lost 3 years of my life. Whenever I turned around someone was there. Then I got involved with the counsellor and I found out it wasn’t about them, it was about me not accepting. I can’t change other people.

I started volunteering with Susan and the group we all started together. When people I knew started to deteriorate, I told Susan I couldn’t cope with that and she suggested the Scottish Dementia Working Group. So I took the bull by the horns, and went in by myself. Once I get comfortable with people I’m fine. I love working in groups. I get a real buzz out of it. Back in those dark days, if I went anywhere, they were looking for me. Since I’ve been with the working group, it’s changed for the better. My family were all surprised I was good at public speaking. I don’t know where that came from. I can’t say I’m not
nervous but I don’t find it hard speaking. I only speak about me, it’s nothing I don’t know. That’s all I can talk about….my life, my experience. A lot of laughter, I love it when we get together and we are sad when someone is ill. You don’t get that elsewhere. All I can say is I thought I’d be dead by now but life is so full. My whole life changed, from me having my son and step daughters, to moving into a flat on my own. There has been lot going on with family in the last few years and I was able to be there for them. Me and my sister have a fantastic relationship and we look after my mum together. It is good getting to know the new people who are joining the group and hearing that things are changing and getting better.

12 May: Tomaž Gržinič, member of the EWGPWD is interviewed on national TV in Slovenia

I was diagnosed with dementia two years ago. When I received the diagnosis my life changed, however, I did not give up any sports and I continue enjoying my many hobbies. My life is still fullfilled and I embrace my life with optimism. I joined the Slovenian Working Group for People with Dementia in 2017 and I was very proud to be elected President of the group. In Autumn 2017, I was nominated by Spominčica (Alzheimer Slovenia) to join the EWGPWD. In Slovenia, I have been very active at public debates, sharing experiences about living with dementia in the media and at gatherings of the Slovenian working group.

In February 2018, I participated in an interview, with a famous Slovenian neurologist, Prof. Dr Zvezdan Pirtošek, which was broadcasted on national TV. In the interview I was able to explain and provide examples of how dementia affects the real life events. I explained my views on decision making and planning the future before dementia is at a more severe stage and how this helps to keep the person’s dignity, integrity, hope, self-esteem and autonomy. This is why timely diagnosis is so important, so you still have time to adapt your activities, treatment, accommodation and express your will, about religion and spiritual issues. When the disease progresses, you need more time to finish some tasks, but also encouragement and step by step process, support from caregivers or supporters. Raising awareness about dementia is important, but you have to accept, that dementia will accompany you for the rest of your life. You learn every day. The saddest thing is, you can’t predict the future. But at early stage of disease, when you are still able to make reasonable decisions, you should tell your inner wishes to your closest ones, as they may need to decide for you later on. I have fears about the progression of the disease. I am afraid of pain and that perhaps I won’t be able to control it. Another fear is that one day I may not recognise myself anymore in the mirror or recognise family members and friends or may behave in an inappropriate way in public and not be aware of it. During the interview I also shared my opinion about medical treatments. I would not like for myself any invasive treatments and heavy medical tubes, injections or drugs at the end of my life. I would rather choose quality of life than prolonging my life just because other people want me to stay alive. I would like to spend my final breath in a quiet room, with family, holding my hands and saying lovely words to me. I would prefer to die at home, if possible. The videoclip of my interview with Prof. Dr Zvezdan Pirtošek was recorded by the Slovenian National Televison. It will be available in 2019. I will keep you posted once it is available!

Tomaž is supported by Alenka Virant, member of staff of Alzheimer Slovenia - Spominčica, to whom we are grateful for her help in translating Tomaž’s words to English.

NEW PUBLICATIONS & RESOURCES

1 May: JAD publishes an open access issue to celebrate its 20th anniversary

On 1 May, the IOS Press announced that 2018 marks the 20th anniversary of the Journal of Alzheimer’s Disease (JAD) with a milestone issue covering 20 years of Alzheimer’s research. This open access issue (Vol. 62, Iss. 3) is now available online and includes 35 specially commissioned review articles and personal perspectives from key researchers in the field.

https://content.iospress.com/journals/journal-of-alzheimers-disease/62/3

7 May: International Summit yields range of publications in the important field of dementia and intellectual disability

The National Task Group on Intellectual Disability and Dementia Practices, along with the Rehabilitation Research and Training Center on Developmental Disabilities and Health (RRTC DD/H) at the University of Illinois Chicago, together with colleagues in Scotland at the University of the West of Scotland (UWS), the University of Stirling, and Alzheimer’s Scotland, organised an ‘International Summit on Intellectual Disability and Dementia’ in 2016 to develop an international policy statement on a number of areas related to dementia and adults with intellectual disability. Recently, the collaborators released a leaflet with an overview of a range of publications in the important field of dementia and disability.
A full list of publications developed from the Summit can be found by clicking here. Readers can access the various papers via this NTG site: http://aadmd.org/ntg/collaborative-projects. Follow this link where summary reports from the International Summit can also be downloaded.

**DONATE NOW!** Help us make dementia a priority

**JOB OPPORTUNITIES**

**24 May: Dublin City University is looking for a Research Project Coordinator on the Irish Dementia Registry project**

On 24 May, the Dublin City University announced an opening for a Research Project Coordinator on the Irish Dementia Registry project to develop and support the design and a proof of concept development of a national dementia registry for Ireland. The primary focus will be on task management and delivery, co-ordinating and managing stakeholder inputs, and providing support for the dementia registry team. This post provides an exciting opportunity to develop project management skills in eHealth research and data terminology services as they relate to dementia, with a dedicated team in Dublin City University (DCU) and the Health Service Executive (HSE). DCU will lead the dementia registry team. This role will be based in the School of Nursing and Human Sciences (SNHS) and will report directly to the Project Lead Dr Louise Hopper.

**Post Title:** Research Project Coordinator-Irish National Dementia Registry

**School of Nursing and Human Sciences**

**Post duration:** 18 Month Part Time Fixed Term Contract (2.5 to 3 days a week)

**Closing Date:** 8th June 2018

Details are available here.

**28 May: BBRC is recruiting a doctoral student for the AMYPAD project**

Barcelonaβeta Brain Research Center (BBRC) is looking to recruit a full-time graduate student within the context of the AMYPAD project, as part of the Neuroimaging Research Group from the Alzheimer’s Prevention Program. The deadline for applications is 31 July 2018. You can find more information about the position here.

**AE CALENDAR**

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<th>Date</th>
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<tr>
<td>5-6 June</td>
<td>EAN Guideline meeting “Medical management issues in dementia” (Vienna, Austria)</td>
<td>Jean</td>
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<td>7-9 June</td>
<td>M&amp;I Forum (Dubrovnik, Croatia)</td>
<td>Gwladys</td>
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<td>12 June</td>
<td>OECD launch of “Care needed, improving the lives of people with dementia” (London, United Kingdom)</td>
<td>Jean</td>
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<td>14 June</td>
<td>Clinova Scientific Advisory Board meeting (Esch/Belval, Luxembourg)</td>
<td>Jean</td>
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<td>14 June</td>
<td>EFPIA Patient Think Tank Meeting (Brussels, Belgium)</td>
<td>Cindy</td>
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<td>16-19 June</td>
<td>EAN Congress (Lisbon, Portugal)</td>
<td>Iva and Jean</td>
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<td>22 June</td>
<td>Meeting with Zitha-Senior (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<td>25-26 June</td>
<td>Alzheimer Europe Board (Brussels, Belgium)</td>
<td>AE Board</td>
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<td>26 June</td>
<td>European Parliament lunch debate “Dementia care in the European Union” (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<td>26 June</td>
<td>Company round table meeting (Brussels, Belgium)</td>
<td>AE Board, members, sponsors and staff</td>
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<tr>
<td>26-28 June</td>
<td>Meeting of the EWGPWD (Brussels, Belgium)</td>
<td>Dianne and Ana</td>
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<tr>
<td>27 June</td>
<td>Alzheimer Europe public affairs meeting (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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**CONFERENCES 2018**

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<th>Date</th>
<th>Meeting</th>
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<tr>
<td>6-8 June</td>
<td>8th Kuopio Alzheimer Symposium, <a href="https://www.uef.fi/fi/web/kuopioadssymposium">https://www.uef.fi/fi/web/kuopioadssymposium</a></td>
<td>Kuopio, Finland</td>
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<td>7-8 June</td>
<td>BestCare4Dem - Sharing effective community-based support in dementia,</td>
<td>Amsterdam,</td>
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<td><a href="https://www.meetingdem.eu/">https://www.meetingdem.eu/</a></td>
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<td>7-8 June</td>
<td>HammondCare International Dementia Conference - Mission Impossible? True</td>
<td>Sydney, Australia</td>
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<td>and Lies in the Age of Choice, <a href="http://www.dementiaconference.com">www.dementiaconference.com</a></td>
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<td>8 June</td>
<td>Alzheimer Scotland Conference: Making sure nobody faces dementia alone,</td>
<td>Edinburgh,</td>
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<td><a href="http://www.alzscot.org/conference2018">www.alzscot.org/conference2018</a></td>
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<td>16-19 June</td>
<td>4th Congress of the European Academy of Neurology,</td>
<td>Lisbon,</td>
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<td>4-6 July</td>
<td>British Society of Gerontology Annual Conference,</td>
<td>Manchester,</td>
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<td>22-26 July</td>
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<td>26-29 July</td>
<td>International Conference of Alzheimer’s Disease International (ADI),</td>
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<td>3-6 October</td>
<td>10th Alzheimer Slovenia Conference, <a href="https://www.spominica.si">https://www.spominica.si</a></td>
<td>Ljubljana, Slovenia</td>
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<td>18-19 October</td>
<td>2nd MINC Symposium, <a href="http://mmni.de/minc-2018/">http://mmni.de/minc-2018/</a></td>
<td>Cologne, Germany</td>
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<td>24-27 October</td>
<td>11th Clinical Trials on Alzheimer Conference (CTAD), <a href="http://www.ctad-alzheimer.com">www.ctad-alzheimer.com</a></td>
<td>Barcelona, Spain</td>
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<td>29-31 October</td>
<td>28th Alzheimer Europe Conference “Making dementia a European priority”,</td>
<td>Barcelona, Spain</td>
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<td>26-31 March</td>
<td>The 14th international conference on Alzheimer’s &amp; Parkinson’s diseases,</td>
<td>Lisbon, Portugal</td>
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<td><a href="https://bit.ly/2hyw3t">https://bit.ly/2hyw3t</a></td>
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<tr>
<td>22-25 October</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague,</td>
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<td></td>
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<td>Netherlands</td>
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**BestCare4Dem**

**SAVE THE DATE! 7-8 June 2018**

We are looking forward to meeting you in AMSTERDAM

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**Alzheimer Scotland Annual Conference: Making sure nobody faces dementia alone**

**Friday 8 June 2018**

EICC, Edinburgh

www.alzscot.org/conference2018

**Early bird tickets available until 30 April**
28th Alzheimer Europe Conference
Making dementia a European priority
Barcelona, Spain
29–31 October 2018

www.alzheimer-europe.org/conferences #28AEC

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