Welcome to the

ALZHEIMER EUROPE

NEWSLETTER

July-August 2016

Editorial

Welcome!

I trust you all had an excellent summer. We've had plenty of sunshine here, but the calendar has not been a holiday one!

Summer began with a series of AE meetings in Brussels at the end of June, including a Lunch Debate at the European Parliament (EP), involving six MEPs. The topic was the Human Rights of people with dementia. Human Rights continued to be on the lips of many during recent weeks, with an EP debate and vote on the subject of the EU implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and a joint call from our friends at Alzheimer’s Disease International (ADI) and the Dementia Alliance International (DAI), to protect the rights of people living with dementia.

In other policy news, we congratulate our friends in Flanders on the launch of their new strategy focusing on human rights.

In late July, I was delighted to be able to attend this year’s Alzheimer’s Association International Conference (AAIC) in Toronto, Canada. It was great to be able to network with upwards of 5,000 dementia researchers. Some of the main stories emerging from this conference, can be found in our “AAIC Watch” section.

Three of the European projects in which we are involved were presenting and I was pleased to see them getting international recognition. The EPAD project was featured very prominently, and you can read our report about this, as well as a report on the PredictND project’s participation, in our “EU Projects” section. The recently concluded PharmaCog project also featured at the conference.

One of the major stories picked up by the media during AAIC 2016, was about the tau aggregation inhibitor drug LMTX. It was interesting to see what a “mixed bag” of reporting this prompted, ranging from hailing it as a success, to a complete failure and everything in between – yet another reminder of the importance of objective scientific reporting. Take a look at the “Behind the Headlines” section for a balanced view of what the study actually found.

Also regarding objectivity, I am very pleased to announce the launch of our Clinical Trials Watch, available on our website. It contains objective, up-to-date information on clinical trials on Alzheimer’s and other dementias, presented in an accessible format.

We have also been very busy preparing our 26th annual conference (26AEC) in Copenhagen and I would advise you to book soon if you have not already done so, as spaces are filling up fast!

Last but not least, we are truly honoured to be among the Top Ten “NGO Influencers” in the EU – alongside such household names as Amnesty International, WWF and Greenpeace – according to a report based on MEP followers on Twitter.

Jean Georges
Executive Director
Alzheimer Europe

27-28 June: AE holds a Board meeting in Brussels

The Alzheimer Europe Board members convened in Brussels on 27-28 June. The meeting agenda included various financial and operational matters, including preparations for the 26th Alzheimer Europe Conference, which will be held in Copenhagen, Denmark from 31 October to 2 November 2016. The Board members also approved the venues for the next three AE conferences:

- 28th Conference in Barcelona, Spain in 2018.
- 29th Conference in Amsterdam or The Hague in the Netherlands in 2019.

The next Board meeting will take place on 31 October in Copenhagen and will be followed by AE’s Annual General Meeting.

28 June: AE lunch debate focuses on the human rights of people with dementia

On 28 June 2016, AE held a lunch debate entitled “Using the UN Convention on the Rights of Persons with Disabilities (UNCPRPD) to support the rights of people living with dementia” in Brussels. The debate was co-hosted by MEPs Marisa Matias (Portugal) and Sirpa Pietikäinen (Finland).

The first speaker was Helen Rochford Brennan, Chair of the Irish Dementia Working Group and also a Vice-Chairperson of the European Working Group of People with Dementia. She presented “Promoting a rights-based approach through the Irish Charter of Human rights for people with dementia”, which detailed her personal experience with dementia and her current activities to help people with dementia in Ireland and throughout Europe.

The next speaker was Jill Stavert, Professor of Law and Director of the Centre for Mental Health and Incapacity Law at Edinburgh Napier University. Her presentation “Human rights and disability rights for people with dementia” focused on how elements of the UN Convention on the Rights of Persons with Disabilities (UNCPRPD) might be used to support the rights of people living with dementia. Prof. Stavert concluded that these elements would help to keep the rights, will and preferences of the individual at the centre of all decisions.

The final speaker was Jonathan Stabenow from the Cabinet of Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility at the European Commission. He presented “The European Accessibility Act (EAA): putting the UNCRPD into practice at EU level". This is a proposal for legislation to prevent and remove barriers for persons with disabilities, so they can access products and services. The act will also make it easier for industry and service providers to distribute products and services such as computers, cash machines, banking and travel services and e-commerce.

Alzheimer Europe was pleased to welcome 60 delegates to the lunch debate, including MEPs Therese Comodini Cachia (Malta), Nessa Childers (Ireland), Sofia Ribeiro (Portugal), Marek Plura (Poland) and representation from MEPs Olga Sehnalová (Czech Rep.) and Dieter-Lebrecht Koch (Germany). We were also glad to see Dr Jacqueline Hoogendam and Mr Bart Ooijen - both Senior Advisors at the Dutch Ministry of Health, Welfare and Sports - as well as representatives from the pharmaceutical industry and colleagues from 18 AE member associations. The next AE lunch debate will take place on 6 December 2016.

For more information, please see the following links:


Impressions from the lunch debate

Helen Rochford Brennan (EWGPWD)
Prof. Jill Stavert, (Edinburgh Napier University)
Jonathan Stabenow (European Commission)

MEP Sirpa Pietikäinen
MEP Marisa Matias
A very full house!
28 June: Alzheimer Europe hosts a Company Round Table in Brussels

Alzheimer Europe (AE) hosted a Company Round Table (CRT) meeting in Brussels on 28 June. The 33 representatives from sponsor companies and 20 representatives from 18 different AE member organisations, alongside 6 members of the AE staff.

Policy Officer Vanessa Challinor gave delegates an update on EU developments in the field of dementia. Overall the message was a positive one: dementia is being made a priority by many entities, including Member States, EU research bodies and projects, Joint Actions, EU Presidencies and the WHO, among others. Vanessa also informed delegates of which Member States have recently developed national dementia strategies and described some of the latest developments at EU level, including the WHO Global Dementia Observatory, which aims to provide data, analyses and global highlights of “dementia burden and response”.

She also provided delegates with an overview of AE’s European Dementia Monitor project, the aims of which are to benchmark national dementia policies, provide a lobbying tool for AE and its members and generally provide simple and reliable figures and statistics. The Dementia Monitor is currently being compiled, following which AE members will give their feedback prior to its launch at our next lunch debate, on 6 December in Brussels.

Executive Director Jean Georges then presented some of AE’s activities, including our upcoming annual conference in Copenhagen and AE’s second Alzheimer’s Association Academy (AAA), to be held in Brussels in December. This second instalment of the AAA is being organised due to popular demand following the feedback after our first AAA in late 2015. Jean also gave an update on three new IMI projects in which AE is involved: AMYPAD, MOPEAD and ROADMAP.

Project Officer Ana Diaz gave an update on the Clinical Trials Watch project and explained its aims to the group, stressing the importance of the involvement of AE’s European Working Group of People with Dementia (EWGPWD), pharmaceutical companies and national member organisations. Ana thanked company representatives present for their contributions to the project. “Without you, we wouldn’t have some of the important information and protocol involved, which can be really important for people with dementia and carers”, she said.

The CT Watch is now live on the AE website.

28 June: AE contributes to debate on dementia at European Economic and Social Committee (EESC)

On 28 June in Brussels, during the meeting of the “Employment, Social Affairs and Citizenship” section of the EESC, Alzheimer Europe (AE) contributed to a debate on dementia. Policy Officer Vanessa Challinor gave an overview of the situation on dementia and the growing problem in Europe.

Other speakers included Jacqueline Hoogendam from the Dutch Ministry of Health, who presented the outcomes of the Dutch Presidency Conference on dementia that took place on 9-10 May 2016. She was followed by Catherine Berens from DG Research, who presented the Joint Programme for Neurodegenerative Disease Research (JPND). Tommy Whitelaw, son, carer, campaigner, presented his mission to raise awareness of dementia from a carer’s perspective and the difficulties he encountered when caring for his mother with dementia.

http://www.eesc.europa.eu/?i=portal.en.home

29 June: AE and its members meet to develop a model for a European dementia strategy

On 29 June, Alzheimer Europe hosted a meeting of its member organisations to develop a working model of a European dementia strategy, based on best practices from countries that already have operational strategies. The agenda featured presentations from the national Alzheimer associations in Austria, France, Ireland, Malta and Switzerland, as well as England and Scotland from the UK.

George McNamara (Alzheimer’s Society UK - England): Recommendations on involving people with dementia, living well with dementia, combating stigma, raising awareness and dementia-friendly communities.

Stefanie Becker (Swiss Alzheimer Association): Recommendations on timely diagnosis, post-diagnostic support, acute and hospital care.

Tina Leonard (The Alzheimer Society of Ireland): Recommendations on home support and care, living in the community, carer support and respite care

Monika Natlacen (Alzheimer Austria): Recommendations on residential and nursing care and palliative care.

Alex Teligadas (AE, on behalf of France Alzheimer): Recommendations on research funding and research coordination.

Charles Scerri (Malta Dementia Society): Recommendations on funding, monitoring, coordination and evaluation.

The presentations were all followed by discussion periods that clearly showed great interest in this topic and highlighted specific needs and concerns from all 12 of the countries represented. AE will now assemble these elements into a draft text of a model European dementia strategy.

The next AE members’ meeting will be an Alzheimer’s Association Academy that will take place on 6-7 December 2016 in Brussels.

13 July: AE delighted to be among top ten most influential NGOs in EU on social media

14 July: GA4GH will start work on harmonising data sharing procedures

On 14 July 2016, the Global Alliance for Genomics and Health (GA4GH) held its second telephone conference. The group agreed on two activities: 1) to look at how existing research groups are sharing data in the dementia field and do a comparative analysis of their governance with the aim of developing common recommendations; 2) to define a common data standard format to make it technically easier to share data. Dianne participated in the meeting. Alzheimer Europe has offered to contribute towards the development of these papers to help ensure that the perspectives and interests of people with dementia are considered.

18 July: INTERDEM offers Masterclass for PhD and postdoctoral students at 26AEC

The next INTERDEM Academy Masterclass will take place on the 1 November under the theme of “Involving people with dementia as advisors to your research”. The Masterclass - aimed at INTERDEM Academy members - will be part of the 26th Alzheimer Europe Conference (26AEC). Speakers include Alzheimer Nederland Director Marco Blom, Alzheimer Europe (AE) Director for Projects Dianne Gove, and the Chairperson of the European Working Group of People with Dementia (EWGPWD) Helga Rohra.

To attend the INTERDEM Academy Masterclass you will need to:

- If you are not already a member of INTERDEM Academy, apply for membership by sending an e-mail to Inge.Klinkenberg@maastrichtuniversity.nl
- Register for the 26th Alzheimer Europe Conference
- Register for the 1 November Masterclass using the form here (password: Mermaid2016).

Other than the Alzheimer Europe registration fee, there will be no additional fee for the Masterclass.

The Masterclass is separate from the Annual INTERDEM Meeting on 31 October in Copenhagen (invitation-only). Please contact Alice van Eijk, secretary to Prof. Myrra Vernooij-Dassen, for more information and registration details for this Meeting: Alice.vanEijk@radboudumc.nl

31 August: Princess Benedikte of Denmark to welcome 26AEC attendees

We are delighted to announce that Her Royal Highness Princess Benedikte of Denmark has accepted our invitation to welcome attendees at our 26th Alzheimer Europe Conference (26AEC) in Copenhagen.

We are also pleased to announce that the Alzheimer Europe Foundation has been able to provide 10 bursaries, of EUR 1,000 each, for participants with dementia to attend this year’s conference. We look forward to welcoming the 10 bursary recipients at our...
Copenhagen conference, which will take place from 31 October to 2 November under the theme “Excellence in dementia research and care”

If you have not yet registered for the conference we advise you to do so soon, as places are filling up quickly, with 531 registrations to date. Regarding the gala dinner we also recommend that you book your seat in advance to avoid disappointment.

We have special rates for the conference, for people with dementia, students and members of the Danish Alzheimer society - Alzheimersforeningen. Special registration forms are available on our website.

Registrations are possible via our website until 23 October, or until maximum capacity is reached. Onsite registration may also be possible subject to availabilities.

1 September: Alzheimer Europe launches new service with up-to-date, accessible information on clinical trials

On 1 September 2016, Alzheimer Europe announced the launch of its Clinical Trials Watch, a new service bringing together up-to-date information on clinical trials investigating drugs for the treatment and prevention of Alzheimer’s and other dementias in an accessible format. To date, only phase III trials currently recruiting participants in at least two European countries are included.

For this innovative new resource, Alzheimer Europe collaborated closely with members of its European Working Group of People with Dementia (EWGPWD) and consulted pharmaceutical companies conducting trials to present basic information. Information is given by country, study name and condition. Each study has been reviewed by a member of the EWGPWD and dementia-friendly versions are available for download. The content will be updated every three months based on information available on public registries.

Jean Georges, Executive Director of Alzheimer Europe said: “Information on clinical trials on Alzheimer’s and other dementias is currently difficult to find and often written in language that is difficult to understand. We hope that our website will become a resource for anyone interested in clinical trials for the prevention and treatment of dementia. If successful, we hope to expand this resource to include phase II trials in the near future”.

Helga Rohra, Chairperson of the EWGPWD, herself diagnosed with Lewy body dementia said: “With this new resource, we want to support people living with dementia in Europe in being truly informed about what research is available. This more dementia-friendly format is a great step in making information on clinical trials more accessible and understandable for people with dementia and people at risk of developing dementia.”

Information on clinical trials is available on: [http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch](http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch)

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

For further information about the Clinical Trials Watch please contact Dr Ana Diaz, Project Officer: ana.diaz@alzheimer-europe.org

EU projects

29 June: Presenting the MinD project: Mindful design for people with dementia

On 29 June, AE hosted a team of researchers from the MinD project during a meeting in Brussels. Dr Kristina Niedderer, Professor of Design and Craft at the University of Wolverhampton, gave a presentation about the four-year project that aims to help people with dementia engage in social contexts to improve psychosocial wellbeing.

Design can offer novel ways of complementing existing care approaches to empower people with dementia in everyday social situations. In this project, mindfulness in design refers to attentiveness to the consequences of actions performed with an object. The project partners, including AE, will focus on two areas:

Designing solutions to help with personal difficulties with social engagement, such as emotions or social interaction.

Designing solutions for environments, to help with social engagement such as mood stimulation and relaxation.

These solutions will be guided by the needs and wishes of people with dementia. AE’s European Working Group of People with Dementia has already provided input and will continue to be involved. AE will also be hosting project events - together with the University of Luxembourg - and will disseminate news and information about the project. More information about the MinD project can be seen at: [www.designingfordementia.eu](http://www.designingfordementia.eu)

13 July: AETIONOMY publishes new study in Alzheimer’s & Dementia journal

On 13 July, members of the AETIONOMY project consortium published a study “Cerebrospinal fluid sTREM2 levels are associated with gray matter volume increases and reduced diffusivity in early Alzheimer’s disease” in Alzheimer’s & Dementia – The Journal of the Alzheimer’s Association.

The study identifies, for the first time, the cerebral structural alterations associated to increased levels of CSF sTREM2, a marker of microglial activation, in the Alzheimer’s disease (AD) spectrum.

“Our results show a positive correlation between gray matter volume and CSF sTREM2 levels in MCI subjects after adjusting for p-tau related atrophy”, the authors say. “To
the involvement of microglial activation in early AD, mediated by TREM2 expression, they conclude.

The AETIONOMY project aims to identify subgroups of dementia and Parkinson’s disease - based on the underlying genetic or molecular causes of the variants - in order to allow tailored therapies. It involves the collection of clinical data, imaging and genetic data, to create a new way to combine all of these and look for patterns.

The European Prevention of Alzheimer’s Dementia initiative (EPAD) has recruited its first research participant in Spain, Maria Carme Garcia (pictured).

The EUR 64 million Europe-wide initiative, which aims to improve our understanding of the early stages of Alzheimer’s disease and how it leads to dementia, is building a registry of 24,000 people and a cohort of 6,000 participants, from which 1,500 will participate in clinical trials on the prevention of Alzheimer’s dementia. 200 participants will be recruited by the Pasqual Maragall Foundation in Barcelona, which announced this first Spanish recruitment on 15 July.

Participants will have regular health checks including blood tests and brain scans. Researchers will also track their thinking skills over time using tests of mental agility. The team hopes to develop tests to identify early signs of Alzheimer’s disease that may indicate when a person is at risk of dementia before symptoms appear. They will then invite these people to take part in clinical trials aimed at testing interventions that could delay, or even prevent, the onset of dementia.

Maria Carme, whose recruitment was done via the BarcelonaBeta Brain Research Center - part of the Pasqual Maragall Foundation - is 61 years old, lives in Barberà del Vallès and has lived alongside Alzheimer’s dementia - first with her father, who was diagnosed in the latter stage of his life, and then with two uncles and two aunts.

“I volunteered because I am surrounded by many affected people. Alzheimer's disease has not been studied enough and is largely unknown”, she said.

According to Dr José Luis Molinuevo, EPAD co-leader and Scientific Director of the Pasqual Maragall Foundation, “EPAD is a unique opportunity to offer healthy people at risk of developing Alzheimer’s dementia the possibility to access an innovative clinical trial designed for the prevention of this disease”.

EPAD involves 36 organisations including universities, commercial partners and patient organisations. Earlier this year the initiative recruited its first research participant, Julie Duffus in Scotland.

The article “European multicentre double-blind placebo-controlled trial of Nilvadipine in mild-to-moderate Alzheimer’s disease - the substudy protocols: NILVAD frailty; NILVAD blood and genetic biomarkers; NILVAD cerebrospinal fluid biomarkers; NILVAD cerebral blood flow” can be seen at: http://bmnopen.bmj.com/content/6/7/e011584.full? keytype=ref&ajkey=kGXiWmh3vHttalU

The main objective of the NILVAD project is to conduct a phase 3 clinical trial of nilvadipine in 500+ people with mild to moderate dementia in nine European countries.

www.nilvad.eu


Lennart Thurfjell of the PredictND project attended the recent Alzheimer’s Association International Conference (AAIC). Mr Thurfjell, CEO of Combinotics sent us the following report:

The Alzheimer’s Association International Conference (AAIC) meeting was held July 23-28 in Toronto, Canada. AAIC is the world’s largest forum for the dementia research community. This year the conference gathered around 5000 researchers from academia and industry. As for previous years, there was also a large exhibition where pharmaceutical, medical device companies and other players active in the field were present.

Such a large conference covers many different topics but research around how to effectively treat Alzheimer’s disease (AD) was as usual one of the main topics. While amyloid (Aβ) plaques and amyloid imaging was a central theme a few years ago, there is now a clear shift towards tau and many of the imaging sessions discussed tau imaging with PET. The hypothesis is that Aβ is upstream of tau in AD pathogenesis and triggers the conversion of tau from a normal to a toxic state. This doesn’t change the role of amyloid and most researchers still believe that anti-amyloid treatments, if used in an early stage, have the potential to slow down or halt the disease process.

Moving AD treatment to very early disease stages was a second central theme of the conference. There were, for example, initial reports from enrollment of subjects into the A4 study. The A4 study is a clinical trial for older individuals who may be at risk for AD but who do not experience any memory of cognitive problems (i.e., they are healthy when assessed with cognitive tests). The challenge for all studies in early disease stages is how to
enroll individuals in a cost effective way. This will become even more challenging if/when a disease modifying drug is approved. As a senior executive for a pharmaceutical company put it: "physicians that today shy away from diagnosing dementia will have to decide which individuals to put on the new drugs. This is one of the top concerns for us".

With the above in mind it is clear that the work in PredictND is very important. Finding the right patient in the right disease stage will become more and more important. There were also several researchers from the PredictND partners present at AAIC and there were two papers presented. Wiesje van der Flier presented a poster with the topic "Cost effective differential diagnostics of neurodegenerative diseases using a stratified approach" and Jyrki Lötjönen had an oral presentation with the title "Towards data-driven medicine in differential diagnostics if neurodegenerative diseases". Both presentations were well received and are perfectly aligned with the problem of early diagnostics outlined above.

The AAIC conference is also a great place for networking and PredictND partners had several meetings around potential exploitation of the PredictND technology. Meetings were held with two pharma companies and with several medical device / biomarkers companies. The main point was to raise awareness of the PredictND technology but there will be follow up discussions based on some of these initial meetings.

In summary, AAIC 2016 was a great meeting and we are already now looking forward to AAIC 2017 which will be held in London July 15-20.

23-28 July: EPAD features prominently at AAIC Conference in Toronto

The Alzheimer’s Association International Conference took place in Toronto from 23 to 28 July. The EPAD (European Prevention of Alzheimer’s Dementia) project funded by the Innovative Medicines featured in a number of key symposia and communications:

- At a joint pre-conference meeting of the Global Alzheimer’s Platform and EPAD on global Alzheimer’s research collaboration on 22 July, EPAD researchers Simon Lovestone (University of Oxford), Luc Truyen and Serge van der Greyn (Janssen), José Luis Molinuevo (BarcelonaBeta Brain Research Center) and Andy Saltin (Eisa) updated the audience on the progress of the EPAD project. Similar initiatives were developed in Australia, Canada, Japan and the US were also presented at this meeting.
- In a session dedicated to risk disclosure in the era of Alzheimer’s prevention studies on 27 July, Krista Tromp from the Erasmus Medical Center presented the EPAD work and recommendations in this field.
- On the final day of the conference, Craig Ritchie presented EPAD in a session entitled “Speeding innovative medicines in need: The Global Alzheimer’s Platform”.

The focus on EPAD, prevention and global research collaboration did not go unnoticed and led to the following comment in a respected forum dedicated to dementia research: "The biggest story at the Alzheimer’s Association International Conference, held July 22-28 in Toronto, unfolded rather quietly. It took place in off-site or pre-meetings, and in a sparsely attended session on the last morning, when a majority of conventioneers had left. It is the story of how multiple powerful interests on either side of the Atlantic and Pacific oceans have coalesced to try to fundamentally reorganize the way clinical trials will be done on Alzheimer’s disease starting in the near future".

For more information on the EPAD presentations and the project’s place in global research efforts, read here: http://www.alzforum.org/news/conference-coverage/coming-center-near-you-gap-and-epad-revamp-alzheimers-trials

24 July: PharmaCog researchers present project results at AAIC2016

Dr Claudio Babiloni and Dr Moira Marizzoni both attended the recent AAIC conference in Toronto to present results from the PharmaCog project.

Dr Babiloni presented:

- "Back-translation of EEG/ERP markers from amnestic MCI patients to healthy young volunteers in the PharmaCog project."
- "Association between EEG/ERP and CSF markers in prodromal Alzheimer’s disease in the PharmaCog project."
- "Spectral on-going EEG markers in TASTPM mice are affected by chronic administration of BACE-1 inhibitor in the PharmaCog project."

He also presented “Uses of electrophysiology in preclinical research, clinical trials and drug discovery in Alzheimer’s disease” at the Electrophysiology PIA (EPIA) Day 2016 in conjunction with AAIC2016.

Dr Marizzoni presented:

- "Cognitive Composite Measures in Amnestic MCI by Different Amyloid/Tau Pathology”
- "Biomarkers of short term disease progression in Mild Cognitive Impairment patients with AD pathology”
- "Association between volumes alterations and CSF biomarkers in amnestic MCI” (Poster)
- "Association between brain MRI diffusion alterations and CSF biomarkers in amnestic MCI” (Poster)

The PharmaCog project developed new models to predict the efficacy of drug candidates by combining past and current data to define a series of biomarkers of dementia progression. The project proposed new methods for successfully developing new drugs for the treatment of Alzheimer’s disease to the pharmaceutical industry and academic research laboratories. During 2010-2016, the partners published over 40 papers and more are expected in the second half of 2016.

www.alzheimer-europe.org/Research/PharmaCog
24 August: AETIONOMY webinar shows project progress

On 24 August, the AETIONOMY team held a webinar to update the partners on the latest activities of the project. The online conference featured six presentations, each of which was followed by a discussion period.

Prof. David Gomez-Cabrero from Karolinska Institutet (KI, Sweden) presented “Patient Stratification in PPMI data”, followed by Dr Bernard de Bono (University College London) who spoke about “Physiology-level hypotheses generated from the analysis of PPMI clinical and radiological data”. These speakers were focused on Parkinson’s disease, which AETIONOMY is studying alongside Alzheimer’s disease (AD).

They were followed by Dr Gordon Ball, also from KI, who spoke about “Combining knowledge with heat diffusion”. Daniel Domingo-Fernández and Alpha Tom Kodamullll, researchers from Fraunhofer SCAI, presented “NeuroMMSiGDB - a database for Multimodal Mechanism Signatures for Neurodegenerative Diseases”. These topics apply to both neurodegenerative diseases.

The final speakers, all Fraunhofer researchers, focused on Alzheimer’s disease. Shashank Khanna presented “Preliminary data analysis and identification of significant features from ADNI for Patient Stratification”. He was followed by Sepehr Golrizkhatami and Anandhi Iyappan, who spoke about “Functional impact assessment of SNPs for interpreting neuroimaging features in the context of neurodegenerative diseases.”

The webinar was attended by Jean Georges and Alex Teligadas on behalf of Alzheimer Europe. From now on, AETIONOMY’s schedule will include more Alzheimer’s disease research and AE looks forward to reporting further project updates.


26 August: IMI publishes dementia projects factsheet

The Innovative medicines Initiative (IMI) Communications Team has developed a factsheet containing information about all of the dementia-related projects they are funding, including four projects in which Alzheimer Europe is currently involved: AETIONOMY, EMIF, EPAD, PharmaCog.

It also lists some upcoming IMI projects in the field. You can view the factsheet here: http://www.imi.europa.eu/sites/default/files/uploads/documents/Publicatio ns/IMIdementiaportfolio_factsheet_June2016.pdf

Alzheimer Europe networking 2016

On 27-28 June (Brussels, Belgium), the Alzheimer Europe Board met.

On 28 June (Brussels, Belgium), Alzheimer Europe organised a lunch debate on “Using the UN CRPD to support the rights of people living with dementia” in the European Parliament.

On 28 June (Brussels, Belgium) Alzheimer Europe organised a company round table meeting with its sponsors and member organisations.

On 28 June (Brussels, Belgium), the Board and members of Alzheimer Europe met with Axovant for an exchange on the company’s clinical trial programme.

On 29 June (Brussels, Belgium), Alzheimer Europe organised a public affairs meeting with its national member organisations.

On 5 and 6 July (Geneva, Switzerland), Jean attended a consultation meeting of the World Health Organisation on the Global Dementia Observatory.

On 7 July (London, UK) Ana participated in a user test for clinical data publication website organised by the EMA.

On 7 and 8 July (Edinburgh, United Kingdom), Jean attended the Programme Board of the EU Joint Action on Dementia.

On 8 July, Dianne participated in the EPF taskforce telephone conference on vulnerable groups on the topic of Roma populations.

On 12 July (Luxembourg, Luxembourg) Jean and Ana met with representatives of Quintiles and Clariness.

On 13 July (Brussels, Belgium), Jean attended a meeting of the European Parliament Interest Group on Mental Health, Wellbeing and Brain Disorders.

On 15 July (London, United Kingdom), Jean attended a Health Advisory Board of GlaxoSmithKline.

On 20 and 21 July (Berlin, Germany), Gwladys and Jean toured a number of potential conference venues for Alzheimer Europe’s 2017 Annual Conference.

On 22 July (Copenhagen, Denmark) Gwladys met with suppliers of Alzheimer Europe’s 2016 Annual Conference.

On 23 to 28 July (Toronto, Canada), Jean attended the Alzheimer’s Association International Conference (AAIC).

On 24 August, Jean and Alex attended an online webinar organised by the AETIONOMY project.

On 30 August and 1 September (Amsterdam, Netherlands) Gwladys attended a Private MICE Forum.
Members of the European Alzheimer’s Alliance

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

Austria: Heinz K. Becker (EPP); Kappel Barbara (NI); Rübig Paul (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: Costas Mamvrides (S&D); Eleni Theocarou (S&D)
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); Anna Jäättteenmäki (ALDE); Miep Kumpula-Natri (S&D); Merja Kyliläinen (GUE/NGL); Sira Pietikäinen (EPP)
France: Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D)
Germany: Angelika Niebler (EPP); Udo Voigt (NI)
Greece: Kostas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimonoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyridaki (EPP); Eleftherios Synadinos (Ni); Eleni Theocharous (S&D)
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)
Italy: Brando Benifei (S&D); Elena Gentile (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D)
Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP)
Malta: Therese Comodini Cachia (EPP); Roberta Metsola (S&D); Alfred Sant (S&D)
Netherlands: Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP)
Poland: Elzbieta Lukacijewska (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); António Marques (S&D); Maria da Graça Fernandes (EPP); José Sanches (EPP)
Romania: Cristian-Silviu Busoi, MEP (EPP); Marian Marinescu (S&D); Marian-Jean Marinescu (S&D); Octavie Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D)
Russia: Andrei Klimov (EPP)
Slovakia: Miroslav Mikolášik (S&D); Anna Zábořská (S&D); Jana Žitnánská (ECP); Ivan Stefanec (EPP); Anna Zagorovskaya (S&D)
Slovenia: Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA)
Spain: Jesús Gutiérrez Serna (EPP)
Sweden: Jytte Guteland (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE)
United Kingdom: Martina Anderson (GUE/NGL); Richard Atkins (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Glenis Willmott (S&D)

European Alzheimer’s Alliance

7 July: Members of the EAA speak up in support of the UN CRPD

On 7 July, during a debate and vote at the European Parliament to adopt a resolution on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), a number of MEPs, including nine members of the European Alzheimer’s Alliance (EAA) spoke in favour of the EU implementing the UN CRPD.

The resolution calls on the European Commission and the EU Council to fully implement the UN’s recommendations.

Alzheimer Europe would like to thank the following EAA members (pictured) for supporting this resolution and speaking up on behalf of people with disabilities, including those living with dementia:

- Martina Anderson, MEP (UK)
- Vilija Blinkevičiūtė, MEP (Lithuania)
- Nessa Childers, MEP (Ireland)
- Rosa Esteras Ferragut, MEP (Spain)
- Marian Harkin, MEP (Ireland)
- Ádám Kösa, MEP (Hungary)
- Kostadinka Kuneva, MEP (Greece)
- Marek Plura, MEP (Poland)
- Sofia Ribeiro, MEP (Portugal)

You can read more about the vote on the UN CRPD resolution here.

EU developments

1 July: Slovakia takes on EU Presidency, plans dementia conference

On 1 July 2016, Slovakia took over the mantle of Presidency of the Council of the European Union (EU) from the Netherlands. Slovakia will preside for the second half of 2016, taking its turn as second in the current Trio Presidency, after which Malta will take its turn for the first half of 2017.
This will be the first time Slovakia takes the helm of the Council of the EU since joining the bloc in 2004. While adhering to the Trio’s approach, Slovakia will be primarily concerned with the political challenges facing the EU, particularly in the wake of the UK’s EU referendum.

The Presidency’s priorities will pivot around the themes of:
- An economically-stronger EU.
- Modernising the Internal Market.
- Sustainable migration and asylum policies.
- A globally-engaged Europe.

On 12 July 2016, in the European Parliament Mr Tomáš Drucker, Slovak Minister of Health presented the health priorities of the Slovak Presidency in front of the Committee on the Environment, Public Health and Food Safety (ENVI) where he announced that Slovakia will host a conference on Alzheimer’s disease on 29-30 November 2016.

Some relevant event dates are:
- 20 September - Conference on prevention of chronic non-communicable diseases and healthy lifestyle
- 3-4 October - Informal EPSCO Health Council
- 9 December - EPSCO Health Council

Website: eu2016.sk/en
Twitter: @eu2016sk

1 July: Eurodiaconia publishes new report on nursing and care assistants across Europe

Eurodiaconia has published a new report “The education, training and qualifications of nursing and care assistants across Europe” which addresses the skills obtained in education and training qualifications of healthcare, nursing and care assistants in different European countries.

The report is particularly useful in showing differences and challenges in how the education or training of such staff varies from country to country. This input should help countries to prepare better for increased demand in long term care and for the further training of staff not trained or educated in the country in which they are employed. The study also aims to raise awareness on the need to increase the comparability of qualifications and training among care professionals across Europe, especially as the demand for care raises.

The full report can be read here:

1 July: “Business as usual” for IMI and Commission-funded projects following Brexit vote

At the start of July, the Innovative Medicines Initiative (IMI) and the European Commission both released statements concerning the outcome of the referendum of the United Kingdom’s membership of the European Union, dubbed “Brexit”.

The European Commission reassured users of its Horizon 2020 (H2020) EU Research and Innovation funding programme that nothing would change, given that the UK has not actually left the EU yet:

“The Statement of 29 June of the Heads of State or Government of 27 Member States, as well as the Presidents of the European Council and the European Commission, confirms that until the UK leaves the EU, EU law continues to apply to and within the UK, both when it comes to rights and obligations. This includes the eligibility of UK legal entities to participate and receive funding in Horizon 2020 actions.”

IMI followed suit, referring back to the Commission’s statement. IMI has also reassured projects individually that the vote will not affect the IMI-2 program, signature of Grant Agreements, nor the funding of projects - including UK partners.

http://www.eurodiaconia.org/events/healthy-aging-and-long-term-care-network-meeting/

4 July: European Patients Forum holds Policy Advisory Group meeting

On 4 July, the European Patients Forum (EPF) held a Policy Advisory Group meeting in Brussels.

The first item on the agenda was an introduction to The European Consultation on a Social Rights Pillar for the European Union and a discussion on opportunities to raise awareness of and include patients’ voices in this pillar.

Other items on the agenda were: chronic pain and the question of how the EPF should address this, an update on the EPF Patient empowerment campaign and EPF Access Campaign, as well as an update on EU policy dockers and current and upcoming consultations, including the European Semester country specific recommendations on health, mHealth, medical devices and medical devices.

Alzheimer Europe Policy Officer Vanessa Challinor attended the meeting.

5 July: Netherlands EU Presidency dementia conference report now available

During its EU Presidency, the Netherlands’ government organised the conference ‘Living well with(out) dementia’ on 9-10 May 2016. A full report of the conference is now available online here. More information about the conference can also be read here.

7 July: MEPs adopt resolution on the implementation of the UN CRPD by the EU

On 7 July 2016, an overwhelming majority of Members of the European Parliament (MEPs) voted to adopt a resolution based on a report concerning the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).
CRPD), which calls on the European Commission and the EU Council to fully implement the UN’s recommendations.

In August 2015 the European Union (EU) was reviewed by the UN Committee on the Rights of Persons with Disabilities on its work to protect and promote the rights of the 80 million persons with disabilities in Europe. Following that review, the UN Committee issued a list of recommendations (Concluding Observations) to the EU.

The European Parliament (EP), whose role in the implementation of the UN CRPD and the UN’s recommendations to the EU is fundamental, has reacted to these recommendations and has produced a report. In line with article 4.3 of the UN CRPD, the text of the report was drawn up with the involvement of disability organisations from across Europe. In particular, the European Disability Forum and its members were included, as was the informal cross-party EP Disability Intergroup of which Belgian MEP Helga Stevens (pictured) is a co-chair. Ms Stevens - the first female deaf MEP - wrote the report, outlining the EP’s views on what the EU needs to do better to implement the UN CRPD.

A record number of Parliamentary Committees were also involved, illustrating that disability is not only a ‘social’ topic but one that crosses all areas of life. Transport, gender equality and disability-inclusive humanitarian aid are just some of the themes of the report.

The resolution is far reaching and comprehensive and states that the EU should lead the way as far as the respect and promotion of human rights are concerned; it shifts the definition of disability from a purely medical one to a broader, more social definition. This provides an opportunity for a complete review of the European Disability Strategy and for the EU to show its commitment to better, more inclusive policies.

The press release from the EP Disability Intergroup can be read here.

7-8 July 2016: Programme Board of Joint Action on Dementia meets in Edinburgh

The new Joint Action on dementia coordinated by the Scottish Governments organised the first meeting of its Programme Board on 7 and 8 July in Edinburgh.

Ms Maureen Watt, Minister for Mental Health welcomed the participants and opened the meeting. She reiterated the commitment of Scotland to European collaboration on dementia and stressed that the Joint Action was a unique opportunity to improve the lives of people with dementia.

Chaired by Geoff Huggins, Director for Health and Social Care Integration of the Scottish Government, the meeting approved the terms of reference of the Programme Board and discussed the consortium agreement and the programme risk register. The Programme Board also approved the work plans which were presented by the leaders of the different work packages, namely:

- Timely diagnosis and post-diagnostic support led by France,
- Crisis and care coordination led by the Netherlands and Italy,
- Residential care led by Norway
- Dementia-friendly communities led by the UK.

During the second day, collaborations with other initiatives were discussed with presentations from the International Consortium for Health Outcomes Measurement (ICHOM), Healthcare Improvement Scotland and the MODEM project (modelling outcome and cost impacts of interventions for dementia).

The Programme Board also approved the plans for the horizontal work packages on coordination and dissemination led by the Scottish Government and on evaluation led by Spain.

Jean Georges represented Alzheimer Europe at the meeting and committed the organisation to supporting the different activities of the Joint Action by ensuring the view of people with dementia, carers and Alzheimer associations were duly represented.

11 July: European Parliament Written Declaration to make dementia a top priority of the EU lapses

In April 2016 11 MEPs submitted a Written declaration which called upon the Council and the Commission to make combating Alzheimer’s and other types of dementia a top priority of the European Union, and to put further emphasis on cooperation among Member States in the areas of research, care and prevention.

The following Members of the European Parliament signed the Written Declaration 0027/2016 on the prioritisation of a European Dementia Strategy which lapsed on 11 July 2016.

The Written Declaration included the following statements:

- Every year 1.4 million Europeans develop some form of dementia, with the World Health Organisation estimating that 6.4 million people are living with dementia in the European Union.
- By 2050 the number of people over 65 in Europe will be three times higher than in 2003, and five times higher in the case of the over 80s, thus widening the pool of people at risk of dementia.
- Dementia and its related health consequences have a tremendous impact on the people affected, their families, caregivers, and society as a whole, and studies have shown that improved cardiovascular risk factors and higher education levels can lead to a reduction in national dementia cases.
- The Council and the Commission are hence called upon to make combating Alzheimer’s and other types of dementia a top priority of the European Union, and to put further emphasis on cooperation among Member States in the areas of research, care and prevention.
- This declaration, together with the names of the signatories, is forwarded to the Council and the Commission.
The declaration required the support of the majority of MEPs in order to proceed further. By the closing date of 11 July 2016 135 (of 751) MEPs had expressed their support. This was clearly short of the majority and caused the declaration to lapse on the same day. Nevertheless Alzheimer Europe wishes to thank all the signatories for expressing their support to improve the lives of people with dementia and their carers in all European countries.

Alzheimer Europe thanks the following signatories for their support.

**Austria:** Becker, Heinz K., Kappel, Barbara. **Belgium:** Vandkenndelaere, Tom, Vautmans, Hilde, Wierinck Lieve.

**Bulgaria:** Mihaylova, Iskra, Uurtchev, Vladimir. **Croa­tia:** Jakovčić, Ivan, Šuica, Dubravka. **Cyprus:** Sylikiotis, Neoklis. **Czech Repub­lic:** Keller, Jan, Konečná, Kateřina, Mašťálka, Jiří, Polták, Stanislav, Sehnalová, Olga, Svbodova, Pavel, Šoltes, Igor, Po­ten演示ev, Evžen, Tošenovský, Pavel, Želozubová, Tomáš. **Denmark:** Schaldemose, Christel. **Estonia:** Toom, Yana. **Finland:** Hannu, Hautala, Jaakonsaari, Liisa, Jäätteenmäki, Anneli, Kyllönen, Merja, Pietikäinen, Sirpa, Pirkko, Takkula, Ruohon­Lerner, Heidi. **France:** Bergeron, Joëlle, Bilde, Dominique, Goddyn, Sylvie, Juvin, Philippe, Morano, Nadine, Morin-Chartier, Elisabeth. **Germany:** Heubuch, Maria, Lehnen, Jo, Köster, Dietmar, Sommer, Renate, Voss, Axel. **Greece:** Chryso­g­onos, Kostas, Epite­dios, Georgios, Fountoulis, Lampros, Kalli, Eva, Kefalogiannis, Manolis, Kuneva, Kostadinova, Kyrtos, Georgios, Papadimoulis, Dimitrios, Sakorafa, Sofia, Synadi­nos, Eleftherios, Zagoras, Theodoros. **Hungary:** Ujhelyi, István, Comi, Lara, Dei, Andor, Hölvényi, György, Kósá, Ádám, Molnár, Csaba, Niedermüller, Péter, Szányi, Tibor. **Ireland:** Kelly, Seán, Clune, Deirdre, Harkin, Marian, Hayes, Brian, McGuinness, Joe, Martin, McGuinness, Julia. **Italy:** Morgano, Luigi, Sernagiotti, Remo, Fitto, Raffaele, Zoffoli, Damiano, Benifèl, Brando, De Castro, Paolo, Adinolfi, Isabella, Bonafo, Simona, Cirio, Alberto, La Via, Giovannai, Luigi. **Lithuania:** Landsbergis, Gabrie­lius, Pakas, Rolandas. **Malta:** Comodini Cachia, Therese, Dalli, Miriam, Metsola, Roberta. **Netherlands:** Lenaers, Jeroen, Schreier, Piek, Annie. **Poland:** Czesak, Edward, Kalinowski, Jarosław, Kozłowska-Rajewicz, Agnieszka, Lybacka, Krystyna, Pitera, Julia, Plura, Marek, Wenta, Bogdan Brunon. **Portu­gal:** Coelho, Carlos, Fernandes, José Manuel, Faria, José Inácio, Ferreira, João, Gomes, Matias, Marisa, Ana, Ribeiro, Sofia, Rodrigues, Liliana, Ruas, Fernando, Zorin­ho, Carlos. **Romania:** Buda, Daniel, Bușoi, Cristian Silviu, Grapini, Maria. **Slova­kia:** Nagy, Júszef, Smolíková, Monika, Štefanec, Ivan, Záborská, Anna, Žitňanská, Jana. **Sweden:** Bogovic, Frans, Fajon, Tanja, Peterle, Alojz, Šoltes, Igor, Tomc, Romana, Vaigl, Ivo, Zver, Milan. **Spain:** Alboli Guzmán, Marina, Becerra Basterrechea, Beatriz, Bilbao Barandica, Ibarsun, Cebezón Ruiz, Solá, González Peñas, Tania, Gambús, Francesc, González Pons, Esteban, López Bermejo, Paloma, Nart, Javier, Punset Carolina, Sánchez Caldentey, Lola. **United Kingdom:** Anderson, Martina, Dodds, Diane, Gill, Neena Hudginton, Khan, Afzal, Ian, McAvan, Linda, Martin, David, Sthillier, Catherine, Taylor, Keith, Ward, Julie.

13 July: EU Compass for Action on Mental Health and Well-being in development

The EU-Compass for Action on Mental Health and Wellbeing is a mechanism to collect, exchange and analyse information on policy and stakeholder activities in mental health. During 2015–18 the Compass plans to undertake action to disseminate the European Framework for Action on Mental Health and Wellbeing resulting from the Joint Action Mental Health and Wellbeing and monitor mental health and wellbeing policies and activities by Member States and non-governmental stakeholders through:

- The identification and dissemination of European good practices in mental health.
- The collection of data on stakeholders’ and member states activities in mental health through three annual surveys.
- The organisation of three annual reports and forum events.
- Holding national mental health workshops in each Member State and Iceland and Norway.

In addition, the EU Compass aims to support the work of the EU-Group of Governmental Experts on Mental Health and Wellbeing through the preparation of four scientific papers. The aim is to develop these scientific reports in collaboration with the Group and under consultation of non-governmental stakeholders into consensus papers.

Find out more about plans for the Compass here:


13 July: European Parliament discusses need of European action on brain and mental health

The European Parliament Interest Group on Mental Health, Well-being and Brain disorders met on 13 July. The meeting was hosted by Members of the European Parliament Marian Harkin (Ireland) and Marek Plura (Poland) and organised by the European Brain Council and GAMIAN Europe.

Herta Adam provided an update on the ongoing activities of the European Commission in the field of mental health and brain disorders with a particular focus on the Mental Health Compass. The need for further coordinated action was presented by Frédéric Destribucq of the European Brain Council and by Raluca Nica from GAMIAN-Europe who called for the development of an EU Action programme on mental health and well-being.

Jean Georges attended the meeting on behalf of Alzheimer Europe.

19 August: EPF launches survey on access to healthcare- Share your experiences

The European Patients Forum (EPF) has launched a unique survey on access to healthcare: to gain knowledge on the experience of patients across diseases and Member States as regards various dimensions of access to healthcare and treatment. This survey will provide key information for the launch of EPF campaign on access to healthcare in 2017.

It looks at five dimensions of healthcare:

- Availability – whether a healthcare service or product is available in the healthcare system of your country
• Affordability – whether seeking healthcare causes financial hardship to patients.
• Accessibility – whether there are barriers, other than financial (e.g. waiting lists, geographical barriers...), that stop patients from accessing healthcare.
• Adequacy – the quality of healthcare and involvement of patients in shared decision making with their healthcare professionals.
• Appropriateness – whether healthcare meets the need of different groups in the population.

Who can take the survey?
The survey has been designed specifically for individual patients with chronic and long term conditions, and their informal/family carers. There is no need for in-depth knowledge on healthcare to complete this survey, questions are primarily about individual experience and there are no right or wrong answers.

Take the survey! It is open until 31 October 2016.

Follow us on Twitter

Members’ news

2 June: Centre for information and consultations for people with dementia starts work in Varna

A new project funded by the Municipality of Varna has allowed Foundation Compassion Alzheimer Bulgaria to provide a “Center for information and consultations for people with Alzheimer’s, dementia and other memory disorders”. The project was launched on 1 June and will run for five months.

The project aims to improve the quality of life of people with Alzheimer’s and dementia, as well as family members who care for them by providing information and consultations. Service users will receive comprehensive information on the disease stages and its development, on what medical and social support is available in Bulgaria and will be referred to specialists and existing social services.

The centre conducts psychological counselling, as well as lectures. The Multidisciplinary team consists of a psychotherapist, animator, art-therapist and a lawyer uses a variety of activities - individual and group sessions, excursions, walks, classes in drawing and music. The Foundation team will also use the widespread and very successful European practice of “Alzheimer Cafés” to support the integration and social inclusion of people living with dementia and their families.

The project was inspired by the exchange of good practices with the Italian organisation Rifugio Re Carlo Alberto during a visit to Italy in April of this year, as a networking initiative of the European Foundations’ Initiative on Dementia (EFID). It is an application of best European practices and promotes a community approach to fighting the disease.

During September, in the city of Varna on the occasion of World Alzheimer Day the Foundation will organise a conference on the subject with the participation of experts, representatives from Varna Municipality, NGOs and the Italian partner organisation.

30 June: ProMenz group helps Vienna become more dementia friendly

Thanks to the involvement of the self-help group ProMenz, Vienna is becoming increasingly dementia friendly.

At the moment, four dementia-friendly districts exist: 3rd, 9th, 13th and 23rd. Each district has its own networking partners, individual priorities and action plans. For example a “dementia-trolley”, set up in the 3rd district, moves around the district, carrying brochures, folders and other helpful information. A big flag is used to draw attention to talks given about memory problems, Alzheimer’s and prevention.

In June, Alzheimer Austria invited people with dementia to a dialogue-oriented guided tour of the famous Belvedere museum and art gallery, exhibiting a collection of paintings by Gustav Klimt, Oskar Kokoschka and Egon Schiele. Designed for persons with memory problems, two guided tours were given about three pieces from the Biedermeier period. Sitting in highly comfortable hairs in front of the paintings, participants were invited to share their thoughts, feelings and knowledge of the elements in the paintings. A fan, a shawl and a fargnon – each of which was depicted - were handed round the group to help enrich the experience by stimulating touch, smell and other senses. The memorable tour ended with refreshments in the studio, where participants were invited to create an artwork of their own.

ProMenz, which is run by people with dementia, was busy inviting new members before the summer and since there are more men currently involved, women were particularly approached.

According to members of ProMenz, the measures offered by the group substantially help them in coping with the disease and Alzheimer Austria therefore believes that similar groups throughout the country would be “highly desirable”, but supporters of “ProMenz” are currently all volunteers and all activities offered are free of charge, so to keep the group going and to help create others, Alzheimer Austria is seeking funding as it says the Austrian government has, until now, not been willing to give much support in this area.

1 July: The Alzheimer’s Society reports on new programme to help people live well with dementia

On 1 July, the Alzheimer’s Society (UK) sent us the following report about a new programme in development. The report was written by Beverley Page-Banks, Programme Development Manager, Service Development Team, the Alzheimer’s Society:
At Alzheimer’s Society we are developing an exciting new programme called “The Live Well with dementia programme”. The programme aims to help people living with early stage dementia develop the understanding, skills and practical tools, to empower and support them to take an active role in the management of their health and well-being.

2013 research showed that people with dementia have much less access to the benefits of self-management programmes, compared to other long term conditions. At Alzheimer’s Society we highlighted a gap in our services for a structured, peer group programme, based on self-management principles, and as a result developed, “The Live Well with dementia programme” with funding from the Lloyds: Live Well Campaign.

This seven session programme is co-facilitated by trained facilitators. The participants of the programme have a vital role as “pathfinders”, and feedback and evaluation based on their lived experience of dementia, directly informs the model.

Following 5 pilot programmes, 20 programmes took place at pathfinder stage involving robust internal and external evaluation during September 2015 - March 2016. Up to 20 further programmes will be delivered across England, Northern Ireland and Wales during September – December 2016 in readiness for project completion in March 2017.

University of Brighton conducted the literature review and are conducting the external evaluation: “It is clear that this programme remains at the cutting edge and at the forefront of a very current and developing area of research and interest”.

People living with dementia who have participated in the programme have said “It’s like taking some control of your life again”, “It has been the learning together and from each other that’s the best part for me”. Early but significant evidence indicates the exciting, positive value and future potential of this programme for people living with early stage dementia.

Reference to the external evaluation brief can be found on University of Brighton’s website.

2 July: Luisa Bartorelli resigns as president of Alzheimer Uniti Italia

With the conviction that it would be a positive move to make way for a new generation of leaders, Professor Luisa Bartorelli (pictured, left) submitted her resignation as president of the association, Alzheimer Uniti Italia. On 2 July, the General Assembly ratified the appointment of her successor Manuela Berardinelli (pictured, right), Chairperson of the local association Alzheimer Uniti Marche.

The members of the General Assembly continue to fully support the many activities planned for the future, with a particular eye on the guidelines suggested by Alzheimer Europe.

Ms Berardinelli will be working closely with the past president, Prof. Bartorelli, who has been designated as the main contact person for all institutions, both national and international. Together they will work with all available resources to create good relationships with other institutions and be open to collaboration with all other associations in Italy.

Alzheimer Uniti also launched a strong appeal: to use resources well, so that they are not wasted and may reach people with dementia and their families. The General Assembly closed on this positive note, looking to continue to build a more dementia-friendly Italy.

12 July: EMDA cooperates with theatres presenting plays about Alzheimer’s

During July July, the Beit Lessin Theater in Tel Aviv was showing the play “The Father”, which conjures up images of life familiar to families living with dementia. EMDA – The Alzheimer’s Association of Israel in cooperation with Beit Lessin Theater, had previously organised a special performance of “The Father” (pictured) for an audience of family members of people with dementia and professionals working in the field on 25 May. After the performance, a discussion was held with:

- Professor Amos Korczyn - Chairman of the Scientific Council of EMDA,
- Debbie Lahav - an occupational therapist and support group leader at EMDA,
- Daphna Golan Shemesh - social worker, arts therapist and group leader
- And actors Sasson Gabai - who plays The Father - and Yael Waksstein, who plays his daughter in the play.

This special performance was viewed by an audience of over 500 people from across the country, family members of people with dementia and professionals working in the field.

In addition, EMDA is cooperating with theatres in Jerusalem on the production of a play based on Amnon Shamosh’s book “Good Morning Aletz Heimer”. Amnon Shamosh is a famous Israeli author and the book describes his experiences while caring for his wife who had Alzheimer’s dementia. The play will open on World Alzheimer’s Day, 21 September.

1 August: Alzheimer Slovenia has a new member of staff from Poland

On 1 August, Slavomir Krajevski (pictured) started an Erasmus for young entrepreneurs exchange at Spominica - Alzheimer Slovenia. He will gain experience and assist with organising events to raise awareness about dementia.
19 August: Colette Kelleher leaves The Alzheimer Society of Ireland

Colette Kelleher (pictured) has decided to leave The Alzheimer Society of Ireland (ASI) to pursue a new opportunity.

In the interim period before appointing a new CEO, Miriam Enright, Head of Operations, will be the point of contact for any queries to the office of the CEO.

Ms Enright can be contacted on miriam.enright@alzheimer.ie

22 August: Alzheimer Croatia is granted funding for five new projects

On 22 August, the capital of Croatia Zagreb approved financing for five projects, to be developed by Alzheimer Croatia will develop during the coming fiscal year. These projects involve wider activities in the field of public health and social care, which Alzheimer Croatia believes will result in better quality of life for people with dementia and their caregivers.

The five projects are:

- Better quality of life for people with dementia (approved by the City Administration).
- Educational programs for caregivers at the Alzheimer Croatia Consulting Centre (approved by the City Office for Health).
- A medical education programme - “10 early signs of Alzheimer’s disease” (approved by City Office for Health).
- A support programme for caregivers at the Alzheimer Croatia Consulting Centre (approved by the City Office for social protection and people with disabilities).
- The Marte Meo programme for people with dementia in Care home for elderly people Zagreb-Dubrava (approved by the City Office for social protection and people with disabilities).

In competition with more than 300 other projects, all the Alzheimer Croatia projects were awarded high scores up to 95% by independent commissions.

Pictured: Croatian capital Zagreb – main street.

23 August: Alzheimer Slovenia issues 24,000 brochures

Spominčica - Alzheimer Slovenia's existing collection of brochures about dementia was recently upgraded with two new ones, called "Personal care of persons with dementia" and "Animation for persons with dementia".

Besides these, Spominčica has four other brochures: "What is dementia?", "Communication with persons with dementia", "Prevention – how to reduce risk of dementia" and "Ethics and the rights of persons with dementia". These six informative brochures with different contents ensure the continuity of Spominčica’s work in supporting carers of persons with dementia and raising public awareness about dementia.

26 August: Finnish Society actively involved in key government project

The Finnish Government has multiple ongoing key projects, of which six are within the administrative branch of the Ministry of Social Affairs and Health. One of the Ministry's key projects is developing homecare for the elderly and informal care in all age groups. One aim of this project is to develop informal care for people with memory diseases (dementia) through broad co-operation.

The Alzheimer Society of Finland (Muistiliitto) is actively involved in this key project, on the steering committee and in the funding preparations, among other things.

EUR 30 million has been allocated for funding.

www.muistiliitto.fi/en

29 August: Swedish Dementia Foundation participates in biggest political event of the year

On 29 August, Demensforbundet reported on its participation in Sweden’s “biggest political event of the year”:

Each year, Sweden arranges a political week on the island Gotland in the town of Visby (pictured). The event is called “Almedalen”. All our top politicians, many big companies and most of the NGOs are gathered in one place to discuss current ‘hot topics’.

The Swedish Dementia Foundation (Demensförbundet) participated for the seventh year, holding a stand providing information materials, visiting other companies and associations working in the field of dementia and elderly care and also by having our own presentations by Yngve Gustafson, professor in geriatrics at Umeå University.

As a result of our participation we have been invited to several conferences this autumn and also next year. As an example we could mention a congress that will be held for all the ambulance nurses in Sweden. As they often come in contact with either people with dementia or their relatives and in many cases in a critical situation, they have a big need for knowing how to treat a person with a dementia diagnosis. The Swedish Dementia Association has already decided to participate again next year, as we see this as an important arena for us to spread knowledge and information about dementia in our country and among our top politicians.
29 August: Pilot project looks into what happens after a dementia diagnosis in Norway

In Norway about 10,000 people get dementia every year. For those who are diagnosed, a new problem arises. What now? What does this mean for me, for us?

A recently-launched pilot project will develop, test and evaluate a programme to follow up newly-diagnosed people in four different municipalities. Later, the intention is to spread the model to all municipalities in the country.

User interaction is at the core of the project and this summer, there have been a number of meetings in the communities involved, to give those who will be using the services a chance to be involved in developing the model from the start.

31 August: Federazione Alzheimer Italia member organises holiday for people with dementia and their families

For the 11th consecutive year, the Alzheimer Verona association - part of Federazione Alzheimer Italia (FAI) since 1998 - organised a “relief holiday” for people with dementia and their families from 26 June to 4 July.

In Castelletto di Brenzone (pictured) near Verona, on the slopes of Monte Baldo, at the “Garda Family House” professionals and volunteers gave a warm welcome to families and people living with dementia, with the aim of give them some relief from and support with their everyday problems.

The programme for the guests included a “Laboratory for Memory”: every day, in the morning and in the afternoon, participants were offered recreational activities designed to create mutual understanding, to encourage socialisation and to stimulate their remaining abilities.

The meetings were managed by a professional, assisted by two expert volunteers, who have repeatedly proposed and conducted part of the activities. In particular, exercises were suggested to evoke past memories, group games and artistic work, using Lake Garda as a focus point.

During activity time, family members had the chance to carve out some space for themselves and also to participate in two self-help meetings mediated by a psychologist, to meet other people and confront issues related to the disease, in a climate of listening and understanding. A volunteer neurologist was also made available to family members in need of medical advice.

This experience proved to be an effective intervention to influence the lives of families living with a person with dementia in a positive way, and could be taken as an example of good practice, said FAI.

It is important that such initiatives are widespread and FAI is working to make the project more widely available for those interested.
Alzheimer’s Association, located in Krapkowice. The organisation of the meeting was supported by local government, the town council, the church, other local institutions and local businesses, which provided some of the funding. It was also a chance for the Opole Association to celebrate its 18th anniversary. The event received quite a lot of media attention locally, in the press and on radio and television.

The aim of the meeting was to discuss problems encountered by Alzheimer’s associations around the country and to agree on common goals for the coming months. One of the main points of the programme was the presentation of the results of the two studies all member organisations had been carrying out in their local communities.

There were two studies: one concerning the level of awareness of Alzheimer’s disease among the general population, and the other concerning the costs of care for family carers. It turned out, on the basis of 1,000 questionnaires in which 10 multiple choice questions about dementia, care and the number of people affected, that awareness was generally quite high, irrespective of age or experience. Less than half of the respondents were aware of the estimated number of people living with dementia in Poland, however, so we agreed that the data should be publicised more frequently, especially among politicians and decision-makers. Far fewer surveys on the costs of care came back, likely due to the more complicated structure and the length of the survey questionnaire. It was decided the questionnaire would be used again in a simplified version. The results of the studies are planned during World Alzheimer’s Week, and at any other opportunities that might present themselves with the government and media.

This year, the annual meeting included several workshops in which we all participated actively: one day was devoted to ways of strengthening our organisations, so we were engaged in listening to a psychologist talking about communication barriers and how to cope with them not only in the work of organisations but in personal life, especially when living with dementia.

We also had some time (perhaps not as much as we would have liked) to have fun and enjoy the sunny weather, as well doing some sightseeing as the meeting was held in a 19th century castle at Moszna (pictured) surrounded by a beautiful park. On the second evening there was also a dinner to celebrate the host organisation’s 18th anniversary.

Overall, the meeting was a real organisational success. It was an opportunity to talk about our work, about problems we face and to learn about good practices to follow. We have learned that two newly-set-up organisations would like to join the Alliance, but agreed that the applicants should only be accepted after they have proven they meet the criteria for membership: Their work needs to focus on awareness-raising in their local community, on the education of carers and they should also run a support group. Some applicants, which concentrate on running nursing homes, have little time or energy to focus on what we believe is the most essential.

There are currently 25 organisations in the Alliance, mostly from the bigger towns in Poland, but this number is growing and we hope they will all make our Alliance stronger and more professional.

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### Policy watch

**5-6 July: WHO launches process for ambitious Global Dementia Observatory**

The WHO convened a two day meeting with representatives of over 30 Member States, researchers, representatives of Alzheimer associations. Kate Swaffer from Australia and James McKillop from Scotland, UK represented the views of people with dementia at the meeting.

The aim of the meeting was to discuss the conceptual framework of the Global Dementia Observatory which will collect data from countries and compare their preparedness and responses to the dementia challenge.

The suggested data points and indicators which were developed by WHO and trialled with a group of pilot countries were presented by the team around Shekhar Saxena and Tarun Dua from the Noncommunicables Diseases and Mental Health Division of WHO. Indicators will cover different domains such as dementia burden and prevalence, dementia policies and strategies, resources for people with dementia and their carers, as well as government support for research and innovation.

At the end of a very lively discussion and constructive contributions, Shekhar Saxena updated the participants about the WHO plan to develop a draft global action plan on dementia which would be submitted to the World Health Assembly in 2017 for adoption.

Jean Georges represented Alzheimer Europe at the meeting.

**8 July: Flemish government releases new Dementia Strategy**

On 8 July, Flanders launched its updated dementia strategy. Prevention, a nuanced perception and quality care and support are the spearheads of this updated dementia plan. The cornerstones of the first Flemish plan (2010-2014) are still very much central.

“Human dignity and quality of life for people with dementia and those around them take centre stage here”, said Jo Vandeurzen, Flemish Minister for Welfare, Public Health and Family. “The Government of Flanders takes note of the plan with which the Flemish authorities want to continue to work towards a dementia-friendly Flanders”.

The Flemish government wants to work together with all stakeholders in the field to reach the goal of a more dementia-friendly society. Some of the priorities laid out in the plan are:
• Policy to resolutely concentrate on prevention and the promotion of a healthy life style - “What’s good for the heart is good for the brain”.

• A nuanced perception of dementia remains important: Continuation of the campaign “Forget Dementia. Remember the Person”. The concept of a “dementia-friendly municipality” will be further promoted also, within the framework of the age-friendly municipalities. By means of a widget, municipalities will be able to make their efforts in the field of dementia more visible.

• Quality care and support. “Proper care and support throughout the stages of dementia is a prerequisite for the quality of life of people with dementia and their loved ones” said Minister Vandeurzen.

• The Flemish authorities will develop criteria to help care providers in offering customised, quality care to people with dementia and their entourage.

• Early detection and proper care at each stage in the process of dementia are major components of the plan. The focus on different and adjusted living arrangements, the growth paths in care and support and the supporting informal care and end-of-life care are continued. With the Flemish Pharmacists Network, an action is set up to give community pharmacists a role in helping to detect difficulties experienced by informal caregivers at an early stage and signposting them to support services.

• Increasing the coverage of culture-sensitive care for people with dementia and to reach immigrant groups more effectively.

• Specific attention is also devoted to people with young onset dementia.

• Flanders will also further support scientific research into dementia and dementia care.

“Quality care for people with dementia, informal caregivers and care professionals requires an integrated policy vision”, said Jurn Verschraegen, Director of the Flemish Expert Centre on Dementia Care. “With this updated Dementia Plan, Flanders joins the European movement towards a dementia-friendly society. From prevention to end of life care, from a nuanced perception to particular focus on people with young onset dementia. This Dementia Plan responds to today’s and tomorrow’s challenges. Moreover, it is fully consistent with the informal care plan which was presented to the Government of Flanders last week. The centres of expertise on dementia are fully committed to this plan!”

The Flemish Expert Centre on Dementia Care will monitor this plan as a partner organisation of the Flemish Authorities and there will also be collaboration with the Alzheimer Association of Flanders.

The new plan can be read here in English and here in Flemish.

For more information see the Flemish Expert Centre on Dementia Care website: www.dementie.be

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8 July: UN Human Rights Council adopts resolution on mental health and human rights

The United Nations Human Rights Council (UNHRC) adopted a resolution on mental health and human rights during its 32nd session, which ran from 13 June to 1 July and on 8 July.

It raises concerns that persons with mental health conditions or psychosocial disabilities (this includes people living with dementia), most particularly those using mental health services, may be subject to “widespread discrimination, stigma, prejudice, violence, social exclusion and segregation, unlawful or arbitrary institutionalization, overmedicalization and treatment practices that fail to respect their autonomy, will and preferences”.

Such practices may “constitute or lead to violations and abuses of human rights and fundamental freedoms”, it stresses.

It emphasises the need for greater commitment to address these challenges and calls for a report on mental health and human rights to be submitted to the 34th Human Rights Council Session. The report will be prepared by Office of the United Nations High Commissioner for Human Rights.

You can read the UNHRC resolution here.

28 July: World Dementia Council meets in Toronto, sets ambitious action plan to tackle dementia

At the first meeting of the independent World Dementia Council (WDC) in Toronto on 28 July, an ambitious action plan was agreed by members. The Council was unanimous in its decision to prioritise work in five key areas:

• Fostering a culture of open science and collaborative global research, including the use of global big data approaches.

• Increasing the speed and reliability of delivering innovative medicines through efficient and effective integrated drug development.

• Advancing levels of innovative and global public and private finance.

• Ensuring the quality of life and delivery of quality care for people living with dementia and the provision of relevant and appropriate support to their carers.

• Reducing the risk of dementia through lifestyle and other approaches.

The WDC plans to “act decisively to influence all stakeholders including heads of state and health, care and finance ministries, business, industry and the research community to step up their response as the prevalence and cost of dementia continues to soar.”


29 July: Spain launches its first national strategy for neurodegenerative diseases

On 29 July, the Spanish Ministry of Health, Social Services and Equality officially launched the country’s first National Health
**25 August: Malta continues to campaign for a WHO action plan on dementia**

In recent months, Malta has continued to campaign for a World Health Organization (WHO) action plan on dementia through its recent participation at the side-event on Alzheimer’s and other related diseases during the 69th World Health Assembly (WHA 69) held in Geneva on 23 May. Indeed, Malta co-sponsored the event, sat on the Ministerial Panel and was represented by the Junior Minister for Rights of Persons with Disability and Active Ageing Hon. Justyne Caruana.

During her intervention, Hon. Caruana mentioned that in recent years, Malta has committed itself to making dementia a top priority through a number of initiatives, including the launch of the national dementia strategy, together with its dementia-friendly version, in April 2015. On this note, she also invited representatives of WHO and other countries to continue calling for dementia to be a priority and to be firmly on the agendas of relevant high level forums and meetings of national and international leaders and bodies.

Hon. Caruana also welcomed the Call for Action adopted by the First Ministerial Conference on Global Action against Dementia held in Geneva in March 2015, as well as the development of the Global Dementia Observatory. Such actions need to be aligned with other initiatives such as the World Dementia Council, the Organization for Economic Co-operation and Development (OECD) work on care indicators and the European Joint Action on Dementia with its focus on diagnosis and post-diagnostic support, crisis management and care coordination, quality of residential care and dementia-friendly communities.

To keep up with the Malta Dementia Society and its activities, see:

https://sites.google.com/site/maltadementiasociety/

**25 August: ADI and DAI call for action to protect rights of people with dementia under UN CRPD**

Alzheimer Europe (AE) would like to call for action to protect the rights of people with dementia using the UN Convention for the Rights of Persons with Disabilities (UN CRPD). Our lunch debate at the European Parliament on 28 June in Brussels focused on using the UN CRPD to support the rights of people living with dementia.

On 25 August, in Geneva, at a side session to the 16th Session of the CRPD Committee and the 10th Anniversary of the Convention, Alzheimer’s Disease International (ADI) and the Dementia Alliance International (DAI) also called for action to protect the rights of people with dementia under the UN CRPD.

Both Professor Peter Mittler (pictured, speaking), member and Human Rights Adviser to DAI, and Glenn Rees CEO of ADI spoke at the event. Their full speeches can be read here: Glenn Rees; Peter Mittler.

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System strategy for Neurodegenerative Diseases (NDs).

The main lines of action in the new Strategy, which was adopted on 13 April this year, are to improve diagnosis, give personal attention to patients and establish programs that facilitate respite for those who care for those affected by NDs.

Spanish Alzheimer association CEAF A, has welcomed the strategy and looks forward to further developments specific to dementia.

The strategy is available here (in Spanish):

http://www.ceafa.es/themed/ceafa/files/doc/189/133/estrategia_enfermedades_neurodegenerativas_del_sns.pdf...

**16 August: New “dementia atlas” reveals disparity of care in England**

People with dementia are being let down by local services across England, according to new government data that critics say has revealed a “postcode lottery” in care.

An interactive “dementia atlas”, published online on 16 August by the Department of Health, shows that standards of care vary widely in different areas, with services failing to reach almost half of patients for check-ups even once a year in one area.

The information exposes wide differentials in aspects of dementia care. For example, while in some parts of England, 85.8% dementia patients have their care looked at every year, in others just 49.3% receive the same service. Those checks are seen as important because, as dementia is a long-term and degenerative condition, “reviewing those with a diagnosis at least annually will ensure that the needs of people with dementia and their carers are discussed and appropriate care plans can be implemented”, the atlas says.

There is also a more than three-fold variation in the number of those with dementia being admitted to hospital as an emergency. That ranges from 1,840 for every 100,000 people aged 65+ to as many as 6,046 for every 100,000.

“Making more user-friendly information on dementia accessible online is a step in the right direction,” said George McNamara, head of policy and public affairs at Alzheimer’s Society. “People can now see which parts of the country are leading the way with developing dementia-friendly communities, and how many dementia friends there are in each area.”

However, the atlas should be expanded to become even more useful by including the experiences people with dementia have had of the health and care systems, in order to enable NHS bosses to make improvements in areas which are lagging behind, Mr McNamara added.

The health secretary is also seeking to improve NHS early diagnosis of dementia by ensuring that people aged between 40 and 64 are asked about it when they have an NHS health check. The new component of the health check will now be trialled through more than 250 GP surgeries in four places: Birmingham, Bury, Manchester and Southampton.

https://shapesatlas.net/dementia/#6/52.945/
The side event follows the formal adoption of a Human Rights Based Approach to dementia advocacy by the 85 country member Council of ADI following DAI’s lead, at the 31st International Conference of Alzheimer’s Disease International in April.

The UN CRPD has been ratified by 166 countries, including all AE member association countries, except for Ireland. UN CRPD Principles and Articles should be clearly reflected in all new dementia policies but this is not always the case.

http://www.alz.co.uk/media/160825

Science – behind the headlines

LMTX drug hailed as “revolutionary” by some, others as a failure - UK Alzheimer’s Society comments

Recent media headlines following the presentation of results from a phase III clinical trial of LMTX - TauRx’s second-generation tau aggregation inhibitor (TAI) - during this year’s Alzheimer’s Association International Conference (AAIC) were rather confusing. Some hailed the drug as “unprecedented” and “revolutionary”, able to slow the progression of Alzheimer’s disease (AD) “by 80 per cent” and “trigger extraordinary recoveries”, while others said it was a “failure”.

To help clear up the reality of what the study presented on 27 July in Toronto actually found, we would like to share this much more balanced look “behind the headlines”, published by our friends at the Alzheimer’s Society (UK):

Research presented today has shown that the drug LMTX may slow down brain shrinkage in some people with mild to moderate Alzheimer’s disease by up to a third.

This research was shared at the Alzheimer’s Association International Conference 2016. It also improved cognition and the ability of some people with Alzheimer’s to carry out their daily activities when taken over a 15-month period.

Overall, the phase III clinical trial of LMTX led by the company TauRX was negative - the drug failed to meet its goal of improving cognition, including attention, memory and language, and ability to carry out everyday tasks in 891 people with Alzheimer’s disease. However, 85% of the participants were already taking existing treatments for the symptoms of Alzheimer’s disease and when these participants were excluded, the researchers reported improvements in cognition, functional abilities and brain volume for those taking LMTX on its own, compared to those taking a placebo.

In the 15% of participants who took LMTX without any other Alzheimer’s medications (82 people in total), there was a reduction in brain shrinkage of 38% for those taking a lower dose, and 33% for the higher dose group. Scores on tests of cognition and performance on daily activities were significantly improved after 15 months in those taking both doses of LMTX relative to placebo.

LMTX stops tau protein from forming tangles in the brain, which cause damage to cells and is one of the hallmarks of Alzheimer’s disease. These are the first phase III trial results to be presented for a drug that targets tau tangles - most other treatments in development for Alzheimer’s disease target amyloid plaques.

Dr Doug Brown, Director of Research and Development at Alzheimer’s Society, said:

“While it’s disappointing to see another large clinical trial for Alzheimer’s disease fail to meet its goal, there appears to have been some striking improvements for the subset of people who took the drug on its own. There are still lots of questions to answer before we know how promising this new treatment could be – why doesn’t it appear to work in those who are already taking other medications for Alzheimer’s disease?”

“Only 82 people in the trial took LMTX on its own, so further trials will be needed before we will know whether it is the first drug to slow down the brain damage that occurs in Alzheimer’s disease.

“Afthe years of failure, we are now starting to see glimmers of hope for dementia drug trials. The headway being made through research is starting to give a real sense of the possibility that we could one day stop dementia in its tracks.”


Science watch

13 July: Changes linked to AD could already be seen in children with APOE4 gene, study finds

The APOE4 gene associated with Alzheimer’s disease (AD) may show its effects on the brain and thinking skills as early as childhood, a study published by the medical journal of the American Academy of Neurology has found. The study, involving 1,187 children aged between 3 and 20 years old, was published on 13 July.

Participating children underwent genetic tests and brain scans and tests of thinking and memory skills. They had no brain disorders or other problems that affecting brain development.

Findings revealed that children with the higher-risk APOE-4 gene had differences in their brain development on
average compared to children with other forms of the APOE gene. The differences were seen in areas of the brain that are often affected by AD.

The study was supported by the National Institutes of Health, including the National Institute on Drug Abuse and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

https://www.aan.com/PressRoom/Home/PressRelease/1481

14 July: Dementia rates lower in Luxembourg than rest of Europe

The Luxembourg Health Institute has completed an analysis, studying 438 people aged 64 or over as part of its MemoVie project. Findings show that Luxembourg’s older residents are less likely than their peers across Europe to have dementia and other memory problems.

It found that 3.8% of the group studied had dementia in Luxembourg, as compared with the European average of 6.4%, 7.1% in Latin America and 8% in Canada.

Meanwhile, only a quarter of the Luxembourg group reported memory problems. Thus far, the only study to be conducted in any other country about memory problems was in Australia where it affected a third of this age group.

“Among these people (Luxembourg’s elderly residents) there is probably an increased cognitive reserve, a formidable resource for the brain due to cognitively stimulating activity throughout a person’s life,” project manager Magali Perquin explained.

She added that it had been proven in the past that people with a high level of education or who frequently used several languages since a young age develop such a cognitive reserve.

“This enables them to be more resistant to the neurodegenerative phenomenon that is dementia” she said.

1 August: New mechanism discovered for Alzheimer's disease risk gene

In a study published in the August 2016 edition of the Journal of the American Chemical Society (JACS), scientists at The Salk Institute for Biological Studies, California, US say they have discovered why people with the apolipoprotein E4 (ApoE4) gene are more susceptible to Alzheimer's dementia.

For decades, scientists have known that people with two copies of the ApoE4 gene are more likely to have Alzheimer’s dementia than the rest of the population. The Salk Institute researchers identified a connection between ApoE4 and protein build-up associated with Alzheimer's dementia that provides a possible biochemical explanation for this phenomenon.

Apolipoprotein E comes in three versions, or variants, called ApoE2, ApoE3 and ApoE4. All the ApoE proteins have the same normal function: carrying fats, cholesterols and vitamins throughout the body, including into the brain. While ApoE2 is protective and ApoE3 appears to have no effect, a mutation in ApoE4 is a well-established genetic risk factor for late-onset Alzheimer’s dementia. Previous reports have suggested that ApoE4 may affect how the brain clears out beta-amyloid, but what was happening at the molecular level was unclear.

"ApoE4 is the most predictive genetic change for late onset Alzheimer’s, but no one has really understood what's going on at the molecular level," said Professor Alan Saghatelian of the Salk Institute. Scientists had previously uncovered hints, however, that ApoE4 might degrade differently than the other variants, but the protein that carried out this breakdown of ApoE4 was unknown.

To find the protein responsible for degrading ApoE4, Prof. Saghatelian and lead study author research associate Dr Qian Chu screened tissues and were able to home in on one enzyme: high-temperature requirement serine peptidase A1 (HtrA1).

When they compared how HtrA1 degraded ApoE4 with ApoE3, they found that the enzyme processed more ApoE4 than ApoE3, breaking ApoE4 down into smaller, less stable fragments. The researchers confirmed the observation in both isolated proteins and human cells. The finding suggests that people with ApoE4 could have less ApoE overall in their brain cells and more of the breakdown products of the protein.

These results need be tested and confirmed in animal studies before researchers can be sure that HtrA1 is the link between ApoE4 and Alzheimer’s dementia in humans.

http://pubs.acs.org/doi/abs/10.1021/jacs.6b03463

ALZFORUM

On 28 July, AlzForum—a news website and information resource dedicated to helping researchers accelerate discovery and advance development of diagnostics and treatments for Alzheimer’s disease (AD) and related disorders—published its “Evolution of Alzheimer’s Disease Research” timeline, showing AD research landmarks since the disease was first described by Alois Alzheimer at a meeting in Tübingen, Germany in 1907.

The timeline can be viewed and downloaded in PDF format for free, here:

http://www.alzforum.org/sites/default/files/Alzforum_timeline_poster_36x48.pdf
18 August: Alzheimer’s Association announces clinical trial competition

The Alzheimer’s Association has announced a new USD 7 million (EUR 6.29 million) investment in clinical trials targeting brain inflammation, but with a twist.

Four cutting-edge studies will receive USD 1 million (EUR 890,000) each over 2 years, but the remainder will go to the clinical trial that demonstrates the most promise for treating Alzheimer’s disease (AD).

The funded projects are as follows:

- A phase 2 clinical trial of sargramostim, a drug approved for reducing and preventing infection in patients who have received chemotherapy, to determine whether it is safe and can help slow or prevent progression of AD.
- A phase 2 clinical trial to determine whether a cannabis-based liquid medication previously tested for alleviating cancer-related pain reduces brain inflammation and slows progression to AD in people with mild cognitive impairment (MCI).
- A phase 2 study to test whether a drug shown to be safe in sickle cell disease and asthma can reduce brain inflammation, alter the rate of brain amyloid accumulation, and improve memory in people with early AD or MCI.
- A phase 1 clinical trial to examine the safety and efficacy in reducing brain inflammation of a novel therapy using stem cells from healthy donors delivered into the bloodstream of people with mild AD.


22 August: University of Oxford launches world’s most in-depth study to detect early signs of AD

A new UK study aims to improve the success rate of clinical trials for treatments in Alzheimer’s disease (AD). The Deep and Frequent Phenotyping study, led by Professor Simon Lovestone (pictured), Professor of Translational Neuroscience at the University of Oxford and funded by the National Institute of Health Research and the Medical Research Council (MRC), will see the most thorough series of tests to detect AD ever carried out.

The landmark GBP 6.9 million (EUR 8.2 million) research project was launched at eight UK universities on 22 August. It also has involvement from the Alzheimer’s Society (UK) and is receiving support from a coalition of biopharma companies.

Together, the researchers will perform up to 50 tests on 250 volunteers from Dementias Platform UK cohorts, including brand new tests to detect dementia. The tests will include wearable devices to give researchers detailed information on people’s movement and gait, as well as sophisticated retinal imaging that will look at subtle changes affecting central and peripheral vision.

These potential new biomarkers will be used alone, as well as alongside tests such as brain imaging and assessment of memory and other cognitive functions. They will allow the researchers to recognise the early stages of the disease and those who may be suitable for clinical trials.

Prof. Lovestone said:

“We know that Alzheimer’s disease starts long before it is noticed by those with the disease or their doctor. Previous studies have shown changes to the brain as early as 10 to 20 years before symptoms arise. If we can identify the biomarkers present in this very early stage, we have the chance of treating the disease earlier, which is vital if we are to prevent damage to people’s memory and thinking. We’re indebted to those volunteers taking part in the study whose time and effort will make a real difference to our ability to diagnosis and treat this disease.”


AAIC watch

Some highlights emerging from this year’s Alzheimer’s Association International Conference (AAIC), held from 24 to 28 July 2016 in Toronto, Canada:

24 July: Behavioural changes may be the earliest signs of dementia

A new Canadian research study shows that persistent changes that alter the normal behaviour of an older person may be the earliest signs of dementia onset. The results are based on a new condition named MBI or “mild behavioural impairment.” According to the researchers, MBI defines a syndrome of later-life acquired neuropsychiatric symptoms (NPS) that are sustained for at least six months. These symptoms centre on five domains: apathy/drive/motivation; mood/affect/anxiety; impulse control/agitation/reward; social appropriateness; thoughts/perception.

Based on this, the researchers created a “checklist” that was distributed to families with older people in the Calgary area. The results showed the presence of neuropsychiatric symptoms that are widely believed to increase the risk of developing dementia.

Dr Zahinoor Ismail, Clinical Associate Professor at the University of Calgary and the principal author of the study, presented the findings at the recent AAIC conference. He said that “out-of-character behaviour can be the first sign of something going wrong in the brain” and that sustained behavioural variations “may be the earliest symptoms of dementia that we didn’t pay attention to before.” He concluded that MBI requires further testing.

www.alz.org/aaic/releases_2016/sun_445_ET.asp
24 July: Complex work may reduce negative effects of poor diet and cerebrovascular disease on cognition

People who have had formal education and complex jobs have a better chance of fighting off the effects of Alzheimer’s disease (AD), because of the complex nature of their jobs, said research presented at AAIC 2016 on 24 July. Two studies – one by scientists at the Alzheimer’s Disease Research Centre in Wisconsin and the other by a team at Baycrest Health Sciences in Toronto – found that people whose jobs combined complex thinking with social engagement – such as social workers, doctors, lawyers, teachers and engineers – were better protected against the onset of Alzheimer’s dementia and the effects of poor diet on cognition, compared to those in manual jobs.

Both pieces of research examined the impact of complex thinking on the onset of Alzheimer’s dementia.

In the first study, researchers examined white matter hyperintensities (WMHs) – white spots that appear on brain scans and are associated with AD – in 284 late-middle-aged participants considered at risk.

They found that people who worked primarily with others, as opposed to with “things or data”, were less likely to be affected by brain damage indicated by WMHs.

While lawyers, social workers, teachers and doctors were best protected, those who enjoyed the least protection included shelf-stackers, machine operators and labourers.

Elizabeth Boots, a researcher on the project, said: “These findings indicate that participants with higher occupational complexity are able to withstand pathology associated with Alzheimer’s and cerebrovascular disease and perform at a similar cognitive level as their peers.

“This association is primarily driven by work with people, rather than data or things. These analyses underscore the importance of social engagement in the work setting for building resilience to Alzheimer’s disease.”

The second study, carried out by Baycrest Health Sciences, in Toronto, examined the diet of 351 older adults.

Researchers found that those who had a traditional Western diet of red and processed meat, white bread, potatoes and sweets were more likely to experience cognitive decline. However, those who adhered to such a diet but who had a mentally stimulating lifestyle enjoyed some protection from such decline.

Dr Matthew Parrott, a member of the research team, said: “Our results show the role higher educational attainment, mentally stimulating work and social engagement can play in protecting your brain from cognitive decline, countering some negative effects of an unhealthy diet...This adds to the growing body of evidence showing how various lifestyle factors may combine to increase or protect against vulnerability to Alzheimer’s disease.”

http://www.multivu.com/players/English/7865351-aaic-2016-alzheimers-
treatment/docs/press-release-67547975.pdf

25 July: Treating people with Alzheimer’s disease may increase survival and reduce cost of care

A new study presented at the AAIC 2016 conference suggested that treating people with Alzheimer’s disease may increase survival and reduce cost, even though the treatment does not change the underlying course of the disease.

The researchers followed 6,553 people with Alzheimer’s disease for two years, placing them in groups based on whether they were prescribed an existing Alzheimer’s disease drug after their diagnosis.

In the first month following diagnosis, average healthcare costs were more than tripled for all participants in the study. However, those receiving a treatment had slightly lower costs compared with those who did not. The people who received treatment had an increase in pharmacy costs during the follow-up period, but their total cost over two years was less than for individuals who did not take drugs. Furthermore, the untreated people had a death rate that was almost twice as high as the people who received treatment and also had more co-morbidities.

“The arguments for early treatment are myriad, but this study shows greater survival and less all-cause healthcare costs among those receiving treatment for dementia,” said Christopher M. Black, MPH, from Merck Research Laboratories. “These results indicate that choosing not to treat, or even a delay in starting treatment, may lead to less favorable results. Early diagnosis and time to treatment should be a priority for policy makers, physicians, and the public.”

Dr Maria C. Carrillo, Chief Science Officer of the US Alzheimer’s Association, said: “The new results support that early Alzheimer’s treatment - even with today’s first-generation therapies - has significant potential to benefit the person with the disease and the economy. Today, Alzheimer’s is incurable and progressive, and some assume that treating dementia is an unjustified cost drain on our healthcare system, but this study presents compelling arguments for prescribing the standard of care.”

www.multivu.com/players/English/7865351-aaic-2016-alzheimers-
treatment/docs/press-release-67547975.pdf

26 July: Smell and eye tests are getting closer to playing a role in detection of memory decline and dementia

Results from four studies investigating the possible use of odour tests and eye tests in diagnosing cognitive problems and Alzheimer’s disease (AD) were released on 26 July at AAIC 2016 in Toronto. Currently, it is only possible to diagnose AD using PET scans or Lumbar punctures, which are expensive, invasive and only able to detect the disease later in its development, the researchers said in their news release. They hope these new studies will lead to cheaper alternatives.

Two of the presented studies, led by Dr William Kreis, assistant neurology professor and physician at Columbia University Medical Center, focused on odour identification and its relationship to cognitive decline. The team used the University of Pennsylvania’s Smell Identification Test
A group of Australian researchers has reported positive initial results of a study aimed at decreasing the use of antipsychotic drugs among people with dementia in nursing homes.

The “Halting Antipsychotic use in Long Term Care” (HALT) project was led by Prof. Henry Brodaty from the Centre for Healthy Brain Ageing at the University of New South Wales in Australia. He said that the team successfully eliminated regular antipsychotic medication from the treatment plan in 75% of 140 study participants after six months.

Prof. Brodaty, who presented the results at the AAIC 2016 conference in Toronto, added that these early findings point to the inappropriate use of antipsychotics: “There’s no point of de-prescribing if behaviours of concern re-emerge and in fact we found no difference in the level of behaviours after de-prescribing the anti-psychotics.”

Antipsychotic drugs are typically used to relieve anxiety, depression, psychosis, agitation and aggression in people with dementia. They are also known to cause sedation and depression, psychosis, delusions, hallucinations and cognitive decline in patients. Ultimately, they say, they discovered that lower UPSIT scores were associated with early stages of AD and dementia in participants.

One study - conducted by a research team from the Institute of Ophthalmology at University College London (UCL), the University of Oxford and the Topcon Advanced Biomedical Imaging Laboratory in New Jersey, US - analysed the results of a physical examination, a cognitive test, and a questionnaire in 33,068 participants. The study concluded that a thinner retinal nerve fibre layer (RNFL) - an extension of fibres from the optic nerve that sends visual information from the retina to the brain - was associated with less cognitive function. RNFL thickness can be detected using simple medical imaging technology.

A second study - conducted by researchers from the University of Waterloo, the University of Rochester, the University of British Columbia, Massachusetts General Hospital, Vivocore Inc. and Intervivo Solutions - analysed the eyes of 20 individuals, post-mortem, who had been diagnosed with AD. The researchers found amyloid beta deposits in the retina, using non-invasive polarised light testing.

26 July: New study successfully reduces use of antipsychotic drugs in people with AD

Researchers from the Mayo Clinic in Jacksonville, Florida, US examined the autopsy and clinical records of 1,606 cases in the State of Florida brain bank in which Alzheimer’s disease (AD) was confirmed post mortem. Men were more likely to have experienced atypical symptoms such as difficulty with speech and movement and the area of the brain involved in memory was more likely to be spared in men, as compared with women. The age of onset for Alzheimer’s dementia also differed between the sexes, with a spike in cases in men in their 60s, compared with more female cases starting in their 70s and beyond.

A second study reported at AAIC 2016 found inconsistencies between the clinical diagnosis a person receives in life and the pathological changes observed in the brain at autopsy. Looking at the clinical and autopsy records from 1,073 people from the National Alzheimer’s Coordinating Center database, researchers reported a correct diagnosis of AD had been made 78% of the time.

In almost 11% of cases there were AD changes in the brain that had not been correctly diagnosed in life. Conversely, almost 11% were ‘false positives’, meaning they received a diagnosis of AD in life but this was not backed-up by AD brain pathology at autopsy. Of the false positives, 30% had brain changes consistent with vascular dementia, 12% with Lewy body dementia, 9% with frontotemporal dementia and 15% with mixed dementia.

26 July: Dementia is harder to diagnose in men

Men with dementia may be more likely to be misdiagnosed, which could explain why the condition appears to be more prevalent in women says new research, presented on 26 July at AAIC 2016 in Toronto.

In almost 11% of cases there were AD changes in the brain that had not been correctly diagnosed in life. Conversely, almost 11% were ‘false positives’, meaning they received a diagnosis of AD in life but this was not backed-up by AD brain pathology at autopsy. Of the false positives, 30% had brain changes consistent with vascular dementia, 12% with Lewy body dementia, 9% with frontotemporal dementia and 15% with mixed dementia.

https://www.alz.org/aaic/releases_2016/tues_245_ET.asp

27 July: Six-year vascular care trial unable to show impact on prevention

A six-year, nurse-led vascular care intervention presented on 27 July at AAIC 2016 did not lead to a reduction of all-cause dementia in a cognitively healthy population. However, fewer cases of non-Alzheimer’s dementia were observed in the intervention group compared to the control group. In addition, the researchers found fewer cases of incident dementia in a subgroup of people in the study with untreated hypertension who were adherent to the intervention.

"The preDIVA Study was negative on the primary outcomes. However, the other study observations suggest once again the benefits – for the head and the heart – of assessing, treating and managing heart health risk factors as we age,” said Dr Maria Carrillo, Chief Science Officer at the Alzheimer’s Association.

https://www.alz.org/aaic/releases_2016/preDIVA.asp
Dementia in society

15 August: Actor Gene Wilder dies aged 83, with Alzheimer’s disease

Much-loved and respected comic actor Gene Wilder, who established himself with performances in Mel Brooks films, an eccentric star turn in the family classic “Willy Wonka and the Chocolate Factory” and in the box-office smash “Stir Crazy” with Richard Pryor, died early on the morning of 15 August at his home in Stamford, Connecticut, US at the age of 83.

His nephew filmmaker Jordan Walker-Pearlman confirmed his death in a statement, saying the cause was complications of Alzheimer’s disease.

16 August: Carey Mulligan aims to change global attitudes towards dementia

Oscar-nominated British actress Carey Mulligan was appointed as the first ever Global Dementia Friends Ambassador on 16 August, by the Alzheimer’s Society (UK) and UK Health Secretary Jeremy Hunt.

Best known for her roles on the silver screen in Never Let Me Go (2010), Drive (2011) and the 2013 adaptation of The Great Gatsby (pictured), Ms Mulligan will use her new role to bring international attention to the benefits of making communities more dementia friendly.


29 August: Prof. Vernooij-Dassen awarded International Psychogeriatric Association award

On 29 August it was announced that Professor Myrra Vernooij-Dassen has been awarded the International Psychogeriatric Association (IPA) Service to the field of Psychogeriatrics award for demonstrating “inspiration, leadership, vision, ethics, innovation, organizational development and motivation in areas of psychogeriatrics”.

“I consider the award not as a personal prize, but a prize for collaborative achievements. Participation in high-profile EU projects…very much contributes to the research profile”, said Prof. Vernooij-Dassen. She is principal investigator at the Nijmegen Centre for Evidence Based Practice at Radboud University, the Netherlands and director of the Nijmegen Alzheimer Centre and is a member of Alzheimer Europe’s Expert Advisory Panel.

The award will be presented during the opening ceremony of the IPA’s 2016 International Congress in San Francisco on 6 September.

You can read more about Prof. Vernooij-Dassen here:
http://alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Expert-Advisory-Panel/Members/Myrra-Vernooij-Dassen

Living with dementia

17 June: EWGPWD Vice-Chair discusses dementia and sensory challenges on Australian TV

During a recent conference in Sydney, Australia Agnes Houston MBE, Vice Chair of the European Working Group of People with Dementia (EWGPWD) was interviewed by the Aged Care Channel Newsroom programme.

During the interview, Ms Houston described some of the sensory challenges she and many others living with dementia experience on a regular basis. She calls these her “daily scary challenges”. One of the main examples she gave is her struggle with Hyperacusis – an increased sensitivity to certain frequency and volume ranges of sound, making everyday sounds seem unpleasantly or painfully loud. She also touched on other challenges, such as visual, auditory and olfactory hallucinations.

Sensory challenges are not well understood or even on the radar of many people, who often associate dementia with memory problems alone and Ms Houston feels very strongly that life for people with dementia who experience these issues would be better were there more awareness and understanding.

In 2015, Ms Houston, with the help of her daughter Donna and funding from the Life Changes Trust, researched and wrote a booklet called “Dementia and Sensory Challenges”.

In September 2015, she and her daughter presented a poster about the booklet project at the 25th Alzheimer Europe conference in Slovenia:

“I was overwhelmed by the positive response it received and so proud that the poster was voted as the best in its category” she wrote, thanking the 25 people with dementia and sensory challenges influenced the content”.

“This booklet does not have all the answers, instead it shows how even with little or no help the people with dementia found their own answers and just got on with life the best they could. I hope this booklet will inspire professionals in the sensory world to use their skills to assist us to remain connected to family and friends, and remain safe in our communities. And to all people with dementia like those of us featured in this booklet: it is possible to have a good life, yes, even with dementia and sensory challenges!”


The interview with Aged Care Channel Newsroom can be viewed here:
http://www.acctv.co/au/newsroom/daily-scary-challenges-agnes-houston/
2 August: James McKillop publishes booklet on driving with dementia

Dr James McKillop has recently published a booklet on “Driving and Dementia - My Experiences”. He has kindly consented to us reproducing the opening lines of the booklet for this newsletter:

“I am a person who lives with dementia and I want to share my experience of giving up driving because I think it will help other people with dementia who have to do the same.

Once you have passed your driving test, the law assumes you are able to drive unless you are disqualified for some traffic offences, or are judged no longer able to drive safely, due to certain illnesses, dementia being one.

(Note that ‘driving’ includes the use of motorbikes and scooters.)

My dementia did cause me to have driving problems, among other difficulties, such as attempting to drive down the wrong side of a dual carriageway several times. I was positioned to turn right, indicating, ready to proceed, and it was only due to oncoming drivers flashing their headlights at me, that I was prevented from making that potentially fatal manoeuvre. Had they not come along at that time, I would have been off down the wrong side. I couldn’t understand where I had gone wrong.

When the average person hits problems, they devise ways to get round them. I was no different. I was also having trouble at roundabouts. When I approached and read the directions, I would forget in an instant where I had to go. I used to circle several times, feeling more and more dizzy and still take the wrong exit in panic. I began to take the first left and, if it was not the correct road, I would do a U turn and return to the roundabout, then take the next left and repeat the process until I reached the exit I wanted. It was a laborious, but safe, way of getting through roundabouts. This worked well until one day I turned left, and came to another roundabout. After that, I steered clear of strange roundabouts, and stuck to local routes.

I also started stalling the car, a thing I had never done since my early "L" plate days. My clutch control was haywire. I blamed the clutch and had it replaced. But I still stalled the car and grumbled that the garage had done a poor job. I hit kerbs (curbs) when turning corners, and I just couldn’t fathom out what on earth was going on. Having been a keen cyclist, I knew how to turn a corner and I never hit a corner when I held a provisional licence. I did report my driving problems to my doctor, who advised me, to stick to roads I knew very well.”

Dr McKillop continues this open and honest account of his driving experiences, delving into areas such as insurance, the effects of medication, licence renewal, passengers and alternatives to driving.

The booklet is available for free download here:
http://www.lifchangestrust.org.uk/sites/default/files/Driving%20with%20Dementia%20website.pdf

23 August: Hilary Doxford writes “A new (un)diagnostic tool?”

Have we found a new (un)diagnostic tool? I don’t think so. So why do I ask?

One aspect of my voluntary work concerns me. I come over as ‘normal’ because I am fortunate in that although my IQ has dropped dramatically, the last time I was assessed I was still above average. This allows me to relatively easily mask the many difficulties I now encounter when trying to process information. Does appearing ‘normal’ do more harm than good when trying to gain the support of people who do not understand dementia?

What concerns and disappoints me, are the number of people with experience of dementia who at conferences will say that the person with dementia (PWD) speaking does not in fact have dementia. It has happened to many of my friends and myself. Very few people will say it to our faces, but will say it to our friends and family members. If they have the knowledge they proclaim, do they not understand the progression of this disease? The early stages are not visible. But for every 15 minute presentation we give, we have done many hours of preparation to try and be as good as we can be.

To those who question us, if you are trying to give me hope, then thank you, but that is not what I hear. I try not to take it personally, but feel I am being told I am a fraud and a liar. It is not the PWD who ‘confirms’ the diagnosis, we only pass on what we have been told. In my case, two separate neurologists have independently told me I have dementia. If a lay person told me I didn’t have it that is perfectly normal. But I am being told that is is not the right diagnosis, and I must have got it wrong. Does it really make any difference to you - to me - to them.

It is not the PW who ‘confirms’ the diagnosis, we only pass on what we have been told. In my case, two separate neurologists have independently told me I have dementia. If a lay person told me I didn’t have it that is perfectly acceptable to me, because I understand and would have said the same a few years ago before I understood this disease. But for someone with knowledge of dementia to say this, is it really acceptable? In fact, they are criticising their qualified peers, who following rigorous tests, give the diagnoses. I know we can be misdiagnosed and how hard it is to be correctly diagnosed, but I do not think anyone can give an informed opinion on the basis of hearing PWD talking in public of their experiences.

If you haven’t yet seen it, please watch the BBC Panorama programme on Living with Dementia, ‘Chris’ story’:
www.bbc.co.uk/programmes/p07dxmyh/panorama-living-with-dementia-chris-story

Chris and his wife Jayne are a lovely couple, who inspire me and I consider really good friends. If you met Chris or listened to him speaking it would be a while before you realised just what he is dealing with. Now watch the programme and you will see just what he and his family are dealing with – they are amazing, brave and incredible role models.

So to all those who tell me and my friends that we haven’t got dementia, I say, I pray you are right. But please remember, our public face does not reflect what goes on behind closed doors or inside our wayward brains.

Hilary Doxford, Vice-chair, EWGPWD.
New publications and resources

30 June: Hello Brain campaign publishes animation videos

Within the framework of their joint Hello Brain campaign, Trinity College Dublin and the Alzheimer Society of Ireland have published several new animation videos for carers of people living with dementia. Hello Brain promotes brain health through easy-to-understand scientific information. You can view the videos and other content here: www.hellobrain.eu/carers

3 August: Toolkit launched to help plan services and treatments for people with dementia

On 3 August, the MODEM (Modelling the Outcome and Cost Impacts of Interventions for Dementia) project launched its “Dementia Evidence Toolkit”, to support those planning and shaping services and treatments for people with dementia and their carers.

The unique toolkit provides easy access to scientific evidence on dementia care and treatment. It gives clear, evidence-based information to people living with dementia, unpaid carers, health and social care workers, decision-makers and researchers, to allow them to make better-informed decisions about which services and treatments to provide and how much they cost.

The toolkit, developed by researchers at the Personal Social Services Research Unit, London School of Economics and Political Science (PSSRU at LSE), brings together more than 3,000 journal articles and 700 reviews of research studies in one place.

It consists of two resources:
- A searchable database with information on over 1433 research studies on interventions for people living with dementia and their carers
- Summaries of the research findings for some of the main care and treatment interventions

The Toolkit can be accessed freely at http://toolkit.modem-dementia.org.uk/

AE Calendar

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>1 September</td>
<td>PRIVATE MICE Autumn 2016 (Amsterdam, Netherlands)</td>
<td>Gwladys</td>
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<td>5-6 September</td>
<td>Site Inspection AEC2018 (Barcelona, Spain)</td>
<td>Gwladys</td>
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<td>12-15 September</td>
<td>WHO Regional Committee 66 (Copenhagen, Denmark)</td>
<td>Vanessa</td>
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<td>13 September</td>
<td>Google training in partnership with SOCAware (Brussels, Belgium)</td>
<td>Kate</td>
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<td>14 September</td>
<td>Opening of the Barcelonabeta Research Centre (Barcelona, Spain)</td>
<td>Joan</td>
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<td>19 September</td>
<td>European Medicines Agency Workshop on social media (London, United Kingdom)</td>
<td>Kate and Jean</td>
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<tr>
<td>20 September</td>
<td>Patients and Consumers Working Party of European Medicines Agency (London, United Kingdom)</td>
<td>Joan</td>
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<tr>
<td>21 September</td>
<td>World Alzheimer’s Day conference entitled “Demenz kennen keine Grenzen (Schengen, Luxembourg)”</td>
<td>Dianne Gove</td>
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<tr>
<td>21 September</td>
<td>Janssen Symposium “The global fight against Alzheimer’s disease” (Bierse, Belgium)</td>
<td>Jean</td>
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<tr>
<td>22-23 September</td>
<td>Joint Action on Dementia meeting on timely diagnosis and post-diagnostic support (Lyon, France)</td>
<td>Jean</td>
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<td>28 September</td>
<td>Value of Treatment workshop organised by the European Brain Council (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>28-31 September</td>
<td>M&amp;I Forum Europe Autumn (Prague, Czech Republic)</td>
<td>Gwladys</td>
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## Conferences 2016

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<tr>
<th>Date</th>
<th>Meeting</th>
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<tr>
<td>6-9 September</td>
<td>19th IPA International congress, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>San Francisco, USA</td>
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<td>29 September-1 October</td>
<td>9th Conference of the German Alzheimer’s Association (DAlzG) on “Dementia. Looking at diversity”, <a href="http://www.demenz-kongress.de">www.demenz-kongress.de</a></td>
<td>Saarbrücken, Germany</td>
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<td>5-9 October</td>
<td>Croatian congress on Alzheimer disease with international participation (CROCAD 16), <a href="http://www.alzheimer2016.com/">http://www.alzheimer2016.com/</a></td>
<td>Tuzepi, Croatia</td>
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<td>31 October-2 November</td>
<td>29th Alzheimer Europe Conference (29AEC) on “Excellence in dementia research and care”</td>
<td>Copenhagen, Denmark</td>
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<td>10-11 November</td>
<td>EDUKAL 2016 – Second educational conference on Alzheimer’s disease, <a href="http://www.edukal.alzheimer.hr">www.edukal.alzheimer.hr</a></td>
<td>Zagreb, Croatia</td>
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<td>9-11 December</td>
<td>2016 IPA Asian regional meeting, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>Taipei, Taiwan</td>
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<td>2-5 February 2017</td>
<td>10th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PICA20) and 2nd Mediterranean Conference Neurodegenerative Disease (McCoND)</td>
<td>Thessaloniki, Greece</td>
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<tr>
<td>29 March-2 April 2017</td>
<td>13th International Conference on Alzheimer’s &amp; Parkinson’s (AD/PO 2017), <a href="http://adp2017.kenes.com/">http://adp2017.kenes.com/</a></td>
<td>Vienna, Austria</td>
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26th Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences #26AEC