Welcome!

Firstly, I would like to warmly congratulate all of our member organisations on another successful instalment of World Alzheimer’s Day (WAD). 21 September marks this important day, used by Alzheimer’s associations around the world to raise the profile of dementia, to support and advocate for people with dementia and to raise funds for dementia care and research. I am delighted to see that we have received no less than 22 articles from 17 different members for our special section, which you can find on pages 11 to 16 of this newsletter.

Also on the occasion of WAD, I was delighted to be able to spread the word about our Clinical trials Watch service, during an interview with Belgian Radio station BEL RTL.

Finally on the WAD front, EU Commissioners Vytenis Andriukaitis and Carlos Moedas issued a special message, calling for cooperation between national governments, researchers, patients’ organisations, medical professionals and the pharma industry, “to face the challenge of Alzheimer’s disease”. It is great to see that dementia continues to be a public health priority and to be highlighted at EU level like this.

There was more good news on the policy front this month, with Denmark launching its new national dementia plan. I congratulate our Danish friends and would also like to thank MEP Ole Christensen, a member of our European Alzheimer’s Alliance, who took the time to comment on this great news for us, lending his full support to the plan and its funding.

Our friends in Portugal also had a good month, taking an important step closer to a national dementia strategy in their country, with the formation of a new working group to prepare recommendations for the government on the main priorities.

On a more global scale, there has also been good progress made for dementia policy this month, with the WHO preparing a “zero draft” of its global action plan on dementia, as well as hosting the 66th edition of its Regional Committee for Europe, in Copenhagen.

On the science front this month, I was privileged to attend the opening of the new BarcelonaBeta Brain Research Center in Spain and to be involved in a Janssen symposium in Belgium also. The latter highlighted the importance of public-private partnerships in the field of dementia research going forward. There was also some not-so-positive research news this month, with yet more disappointing research results from a phase III clinical trial, this time from Lundbeck.

On another note, I would like to draw your attention to the fact that we are hiring! Three Luxembourg-based positions are available: two Project Officers and one part-time Administrative Assistant. If you, or someone in your network is interested in applying, please do so before the deadline of 7 October. I look forward to welcoming our new colleagues soon!

And last, but not least, our 26th annual conference is almost here! Only a few weeks until 26AEC in Copenhagen and I am pleased to announce that the detailed programme and abstracts are now online. We hope you’re looking forward to it as much as we are. See you there!

Jean Georges
Executive Director
Alzheimer Europe

13 September: Detailed 26AEC conference programme and abstracts now online

As of 13 September, the programme Alzheimer Europe (AE) has put together for the 26th edition of its annual conference (26AEC) is available online, as are the corresponding abstracts. 26AEC will take place in Copenhagen, Denmark from 31 October to 2 November.

Click here to see the detailed programme and abstracts.

Online conference registration is open until 23 October. For information on registration fees, click here.

Don't miss out on the gala dinner on the 1 November at the Scandic Hotel Copenhagen, an evening of fine dining and surprising entertainment.

Special discounts are available on your flight for 26AEC. For information on how to benefit from the discounted rate, click here.

21 September: BEL RTL news talks to us about our Clinical Trials Watch on World Alzheimer’s Day

Belgian radio station BEL RTL recently contacted Alzheimer Europe (AE) to ask about our Clinical Trials Watch (CTW), 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. The CTW went live on 1 September 2016.

BEL RTL news interviewed AE Executive Director Jean Georges for segments aired during its 8.00 and 17.00 news bulletins on World Alzheimer’s Day, 21 September.

21 September: “Dementia knows no borders” event organised on WAD by Luxembourg, Germany and France

Alzheimer associations in Luxembourg, France and Germany met, along with politicians, on 21 September at Schengen High School (pictured) in Perl, Germany to celebrate World Alzheimer’s Day. The aim of the meeting was to raise awareness about dementia and share experience between the three countries.

The meeting was hosted by Dagmar Heib, Chair of the Dementia Association in Saarlouis (Germany) and Ben Homann, Mayor of Schengen (Luxembourg). Greetings were given by Corinne Cahen, Minister of the Family, Integration and the Grand Region (Luxembourg) who emphasised the need to tackle the taboo surrounding dementia and the importance of using new technologies and the media.

Lydia Mutsch, Minister for Health and for Equality of Chances (Luxembourg), also greeted the audience and described dementia as a major cause of disability and dependency. She was enthusiastic about the recent change of paradigm, which has resulted in greater attention being paid to timely diagnosis and the promotion of autonomy, as well as to the need to support families.

Finally, Alzheimer Europe (AE) Chairperson Heike von Lützau-Hohlbein gave a speech about the situation of informal carers in the European context, drawing on her own experience as a carer and briefly presenting some of the preliminary findings from a survey currently being conducted by AE, the final results of which will be published in December 2016.

EU projects

20 September: PredictND completes baseline data collection for early detection of neurodegenerative diseases

Neurodegenerative diseases (NDs) are hard to diagnose and many of them are known to progress years or decades before the symptoms appear. When first memory problems are apparent, there is no single test which would immediately give conclusive information to make the correct diagnosis. Instead, several tests need to be done to collect possible indicators of the actual cause and to rule out other reasons behind the symptoms.

The research project “From Patient Data to Clinical Diagnosis in Neurodegenerative Diseases” (PredictND) finished its baseline data collection in June 2016. The collected data consists of ca 800 suspected neurodegenerative disease cases from four memory clinics. The data collected are used for development and validation of clinical decision support methods for differential diagnostics. With about 350 cases (of the 800) data were also collected for finding low-cost indicators of neurodegenerative diseases at the pre-symptomatic phase. The collected prospective data allows scientific research for improvements in early detection of the diseases. The PredictND project will continue until January 2018 and will also collect follow-up data with the same volunteers.

The PredictND project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration. The project team consists of nine European institutes: VTT Technical Research Centre of Finland Ltd. (Finland), University of Eastern Finland (Finland), Imperial College London (UK), University of Eastern Finland (Finland), Rigshospitalet/Region Hovedstaden (Denmark), VUmc (The Netherlands), University of Perugia (Italy), Alzheimer Europe (Luxembourg), and Combinostics Ltd (Finland).

http://www.predictnd.eu/
21 September: The SyDAD project is on Facebook!

SyDAD (Synaptic Dysfunction in Alzheimer’s Disease) is a European Training Network, sponsored by Horizon 2020 Marie Sklodowska Curie Actions. The research programme will focus on synaptic dysfunction, the main connection point between pathology and cognitive decline in Alzheimer’s disease.

22 September: MinD project visits Berlin and Dresden

The third secondment of the MinD project ‘Designing for People with Dementia’ in September saw the start of the data collection process, with people with dementia and their carers in four countries.

MinD researchers and designers were hosted by Alexianer St Hedwig Kliniken in Berlin and by the Technische Universität Dresden (TU Dresden) for their two-week visit to Germany.

The first week was devoted to familiarising visiting colleagues with the dementia care environment of the hospital, as well as to preparing for the first data collection event.

Consortium members finalised visual triggers in a form of specially designed visual cards (pictured), to support data collection in focus groups and in individual interviews with people with dementia.

A draft of the complimentary visual diary in the form of creative exercises for participants with early-mid stage dementia was reviewed and improved. Data analysis and coding schemes for both textual and visual data were discussed and developed from these focus groups and interviews.

The second part of the secondment, in Dresden, focused both on the data collection and on adding the design component to the data collection with presentations about design methods and strategies. As well as several presentations about design methods, given by colleagues from the project team, this included a short presentation of design ideas for people with dementia, by TU Dresden students. Furthermore, the team attended a lecture by Professor Gesine Marquart from the Center for Demography and Diversity (CDD) at TU Dresden, on “designing hospital interiors for elderly patients with orientation problems”.

The most important part of this secondment was a first focus group data collection. The secondment was also very important for examining and debating the methodology for the data analysis stage, including visual analysis techniques, thematic analysis as well as discourse analysis methods. The secondment was rounded off by a visit to the Museum of Decorative Arts in Pillnitz to enjoy some of the country’s culture and the splendid sunshine in the beautiful park.

27 September: AETIONOMY recruitment now over 100 patients in the clinical study

AETIONOMY, an IMI funded project, has now recruited over 100 people into the Parkinson’s disease (PD) portion of the European clinical study on neurodegenerative diseases such as Parkinson’s and Alzheimer’s diseases. This milestone means that the project is 25% completed in the PD portion. The Alzheimer’s disease (AD) portion is being recruited via EPAD which is now also actively recruiting. Within the project, patients with neurodegenerative diseases and healthy people are providing blood and cerebrospinal samples to undergo detailed molecular analysis at leading European laboratories.

The purpose of AETIONOMY is to propose novel patient classification based on mechanism-based taxonomies, for both PD and AD. “The AETIONOMY study will allow us to validate in real patients two hypotheses for PD and for AD,” explained study coordinator Prof. Jean-Christophe Corvol of ICM, Paris. “This will then allow clinicians to stratify patients according to biological mechanisms of the disease and potentially to target specific sub-population for drug development.”

28 September: European Brain Council holds Value of Treatment strategic workshops in Brussels

On 28 September 2016, the European Brain Council held a strategic workshop in Brussels for the Value of Treatment project. Participants worked in groups around several conditions such as headache, multiple sclerosis and Alzheimer’s disease, to name but a few.

AE Director for Projects Dianne Gove contributed towards the working group, which aims to develop a model that could indicate the costs that could be saved by starting treatment before the onset of dementia. This work is based on a hypothetical situation in which treatment exists, which could delay the onset of AD dementia.

During the meeting, the group focused on developing a patient journey for AD and on methodological issues. Prof. Martin Knapp (pictured) gave an overview of the economic evaluation related to the various conditions.
Alzheimer Europe networking 2016

On 1 September (Amsterdam, Netherlands) Gwladys attended the MI private forum.

On 5 and 6 September (Barcelona, Spain) Gwladys went on a site inspection for the 28 AEC.

On 12-15 September (Copenhagen, Denmark) Vanessa attended WHO Regional Committee 66.

On 13 September (Brussels, Belgium) Kate attended an information day about the “Google for Nonprofits” programme.

On 14 September (Brussels, Belgium) Kate attended the EDF – EESC civil society hearing on the progress of the implementation of the UN CRPD in the EU.

On 14 September (Barcelona, Spain), Jean attended the official opening of the Barcelonaβeta Brain Research Centre of Fundació Pasqual Maragall.

On 19 September (London, United Kingdom) Kate attended the EMA Joint PCWP/HCPWP workshop on social media.

On 20 September 2016, Dianne participated in the EPAD WP8 teleconference.

On 20 September (London, United Kingdom), Jean attended the Patients’ and Consumers’ Working Party (PCWP) of the European Medicines Agency (EMA).

On 21 September, Vanessa attended an EFPIA Think Tank meeting by teleconference.

On 21 September, Dianne and Heike took part in the “Dementia knows no borders” event organised by Luxembourg, Germany and France to mark World Alzheimer’s Day.

On 21 September (Beerse, Belgium), Jean participated in a symposium on Alzheimer’s research organised by Janssen to commemorate World Alzheimer’s Day.

On 22 and 23 September (Lyon, France), Jean attended a meeting of WP4 (work package dedicated to timely diagnosis and post-diagnostic support) of the European Joint Action on Dementia.

On 23 September, Dianne and Ana took part in a teleconference for the MinD project.

On 26 September, Dianne took part in a teleconference for the EPF task force on vulnerable groups.

On 28 September (Brussels, Belgium), Ana attended the meeting “Towards a UN Convention on the rights of older persons?” at the European Parliament.

On 28 September (Brussels, Belgium), Dianne participated in the Value of Treatment project meeting organised by the European Brain Council.

On 29 September, Ana and Dianne participated in the SMART4MD management teleconference.

On 28-30 September (Badhofgastein, Austria) Vanessa attended the European Health Forum Gastein (EHFG). Helen Rochford Brennan also represented the EWGPWD at this forum.

On 28-30 September (Prague, Czech Republic) Gwladys attended the MI Autumn Forum.

On 29 September (Brussels, Belgium) Hilary Doxford represented the EWGPWD at an IMI stakeholder meeting.

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); Barbara Kappel (NI); Paul Rübig (EPP), Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE), Bulgaria: Andrey Kovatchev (EPP), Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR), Cyprus: Costas Avgvrides (S&D); Eleni Theoccharous (EPP), Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP), Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D), Estonia: Urmas Paet (ALDE); Finland: Liisa Jaakonsaari (S&D); Anneli Jääteenmäki (ALDE); Mapietra Kumpula-Natri (S&); Merja Kyllonen (GUE/NGL); Sirpa Pietikäinen (EPP), France: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Charter (EPP); Gilles Pargneaux (S&D), Germany: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Kostas Chrysogonas (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP); Eleftherios Synadinos (NI); Elisavet Vozemberg (EPP), Hungary: Ádám Kösa (EPP), Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke 'Ming' Flanagan (GUE/NGL); Marrian Harkin (ALDE); Brian Hayes (EPP); Séan Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL), Italy: Brando Benifei (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (EPP); Patrizia Toia (S&D); Damiano Zoffoli (S&D)

Lithuania: Vilija Blinkevičiute (S&D), Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP), Malta: Therese Comodini Cachia (EPP);
European Alzheimer’s Alliance

7 September: MEP Stefano Maullu joins the European Alzheimer’s Alliance

The European Alzheimer’s Alliance is pleased to welcome a new member as of 7 September, MEP Stefano Maullu (EPP, Italy). This brings the total membership up to 127 MEPs from 27 countries. Mr Maullu sits on the Committee on Culture and Education and is a substitute on the Committee on Legal Affairs.

http://alzheimer-europe.org/Policy-in-Practice-2/European-Alzheimer-s-Alliance/Members/Maullu-Stefano

EU developments

13 September: MEPs adopt report on Creating Labour Market Conditions Favourable for Work-Life Balance

On Tuesday 13 September in the European Parliament MEPs adopted a report on Creating Labour Market Conditions Favourable for Work-Life Balance. The aim of the report is to feed into the Commission’s upcoming work-life balance legislative package. The report calls for adapting policies to today’s diverse society and asks for legislative proposals on maternity, paternity and carers’ leave. The EU and its Member States need to adapt work-life balance policies to today’s reality by promoting gender equality in employment and other spheres of life, but also by taking into account the needs of an increasingly diverse society. This requires a better sharing of paid work and caring responsibilities between men and women as well as society as a whole.


14 September: EDF and EESC host civil society hearing on the progress of the rights of persons with disabilities in the EU

On 14 September, the European Disability Forum (EDF) and the Economic and Social Committee co-hosted a civil society hearing on the progress made on the implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD). The hearing was held at the EESC offices in Brussels and chaired by EDF Director Catherine Naughton.

Opening remarks were made by Bernard Noel, President of the Permanent Study Group on Disability Rights of the EESC, Ioannis Vardakastanis, EDF President and member of the Permanent Study Group on Disability Rights of the EESC and Emmanuelle Grange, Head of Disability and Inclusion unit, DG Employment at the European Commission.

Mr Noel, a former trade union leader, stressed the desperate situation for migrants with disabilities, who are some of the most vulnerable people currently in the EU. He also drew attention to the importance of employment and independence for people with disabilities and reminded participants of some of the disastrous consequences of austerity on disabled and vulnerable people in particular.

Ms Grange began her speech by paying tribute to disability activist and EDF Board Member Peter Lambrechts, who recently passed away. She gave an update on the European Accessibility Act, including discussions with Member States and the European Parliament and meetings with the Slovak Presidency of the. An informal document may be available in draft format by the end of September, but a formal update to the Declaration of Competence will take longer due to the large volume of feedback from public consultations.

Mr Vardakastanis was keen, like Mr Noel, to draw attention to the plight of migrants and the victims of the crisis and of austerity measures. “We cannot keep ignoring these people and leaving them behind”, he insisted. Mr Vardakastanis believes the EU needs to re-think how to continue implementing the UN CRPD and to learn both from its past mistakes in the ten years since the Convention was first adopted and from emerging best practices. An overarching strategy 2020-2030 is needed, based on an inter-institutional agreement, he concluded.

EDF Human Rights Officer An Sofie Leeknecht went into further detail about three recommendations described by Ms Grange: the recommendation on the Declaration of Competence, the recommendation on the European Accessibility Act (EAA) and the Recommendation of the Monitoring Mechanism.

The floor was then open for representatives from participating organisations to give feedback on the progress (or lack thereof in some cases) made for the people they represent. Comments came from Coface.
Inclusion Europe, European Network on Independent Living (ENIL), the European Network for [ex]-Users and Survivors of Psychiatry (ENUSP), Autism Europe, Mental Health Europe, the European Union of the Deaf (EUD), the European Association of Service Providers for Persons with Disabilities (EASPD), the International Disability and Development Consortium (IDDC), Light for the World, Eurochild, the European Women’s Lobby (EWL), AGE Platform Europe, Human Rights Watch (HRW) and Equinet - European Network of Equality Bodies. Some of the points made could help support people to live better with dementia, if taken account of moving forwards: The importance of rights being both universal and portable, not stopping at borders; the importance of an absolute ban on the deprivation of liberty (putting a complete stop to practices that continue in some parts of the EU, such as the use of “cage beds” and 23 hours-a-day chemical and physical restraints; the replacement of substitute decision-making with supported decision-making; and the importance of including people with psychosocial disabilities in further shaping the EAA, as it is currently more focused on those with physical disabilities.

Representatives from of the European Parliament, the European Ombudsman, the Fundamental Rights Agency and the European Commission were able to respond briefly to some of the points raised and to reassure participants that the bodies involved in implementing the UN CRPD are doing everything in their power to ensure things move forward as quickly as possible.

The meeting was closed by Mr Vardakastanis, who thanked speakers and delegates alike for their contributions and again stressed the importance of an overarching strategy.

21 September: EESC shines spotlight on vital role of live-in carers

The European Economic and Social Committee (EESC) has adopted an opinion on the rights of live-in care workers. It urges policy-makers to fully recognise their contribution to long-term care, to treat them in a similar way to other care providers and to regularise the status of undocumented workers.

An ageing population and cuts in public-sector spending have created a shortfall in the provision of long-term care. While live-in care workers – who are often unregulated – have helped to alleviate acute labour shortages in this sector, many work in precarious labour conditions including bogus self-employment. Eastern Europe supplies many live-in care workers to other countries, despite a depleted domestic care workforce, and if fired, these workers can find themselves homeless.

“In the context of a poorly recognised and remunerated care workforce, live-in care workers have for too long remained invisible to policy-makers,” said Adam Rogalewski (pictured), EESC Rapporteur on the opinion.

At present, there is no EU-level legislation on this and no proposals in the pipeline. As a first step, the EESC wants to start a discussion on a common occupational definition of “live-in” care work in Europe. This should recognise live-in care as a form of homecare provision and cover employment arrangements for workers living in private residences.

The EESC believes that live-in care workers should be treated as part of the system of long-term care provision, with similar rights as other care workers when it comes to remuneration, health and safety protection, social security and the right to freedom of association.

In practice, this means:

- Including the rights of live-in carers and their care recipients in future revisions or proposals of European and Member States’ legislation.
- Monitoring and improving posting of live-in carers by implementing the principle of equal pay for equal work.
- Tackling social dumping and exploitation.
- Proactively regulating the long-term care sector, especially in relation to compliance with employment laws, to ensure care recipients as well as live-in care workers are protected.
- Achieving Member State ratification and implementation of International Labour Organisation (ILO) Convention No 189 to regularise the status of live-in care workers.

In addition, significant numbers of these workers possess skills and qualifications resulting from years of experience or from unrecognised formal training and certification programmes. These should be recognised, insists the EESC. Financial support for patients relying on live-in care workers must also be met through adequate long-term and sustainable public investment.

In order to effect these changes, trade unions, employers and civil society organisations need to get involved in policy planning, says the EESC. A major achievement of the EESC’s opinion is that it successfully brought together advocates for a sustainable and equitable long-term care sector with labour and migrant rights advocates.

The EESC plans to build on this and promote the development of European policies that support carers, care recipients and their families by, amongst other things, organising a conference on the future of live-in care work in Europe in the second half of 2017 to discuss concrete steps towards properly regulating the sector.
21 September: EU Commissioners issue World Alzheimer’s Day message

On 21 September, World Alzheimer’s Day (WAD) Vytenis Andriukaitis, Commissioner for Health and Food Safety and Carlos Moedas, Commissioner for Research, Science and Innovation issued a message, putting IMI dementia projects in the wider EU context and issuing a call to action.

Their message lays out the current situation with regards to the ageing population, the prevalence and impact of dementia and the commitment of policy makers in all European Union countries to support people living with dementia.

The Commissioners draw our attention to:

The European Commission’s Communication on Alzheimer’s disease and other dementias, adopted in 2009, which calls on EU Member States to work together to ensure early diagnosis, better knowledge and coordination of research and best practices for care and respect of the rights of people with dementia. To help EU countries in this regard, the Commission supports joint actions (EU co-financed cooperation) with Member States and experts under the EU Health Programme which are aimed at improving diagnosis and post-diagnostic services, care, and at fostering dementia-friendly communities.

The Commission has also set up a Group of Governmental Experts on Dementia – a platform for EU countries to exchange experiences and good practices. Furthermore, the Commission supports global activities initiated by the G7 countries and by the World Health Organization (WHO), e.g. the establishment of a Global Dementia Observatory, which will pool information on dementia and policies to address it.

The EU has also invested almost EUR 600 million into research on neurodegenerative diseases, including Alzheimer’s, under its 7th Framework Programme for Research and Innovation (FP7), running from 2007 to 2013. Under Horizon 2020, the current research and innovation funding scheme, already around EUR 143 million go to research projects on dementia. These projects are trying to answer crucial questions, such as whether we can delay physiological aging of the brain, how we can prevent age-related brain disorders, and if we can reverse diseases such as Alzheimer’s.

They also refer to: the project LIPIDIDET: a large investment of EUR 1 billion to the Human Brain Project (HBP); the Innovative Medicines Initiative (IMI2); collaboration with the pharmaceutical industry to accelerate drug development; investment in the Joint Programming Initiative on Neurodegenerative Diseases (JPND) and the Global Alliance for Chronic Diseases (GACDI).

The WAD message highlights the fact that six out of the first nine IMI2 calls including EUR 75 million committed by the EU have addressed brain research, “Alzheimer’s and other dementia are global challenges which require global solutions. More cooperation is needed on a global scale” they say.

“So today, on 21 September...we would like to call upon national governments, researchers, patients organisations, medical professionals, the pharmaceutical industry and others concerned to continue their efforts and actively support the ongoing initiatives at EU level. Only by joining forces will we be able to face the challenge of Alzheimer’s disease.”


Members’ news

21 July: EMDA hosts brainstorming session with Alzheimer’s researchers

On 21 July, EMDA – The Alzheimer’s Association of Israel held a brainstorming session. Participants were the best researchers (not physicians) in the field of Alzheimer’s. During the brainstorming session there was a review of advanced Alzheimer’s research in Israel.

Professor Amos Korczyn, the head of EMDA’s scientific committee, gave a lecture from a clinical perspective: “Why have we failed so far?”

In addition, other lectures were given on a variety of subjects including: Identifying new small molecules as candidate drugs targeting neuroinflammation, Angiotensin-related drugs modulate brain inflammation and neuronal loss: Possible role in AD, APP – a novel target for AD treatment, and Caspase inhibitors.

6 September: German Alzheimer association launches nationwide campaign “Demenz Partner”

On 6 September, the German Alzheimer association marked World Alzheimer’s Day 2016 with a nationwide campaign called “Demenz Partner” (Dementia Friends). The aim of this initiative is to spread knowledge and information about dementia and to change the way people with dementia are treated.

The Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz (DAIzG) – the German Alzheimer association - is very proud that both the Minister of Health Hermann Gröhe and the Minister for Family Affairs, Senior Citizens, Women and Youth Manuela Schwesig, together with DAIzG...
Chairperson Monika Kaus, officially launched the campaign in Berlin.

Ms Kaus said “People with dementia want to stay in their familiar environment. They need understanding not only from family members, friends and neighbours but also when going shopping, walking in town and continuing with other activities.”

Central to the Demenz Partner campaign are free courses in which participants learn the most important facts about the disease and learn how best to interact with people living with dementia. Furthermore they get information about regional Alzheimer associations and other advisory services.

Local Alzheimer associations and other institutions that offer such courses are registered on the website www.demenz-partner.de. Course participants are provided with materials including presentations, films and brochures.

To illustrate that this campaign is not just a German project but a worldwide movement, the campaign has adopted the same forget-me-not-logo as that used by the Dementia Friends programmes in the UK and a number of other countries.

The German Ministry of Health and the Ministry for Family Affairs support the campaign not only financially: Mr Gröhe attended a Demenz Partner course himself and the DAIZG gave a course to the employees at the Ministry of Health. Furthermore the association had the honour to present the initiative during a festival under the patronage of the German President, Joachim Gauck.

Finally the DAIZG has organised a conference, during which the 100 or so delegates will hopefully become the some of the first Demenz Partners of many.

13 and 17 September: Alzheimer Italia hosts two conferences

On 13 and 17 September, during the 5th “World Alzheimer’s Month”, Federazione Alzheimer Italia (FAI) held two conferences, one in Milan and one in Abbiategrasso – a town where the first pilo project in Italy for a Dementia Friendly Community recently started. Both conferences received an award from the Italian President.

The Milan conference had national and international speakers who gave an overview of what has been done in the field of dementia at medical, scientific and political levels.

For the first time in Italy, the introduction was made by a person with dementia, a missionary priest, who spoke about his experience with the disease, his difficulties and the willingness to “be the protagonist of his life”. As for the international experiences, Philip Scheltens (pictured), Dutch professor of neurology and Director of the Alzheimer Centre, VU University Medical Center in Amsterdam spoke about the Dutch National Plan “Deltaplan Dementie”, launched in 2011.

Particularly appreciated was the speech by Marco Trabucchi- Professor of Neuropsychopharmacology, Tor Vergata University of Rome and president of the Italian Association of Psychogeriatrics, who introduced the topic of isolation for caregivers and people with dementia.

The conference also focused on the first Dementia Friendly Community project in Italy. FAI identified Abbiategrasso, a town with a population of 32,000, as the ideal place to launch its pilot project, which aims to involve the population, institutions, associations and professional groups to create a network of informed citizens who know how to relate to people with dementia. Pierluigi Arrara, Mayor of Abbiategrasso shared his hope of overcoming the stigma and finally creating a community where everyone can find a place and in which everyone supports vulnerable people and helps them to overcome difficult moments.

At the end of the day, Salvini Porro, FAI President and Francesco Brancati President of the National Scientific and Medical Information Society (UNAMSI) presented the 5th edition of the "Alzheimer’s: inform to know - Care, Research and Assistance" award for journalists who wrote about dementia in a comprehensive and sensitive way, highlighting the fact that the fight against stigma and social exclusion starts with correct information.

The second conference, held in Abbiategrasso, had the aim of raising awareness among the town’s population and to present the first results of the caregiver survey.

Keynote speaker for the day was Ian Sherriff - Academic Partnerships Lead for the Dementia School of Medicine, Plymouth University, UK - who enthusiastically invited everyone to work together to achieve a Dementia Friendly Community and explained the change of perspective that the participation in this project would engange.

The conference closed with a visible signs of unity in the town of Abbiategrasso, in particular for families who are close to a person with dementia: Visconti Castle was entirely illuminated in blue – FAI’s colour - as a sign of the solidarity, awareness and commitment of the Municipality.

14 September: Bosnia launches new Declaration during dementia symposium

Bosnian dementia association Udruženje AI R’s dementia centre organised a symposium on “Different aspects of dementia treatment” on 14 September, in partnership with the Faculty of Philosophy of the University of Sarajevo. The symposium, which included twenty different optics across five sessions, took place in the Faculty’s Amphitheater.

Event speakers included eminent professors - neuropsychiatrists, neurologists, internists, psychologists, sociologists, nutritionists and family carers of persons with dementia.

There were guests from Alzheimer Austria (Monika Natlacen) and Spominica-Alzheimer Slovenia (Stefanija
Zlobec), who spoke about the Austrian social system and the road to adopting the Slovenian national strategy.

The symposium concluded with the launch of a Declaration on Dementia for Bosnia and Herzegovina. The basis for this new Declaration is Alzheimer Europe’s Glasgow Declaration.

The Declaration on Dementia calls for:

- Adoption of the BH national dementia strategy;
- The right to a timely diagnosis;
- The right to quality post-diagnostic support;
- The right to person-centred, coordinated, quality care throughout the illness;
- The right to equitable access to treatments and therapeutic interventions;
- The right to living in a dementia-friendly society;
- The right to be respected as an individual in the community.

It includes and invites all levels of authority to support the fight against dementia stigma in Bosnian society.

Before the symposium, a public campaign was carried out on TV, radio, newspapers, as well as via the web and social media (Facebook).

16-17 September: Spominčica hosts 8th Psychogeriatric Conference in Dobrna

On 16 and 17 September Alzheimer Slovenia (Spominčica) and the University Psychiatric Clinic Ljubljana organised the 8th Psychogeriatric Conference in Terme Dobrna under the banner “Living with dementia in a dementia-friendly environment”.

Speakers included a psychiatrist, neurologists, researchers, scientists, representatives of institutions such as the Ministry of Health and Ministry of Social Affairs and Labour, the Deputy of the Human Rights Ombusman and a carer.

Delegates included more than 170 professionals from the field of dementia, individuals coming into contact with persons with dementia and family carers. Participants shared the view that the conference was an important knowledge base for the professional training of those coping with dementia, including employees in the health sector, social sector, administrative workers and NGOs.

The first day of the conference was concluded with a round table, at which the intense discussion finished little before 9pm and only then because dinner was served! Discussions continued during dinner and later on at the hotel dance. Despite the late finish on Friday night, the Saturday conference was attended by most of the participants and on Saturday morning a small “memory walk” was also held between the Hotel and the conference centre, weaving through the town of Dobrna.

The conference was organised after a five year break from the event and Spominčica is pleased to be able to continue the work of its late founder, Professor Aleš Kogoj, a specialist in psychiatry, who founded the Psychogeriatric Conference in 1998.

Next year Spominčica will celebrate 20 years and is pleased glad to announce the 9th Psychogeriatric conference, planned on 20-21 October 2017.

17 September: Norway launches new dementia campaign

The Norwegian Health Association has, for the first time, launched a mass media campaign in order to raise funds for research and to raise awareness. The slogan is “One fine day dementia will be forgotten”, and only real life stories have been used.

The elements of the campaign are digital advertising, video shared via Facebook, “klick-ads”, advertising in analog media, door-to door collections and mailings to most Norwegian households.

During the most active week, 17 to 22 September, there were also a lot of open meetings and different events held.

22 September: “Daredevils” skydive in aid of Jersey Alzheimer’s Association

Mark Blamey, Manager of the Jersey Alzheimer’s Association (JAA) sent us the following report on 22 September, about some of the “Daredevils for dementia” – a group of seven brave souls, including Mr Blamey himself, who are skydiving to raise money for the JAA:

A total of seven brave “daredevils” are skydiving to raise money on behalf of Jersey Alzheimer’s Association. This event is part of a “Be a Daredevil for Dementia” fundraising drive. Earlier in the year a Sponsored Abseil took place at Mont Orgueil Castle in Jersey.

As at 22 September Mark Blamey and two supporters of the charity had completed the Skydive - which was AMAZING!!

A huge thank you to Mally and his brilliant colleagues at Skydive Jersey who made the experience so memorable.

The remaining four members of the team have booked dates in the next week or so.

Thank you to everyone who is sponsoring the team.

So far, the team (pictured) have smashed the target and raised well over GBP 3,500 (EUR 4,050)!

The money raised will make a substantial difference to the lives of people living with dementia and those who provide care in Jersey.

Team members participating in the tandem Skydive include Mark Blamey, Mark Duffy from World Duty Free, Ruthie Hawkesford and Emily Devon from Uba Studio and Rachel
McBride from the Health and Social Services Department of the States of Jersey.

There is still time to support the team, who are free falling from 10,000 feet above Jersey. Help them by visiting their JustGiving page [https://crowdfunding.justgiving.com/jaa](https://crowdfunding.justgiving.com/jaa)

22-23 September: Prague Gerontology Conference “Living with Dementia- New Perspectives” takes place

The annual Prague Gerontology Conference took place from the 22-23 September 2016, this year under the theme “Living with Dementia- New Perspectives”. The conference was opened by Martina Mátlová from the Czech Alzheimer’s Society and began with a talk from Nina Baláčková, member of the European Working Group of People with Dementia (EWWGPD), who shared her personal experiences of dementia since her diagnosis over nine years ago.

The first section of the conference was chaired by Iva Holmerová from the Centre of Gerontology and Vice-Chairperson of Alzheimer Europe. Speakers addressed various approaches to caring for people with dementia and managing complex behaviour. This topic was complemented by an afternoon session, in which speakers turned their attention to recent advances in diagnosis and treatment. Attendees also had the chance to hear from several experts in the field of architecture, who discussed topics such as current trends in the design of housing for people with dementia and Parkinson’s disease, as well as the application of Montessori methods for people with dementia.

The second day of the conference provided an opportunity for participants to attend a range of specialist workshops on topics such as ethical care and cognitive training. The conference concluded with two presentations on British models of community support for people with dementia which preceded an audience debate during which attendees voiced their thoughts on current dementia policy in the Czech Republic.

23 September: Bosnian association Udruženje AiR gets support from mayoral candidates in Sarajevo

The association Udruženje AiR in Bosnia and Herzegovina organised a meeting with mayoral candidates and parliamentary candidates for the municipality of Sarajevo, at its dementia centre.

The mayoral candidates gave their support to the work the association and its dementia centre are doing. They know what a difficult task it can be, caring for people with dementia. They are aware of the impact of dementia and of the problem with stigma in the country.

They promise that, if elected, they will work towards creating a more dementia-friendly community, and that they will give the association the necessary support, as well as lending it their support, through the projects in their community.

25 September: First-of-its-kind specialised dementia nursing home is on the horizon in Croatia

Alzheimer Croatia has accepted to be an advisor on the design of the first fully specialised nursing home for people with dementia in Croatia, the opening of which is planned for 2017.

The adaption of a modern, award-winning “safe house”, previously used for vulnerable children, will include ensuite bathrooms visible through glass doors from residents’ beds, night lights, very strong lighting in all indoor spaces, a large patio and garden with helpful landmarks and signposts, colour-contrasting cutlery, a bright light therapy room and a studio for physiotherapy, among other facilities.

Interiors will avoid highly-reflecting surfaces and use eye-catching, contrasting colour schemes as well as large, clear signage placed in the lower visual field. Residents’ rooms will be recognisable by different-coloured doors, memorabilia and decor. To avoid reflections on the large glass walls of living rooms in the evening, surrounding gardens will be lit with appropriate care. A fake bus stop is also planned in the garden, near the exit.

The new nursing home will also have a day-care centre for people with dementia, with catering facilities for families of people with dementia in the surrounding area.

27 September: Alzheimer Scotland calls for abstracts for its 2017 conference

For the first time ever, Alzheimer Scotland is offering colleagues the opportunity to present at its annual conference on 2 June 2017, via an abstract submission. All abstracts must be received by 4 November, there are 3 categories available and both parallel and poster presentations are available.

Alzheimer Scotland’s annual conference will bring together 550 delegates at the world-class Edinburgh International Conference Centre, for an innovative programme with key international, national and Scottish speakers.

Delegates include people with dementia, carers, policy makers, national and local government staff, academics, health and care professionals, staff from Alzheimer and dementia associations, along with representatives from the pharmaceutical industry, financial, legal, property and technology sectors.

Alzheimer Scotland invites those wishing to be considered to speak at the conference (as a parallel presenter) and/or display a poster presentation to submit an abstract outlining the area of work or research that he/she wishes to present at the conference.

World Alzheimer’s day

20 September: The Alzheimer Society of Ireland hosts Dementia Showcase for World Alzheimer’s Day

On the eve of World Alzheimer Day, The Alzheimer Society of Ireland (ASI) hosted a national dementia showcase in partnership with the Health Service Executive (HSE).

The Dementia Showcase at The Helix theatre and conference venue in Dublin brought together people with dementia, their families, carers, health professionals and services to discover and experience the latest innovations in dementia awareness, education and care.

Pictured: Members of the Forget-Me-Not Choir performing at the Dementia Showcase

20 September: Irish dementia friendly communities toolkit launched in time for World Alzheimer’s Day

The Alzheimer Society of Ireland (ASI) launched its new Dementia Friendly Communities Toolkit at its dementia showcase event, on the eve of World Alzheimer’s Day.

This toolkit contains resources, which will support organisations, businesses and communities to be more informed and enabled to support people with dementia and their loved ones to stay living well.

It contains a guide that provides a practical framework based on ASI’s experiences over the past three years in supporting communities to work towards becoming more dementia friendly.

It also contains a number of information resources for various services, businesses, emergency response teams and people working in the areas of arts and leisure providing them with hints and tips for how they can support people with dementia:

- Retailers
- Pharmacists
- Information providers
- Religious and spiritual providers
- Emergency services
- Arts and cultural facilities
- Leisure and recreation organisations
- Transport providers


21 September: Finland celebrates memory Week

Memory Week is annually celebrated in Finland around World Alzheimer’s Day. Memory associations organise hundreds of events all across Finland throughout the week. This year, The Alzheimer Society of Finland (Muistiliitto) also gave awards to a “Memory Friend of The Year” and “Brain Health Ambassador of The Year”.

During Memory Week, the Society also published the fourth and completely revised “Criteria for Good Care” (pictured), originally published in 1996. The publication gives guidelines to healthcare and social services professionals, to allow them to continually develop and regularly evaluate their work so that people with memory diseases and their loved-ones can live with the support they need. The publication also helps people with memory diseases and their caregivers to find appropriate care, rehabilitation and services.

21 September: Alzheimer Croatia marks World Alzheimer’s day with a series of events

The numerous activities of Alzheimer Croatia during World Alzheimer’s Month culminated on World Alzheimer’s Day (WAD) in the capital city of Zagreb. The traditional event and fund-raising campaign “autumn rose for the autumn of life”, an open air string concert and its annual Memory Walk attracted many people. Croatians are becoming increasingly aware of the impact of Alzheimer’s and other dementias and the need for a more dementia-friendly environment.

Throughout the country, Alzheimer Croatia and its subsidiaries were also very active, hosting Alzheimer’s workshops, organising Alzheimer Cafés and giving public speeches.

There was a lot of media coverage, including reports on the evening TV news and in top newspapers. Coverage like this is helpful for the destigmatisation of dementia and in raising the profile of Alzheimer Croatia.

21 September: Ljubljana Castle coloured blue for World Alzheimer’s Day

For World Alzheimer’s Day, under the slogan “Remember Me”, the Mayor of Ljubljana accepted Alzheimer Slovenia (Spominčica)’s request to bathe Ljubljana Castle in blue light on the night of 21 September.

For those who missed it the first time, there was good news, as on 24 September when the Ljubljana Memory Walk was organised, the castle was...
The beautiful photo of the castle was taken by Spominčica’s Erasmus exchange colleague from Poland Slawomir Krajewski, who joined the association on 1 August.

For World’s Alzheimer Month, the association posted information about the Memory Walk on public buses in Ljubljana. A Memory Walk traditionally take part in Ljubljana and in other regions around Slovenia on or around World Alzheimer’s Day.

21 September: Bosnian association marks World Alzheimer’s Day with a TV and radio campaign

The Bosnian dementia association, Udruženje AiR marked World Alzheimer’s day with a public campaign about dementia carried out on three national television channels and one national radio station.

The topic for the campaign was Alzheimer day and included conversations about stigma in Bosnian society, what dementia is and what its symptoms are, which problems people with dementia may encounter in the social and health system, training caregivers, and the benefits of early diagnosis, among others.

21 September: Norway hands out 19 dementia awards on the occasion of World Alzheimer’s Day

Each year, the Norwegian Health Association honours worthy recipients in all its counties with “dementia awards”. These are a tribute to efforts above and beyond what is ordinary.

Both individuals who do voluntary work and individuals and groups in the public sector who exhibit innovation and commitment are eligible to receive a dementia award.

Among the recipients this year were care homes, activity centers. Most particularly, some people with dementia and carers were honoured for their openness about dementia - In Hedmark county the dementia prize 2016 was awarded to carer Tor Eliassen (pictured) for his openness and honesty about dementia.

21 September: Portugal’s Memory Walk 2016 has a celebrity participant

World Alzheimer’s Day in Portugal was marked with the sixth edition of Alzheimer Portugal’s Memory Walk - the annual solidarity event of the Association - which took place in 14 cities across the country.

With this event, the Association aims to inform and raise awareness of the importance of reducing the risk of developing dementia, of the warning signs of the disease and, particularly, the importance of timely diagnosis.

The memory Walk initiative came to Portugal in 2011, when hundreds of people walked 6km for the first edition, which took place in Oeiras. Since then, new cities have joined and assisted in raising funds for Alzheimer Portugal, as well as raising awareness of dementia.

This year, the Memory Walk featured a very special participant: Internationally recognised Portuguese actor Joaquim de Almeida (pictured), on the occasion of the premiere of the movie “Of Mind and Music”, in which Mr de Almeida plays the role of a renowned neuroscientist investigating Alzheimer’s disease. He participated in the Memory Walk in Oeiras.

Of Mind and Music - A touching and inspiring story, with which a lot of people will certainly identify. The movie show the day to day difficulties, questions and problems with which a family member of someone living with dementia is faced every day. The plot:

Renowned Neuroscientist Dr Alvaro Cruz (Joaquim De Almeida) returns home from a lecture in Paris, heartbroken and disillusioned. In his absence, his mother has been diagnosed with Alzheimer’s disease. Nothing in his research or scientific knowledge can stop this from happening.

He decides to take some time off work and reconnect with the love of music that he shared with his mother, finding solace in the music that permeates New Orleans’ French Quarter. He hears the mesmerizing voice of Una Vida (Aunjanue Ellis) for the first time. After listening to her songs on repeat, he realises that she too has Alzheimer’s disease and that her unconventional “family” cannot cope with her declining health.

His wife, Angela (Sharon Lawrence) is confused by his desire to seek out Una Vida’s long lost son, in the hopes of finally putting the grief, loss and longing that overshadowed her difficult but also beautiful life to rest.

21 September: French survey shows 80% of family carers in employment face work-life balance issues

Eight in ten caregivers in France face difficulties in reconciling work with their caregiving responsibilities, say the results of a survey conducted by France Alzheimer. Responses were gathered from 1484 caregivers, simultaneously in employment and caring for a loved one and were published on the occasion of World Alzheimer’s Day, 21 September.

Results also show that 90% feel more tired and stressed than previously and 72% find it harder to concentrate and to be efficient at work. Moreover, half of those who responded to the survey said they felt unable to talk about any of this with their employers.

It was also clear, however, despite the negative aspects of trying to maintain employment while caring for a family member with dementia, 96% of the respondents said they wished to maintain their employment, not only for...
financial reasons but for the job satisfaction and the chance to think about something else too. You can download the summary of the survey (in French): http://www.francealzheimer.org/actualit%C3%A9s/vie-aidants-au-travail/1714

Following the results of this survey, France Alzheimer has launched a White Paper advocating for better conditions for caregivers in employment.

21 September: Alzheimer Scotland drafts White paper to advocate for family caregivers in employment

France Alzheimer has drafted a White Paper in which it puts forward 13 concrete proposals to advocate for the rights and wellbeing of family caregivers who are in professional employment alongside their caring duties. The paradox denounced by France Alzheimer in its White Paper is that the very care system that is supposed to look after the elderly and the most vulnerable people is relying more and more on the support of family caregivers, which increasingly leads to illness and other problems for these people. Many caregivers in other professional employment alongside their care duties are exhausted, stressed and isolated, as well as facing issues in their work due as a result of this impact and of the time needed to carry out their care duties.

The White Paper was officially unveiled on 21 September, World Alzheimer’s Day and was delivered to Pascale Boistard, Secretary of State for Older People and Autonomy.

21 September: Alzheimer Scotland’s World Alzheimer’s Tartan worn by Game of Thrones actress

Alzheimer Scotland ambassador and Scottish actress, Kate Dickie (pictured, modelling a bespoke frock coat made from the tartan) is perhaps best known for her role as Lysa Arryn on the HBO series Game of Thrones. The cause is close to Ms Dickie’s heart, after losing her mother to early-onset Alzheimer’s dementia.

http://www.alzscot.org/news_and_community/news/3700_world_s_first_alzheimer_s_tartan_unveiled

21 September: EMDA hosts events for World Alzheimer’s Day

Every year, EMDA holds national conferences and conducts informational activities, training and raises awareness on World Alzheimer’s Day (WAD), 21 September.

This year, EMDA has harnessed several organisations involved in the area of Alzheimer to create an evening to raise awareness. A panel, made up of the Minister of Health, the CEO of the National Insurance Institute of Israel, directors of hospitals and directors of healthcare organisations, discussed long-term care insurance.

The association also organised a play to mark WAD, in cooperation with theatres in Jerusalem. The play is 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.

EMDA also held its annual conference at the University of Haifa and for the first time, a lecture was given by a person with dementia, a member of Dementia Alliance International (DAI). Another lecture at the conference was delivered by a senior geriatrician from the rehabilitation centre in Toronto.

21 September: The Alzheimer’s Society UK reports on its World Alzheimer's Day events

World Alzheimer’s Day is one of the most important calendar dates of the year in raising understanding of dementia. This year Alzheimer’s Society ensured that awareness of dementia was spread as far and wide as possible. The day was marked in a number of ways both across Alzheimer’s Society, the UK and around the world.

It started in Los Angeles, where our UK Global Dementia Friends Ambassador, actress Carey Mulligan (pictured), took time out from her busy schedule in the US and delivered a Dementia Friends Information Session to a secondary school in West Hollywood. The Information Session was a huge success and was complemented by articles in several papers and magazines in the UK and USA. Check out Carey Mulligan’s Huffington Post piece to find out more!

A dementia focused supplement was published in The Guardian with a foreword from Jeremy Hughes, our CEO, and a powerful piece from our supporter, Michael Parkinson, highlighting the findings from our Fix Dementia Care hospitals report.
Staff, volunteers and supporters continued to spread the word and tackle stigma of dementia through a variation of activity including delivering Dementia Friends Information Sessions wherever and whenever possible.

To finish the evening our inaugural World Alzheimer’s Ball took place in London. This very special event was organised by Alzheimer’s Society and Dementia UK in partnership with 18 Embassies and High Commissions. The evening sent a powerful message about countries from around the world coming together to champion the dementia agenda and deliver meaningful change. Over 300 guests attended the Ball and raised an astounding GBP 250,000! (EUR 288,800)

Although World Alzheimer’s Day has passed, activity is continuing throughout the rest of World Alzheimer’s Month, and beyond. It has been fantastic to see the passion and engagement of people wanting to change the face of dementia, and we’re looking forward to seeing the impact that this has.

21 September: Alzheimer Uniti Italy commemorates World Alzheimer Day 2016

During the month of September, the various local associations that are part of Alzheimer Uniti Italy (AU) commemorated World Alzheimer Day, as they do each year with various conferences and activities. But this year, AU tried to homogenise the activities throughout the country, in an effort to show unity in their work and programmes. For example, some associations hosted meetings for the public with scientists to explain the most up-to-date programmes for therapy and assistance.

Local associations set up tables in central piazzas, where the public could stop off to gather information. Some associations promoted activities that were based on local customs and habits. For example, Novara and Modena sponsored a day of cycling (“la biciclettata”) whereas others sponsored walks (“walking for memory”), while some had film projections (“memo–films”). Yet others held concerts and had pizza in their piazzas.

In Rome, Alzheimer Uniti hosted its 18th Alzheimer conference at the Campidoglio. This year, the annual Savvy Caregiver prize was given to a Roman man, the son of a person with dementia, who was recognised not only for his extensive care of his mother but also for his support as a spokesperson for the work of associations in the care of people with dementia.

21 September: Professor Magda Tsolaki reports on the Panhellenic Federation’s WAD activities

This September, several activities took place all over Greece to mark World Alzheimer’s Day (WAD).

Conferences and seminars were organised in Athens, Crete (Heraklion) and Rhodes. In Ano Patsia-Athens (under the auspices of the Archdiocese), in the Municipality Ilion of Athens and in many other areas of the Greek capital, in Patra, in Messolongi, in Purgos, in Corfu, in Ioannina, in Chalkida, in Volos, in Chania, in Kimi, in Aliveri, in Serres and in Thessaloniki, plenty of events were organised, where theatrical plays and movie screenings took place, a press conference and an awareness race for Alzheimer’s were held, informative speeches were given, campaigns on social media were launched, there was TV and radio coverage of our events and causes. Finally, memory tests were conducted for people who wanted to get tested.

In 1994, when we began this effort timidly, we could not have imagined that 22 years later, all of Greece would come together in September to struggle against dementia. We live in hope, in years to come, of being one of the first countries in the world WITHOUT DEMENTIA, and we will struggle together with many other countries for the WHOLE WORLD without dementia!

21 September: Alzheimer Nederland launches “Dementia-friendly communities” campaign

Alzheimer Nederland has launched its news “Dementia-friendly communities” campaign.

The campaign’s TV commercial aired for the first time on the evening of 21 September, to mark World Alzheimer’s Day. It can be viewed (in Dutch) on the campaign website:

www.samendementievriendelijk.nl

21 September: Pope Francis delivers World Alzheimer’s Day message

On World Alzheimer’s Day (WAD) 21 September, Pope Francis gave an appeal in Italian, during his weekly Papal Audience in St Peter’s Square, in support of caregivers and people living with dementia:

"Today marks the XXIII World Alzheimer’s Day, whose theme is “Remember Me.” I invite all those present to "remember", with the solicitude of Mary and with the tenderness of the Merciful Jesus, those who are suffering from this disease and their families, to make our closeness to them heard. We also pray for those who are close to persons with dementia, to be able to understand their needs, even the more subtle ones, because they are seen with eyes full of love.”

Federazione Alzheimer Italia did a press release on the subject, picked up by the Vatican Radio, among others.

http://press.vatican.va/content/salastampa/it/bollettino/pubblico/2016/09/21/0661/01480.html
21-26 September: Italy celebrates WAD with guerrilla marketing initiative “AL (z)–CINEMA”

On the occasion of the 23rd World Alzheimer’s Day (WAD), Federazione Alzheimer Italia (FAI) promoted “AL (z)–CINEMA”, the first guerrilla marketing event ever made in Italy, to raise awareness about Alzheimer’s disease in order for people with dementia not to be alone, whether they are family members, friends or strangers.

Imagine yourself sitting down to watch a movie at the theatre and the wrong movie comes on: this is what the Italian audiences who went to the movies on between 21 and 26 September experienced.

Just before the start of the scheduled film, a movie with different content from the expected one was showed and after a few minutes, a voiceover reminded the audience that there are over 700,000 people living with dementia in Italy and the feelings of loss and confusion that the audience was experiencing in the theatre are their companions of every day.

FAI invited audiences to find out more about Alzheimer’s on www.alzheimer.it

Throughout Italy, on almost 400 screens, between 21 and 26 September, almost 150,000 spectators experienced in person, for a few minutes only, something that can evoke the same feeling of confusion and disorientation experienced by people living with dementia, wrote FAI.

Right now awareness of Alzheimer’s disease and other causes of dementia, and of the difficulties encountered by those affected is still very limited in Italy. This initiative aimed, therefore, to better involve the public and the media.

Comments from the spectators in the audience were very different, and were captured, along with a number of interviews, by a FAI film crew in a movie theatre in Milan.

FAI is now producing a video that will be published soon on social media, to tell the experience of these people, helping to fight stigma and raise awareness, delivered by a senior geriatrician from the rehabilitation centre in Toronto.

22 September: The Alzheimer’s Society reports on “The Global Launch of Dementia Friendly London”

People with dementia in London have told us that they want to live in a city where their condition is understood and they are valued as members of the community.

We want to realise their vision of London becoming a Dementia Friendly capital city, where every person with dementia can live as full a life as they choose. A city as dynamic as London can and should be a global leader in dementia care and dementia friendliness.

As a step to making this vision a reality we invited stakeholders from across London together on Thursday 22nd September. The event took place in City Hall, London and included the Deputy Mayor and other Assembly Members, NHS, transport, retail, housing, tourism, emergency services, faith groups and businesses.

Speakers on the night included our CEO Jeremy Hughes, Professor Alistair Burns, the Deputy Mayor, Assembly Members and a carer of a person affected by dementia. Each speaker shared their vision of and commitment to making London Dementia Friendly and highlighted the importance and role of how everyone can make this a reality.

The launch was a great success with nearly 100 attendees. During the launch each person was asked to pledge their support and commitment to attend and join working groups to put together plans and start to take action to turn our vision into a reality.

Over the next six months we will be running roundtable discussions focusing on 11 themes: Health and care, transport, young people, prevention, housing, business, emergency services, tourism, leisure and the arts, faith groups and digital.

The numbers of people affected by dementia has never been greater and the number is increasing every day. The time is now for each of us to recognise the part we must play in creating a Dementia Friendly London for those living with dementia today and for the generations to come. Dementia is a cross society issue and a challenge in London that cannot and must not be ignored.

22-23 September: Slovakia organises 8th International Scientific Conference

On 22-23 September in Bratislava, the Slovak Alzheimer’s Society organised its traditional annual conference “Senior’s Training and Non-pharmacological Intervention for Alzheimer’s Disease” for the occasion of World Alzheimer’s Day.

Lecturers Slovakia, the Czech Republic, Spain, the United Kingdom and Israel presented research and examples of best practices in dementia care. Also, as in previous years, five experiential workshops were organised.

Some of the different themes of the conference and workshops were: “From molecules to cognition”, “Boundary dilemmas for care home workers and resident relationships”, “Post-diagnostic care for people with dementia in the European context”, “Just good intention is not enough... ([Competences of social workers])”, “EURAG Memory Training Center helps to increase self-confidence in seniors around the world”, among others.

The Slovak Alzheimer’s Society hopes to continue this tradition of hosting an event at which delegates leave with plenty of new knowledge and inspiration.
24 September: Spominčica commemorates World Alzheimer’s Day with Memory Walks around Slovenia

Branches of Alzheimer Slovenia (Spominčica), together with retirement homes and other organisations all around Slovenia organised a number of Memory walks and other events, for World Alzheimer’s Month.

The aim of these events was mainly to support people with dementia and their carers, but they also gathered people together to raise awareness about dementia.

On Saturday 24 September, the Ljubljana Memory Walk took place. This year, information points were set up in three different locations: Prešeren Square, in the front of Modern Gallery and in the front of the International Centre of Graphic Arts in Tivoli.

Participants met in front of the Modern Gallery and walked together to the Town Hall, where they were adressed by Vice-Mayor Dejan Crneč.

Transport for people with mobility problems was arranged in the form of two electric vehicles called “Kavalirs” (“Gentlemen”), which ran between the Modern Gallery and the Town Hall.

There was also a short cultural programme and exercises with hula hoops organised in the front of Modern Gallery.

24 September: Luxembourg organises 15th annual Memory Walk

On Saturday 24 September, Luxembourg’s annual Memory Walk took place, starting from the Place Clairefontaine in Luxembourg City. This was the 15th time that the Luxembourgish Alzheimer Association (ALA) organised the event to mark World Alzheimer’s Day. The principal aim of the Memory Walk is to raise awareness among the general public concerning Alzheimer’s and other dementias and to show solidarity with people living with dementia, their families and caregivers.

There were three walks organised throughout the day, starting at 1.00pm, 2.30pm and 3.30pm.

ALA also used the event as an opportunity to talk about the work it is doing and to distribute information about the different types of support it can provide and to share experiences.

Also present at the Place Clairefontaine were colleagues from the Ministry of Health project “Programme Dementia Prévention” (PDP) and the Ministry of the Family’s dementia information centre (f-ZD).

Entertainment was provided in the form of two bands - Jukebox and Heavy Patrol - and the association “Île aux Clowns”.

This year the event slogan was “Seeldanz zwéschent fréier an haut” (tightrope walk between the past and present). For people with dementia, the memories of the past have an important place in their communication and the way we support them, says the ALA. In collaboration with the photographer Gery Oth and the museum “A Possem” in the town of Bech-Kleinmacher, ALA has launched a project to help awaken the past for people with dementia, through the use of a suitcase of antique toys. Residents at the Nursing Home “Beim Goldknapp” and daycare visitors were able to look through and play with the antique toys, providing some great photo opportunities. The resulting photos are available as postcards and were shown and distributed for the first time during the Memory Walk.

Spotlight on: EMDA-The Alzheimer’s Association of Israel

This month, we are shining the spotlight on our Israeli member, with thanks to Avishag Ashkenazi, Head of Information Center and Gery Rot, CEO for writing this piece about the history of the association and some recent events:

The State of Israel has a population of about 8.5 million people. The number of people living with Alzheimer’s disease (AD) and related disorders in Israel is currently estimated at 120,000.

EMDA – The Alzheimer’s Association of Israel was established in 1988 by family members of people with AD. The association began its activity in a support group for family members in Ramat Gan, a city in the Tel Aviv District of Israel. This group of volunteers made considerable efforts to raise awareness and recruit members. However, to run this activity volunteers weren’t enough, because they were preoccupied with taking care of their loved ones who had dementia.

That is why, in 1989, the chairman of the association Dr Shmuel Moran met with the CEO of JDC-Eshel in Israel - an organisation, which EMDA continues to cooperate with to this day - and received a grant to hire a staff member for the association. After receiving the grant a coordinator was hired to coordinate the activities of the association, allowing the association to grow and expand its activities.

By 1993 the association operated ten support groups all over the country and started to reach out to ministers and Members of Parliament. In the same year, it also became a member of Alzheimer Disease International (ADI).

In November 1996, ADI’s international conference was held in Jerusalem. Forty one delegations from around the world attended the conference. The conference dealt with
major issues in the field of AD and social, economic, legal and medical aspects of this disease.

EMDA’s scientific council, headed by Professor Amos Korczyn, held its first meeting in 1997. Members of this committee were top-ranking professionals in the country in the field of dementia.

In 2000, one of EMDA’s accomplishments was the successful conclusion of its long and hard-fought campaign to include medications approved by the Ministry of Health for the treatment of AD in the “Healthcare Basket”, which includes all services, medications, supplies and medical equipment the insured is entitled to receive, according to Israel’s National Health Insurance Law.

In 2004, EMDA started operating the "Activities for Health" project in which volunteers make home visits and provide patients with stimulation based on the activities in the "Activities for Health" kit.

In 2006, Gery Rot became the CEO of EMDA, a role which he remains in to this day.

In 2011, EMDA held a Consensus conference that aimed to determine the guidelines for prevention, diagnosis and therapy of dementia, ranging from core criteria for defining dementia, to identifying risk factors, to medication.

In 2013, The National Plan for Addressing Alzheimer’s Disease and Other Types of Dementia was launched. EMDA is one of the initiators of the National Plan and remains active in its implementation.

In 2014, EMDA held a Consensus conference that aimed to develop a series of recommendations and guidelines for all aspects of non-drug related diagnosis and treatment of dementia, in order to form the basis for improving care provided to people with dementia and their families and to develop policy-relevant issues.

Today, EMDA continues to function through volunteers in branches all over the country. Its financial sources are: annual subscription fees, grants from funds and authorities and donations.

The association is run by a governing council, elected by a general assembly, working together with a scientific council, most of whose members are top-ranking professionals in the country in the fields of medicine, nursing and law.

**Aims:**

- Creation of an informative and emotional support network for families of people with dementia.
- Development of a support services framework for people with dementia and their families.
- Giving information to the public about AD and its problems, rights of people with dementia and families.
- Influencing policy makers to increase the “basket” of services, promoting rights of people with dementia and their families.
- Co-operation with professional bodies.
- Promotion of research on AD, setting up an information centre and a hotline.
- Development of projects aimed at enhancing the quality of life for people with dementia and their families.

**Activities and projects:**

- **Support Groups** - EMDA continues to operate 63 support groups throughout Israel.
- **"Activities for Health" project** - EMDA operates this ongoing project in various regional councils in Israel, covering the main urban areas nationwide.
- **Intervention programme** - EMDA provides individual support to families of people with dementia, according to the model of Professor Mary Mittelman, New York University. Ten local authorities and health service organisations throughout Israel have joined the project.
- **"Music awakening to life" project** - The aim of the project, inspired by the Music & Memory project in US, is to create a personal musical album on MP3 devices for people with dementia living in nursing homes. The song selection is made by conducting interviews with nursing home staff or family members.
- **Dementia Friends** - The aim of the programme is to raise awareness among the general public, about dementia and the difficulties people with dementia encounter, as well as to create dementia-friendly communities. The programme is based on one-hour sessions are given by "Dementia Champions" - volunteers devoted to the cause.
- **Advanced Dementia** - The association is active in training professional staff and family caregivers in various settings, including support groups, seminars, conferences, etc., in order to increase awareness of the needs of people in the advanced stages of dementia, and treatment opportunities.

**Policy watch**

1 September: WHO prepares “zero draft” of global action plan on dementia

In response to the growing public health impact of dementia and following a Draft Decision on dementia urging the WHO to take action on dementia, which was adopted on 30 May at the 139th Executive Board meeting of the World Health Organisation (WHO), WHO has prepared a “zero draft” of the global action plan on the public health response to dementia. The “zero draft” will be used as the basis for informal consultations, it includes the proposed vision, strategic action areas and a set of recommended actions which will improve the care and quality of life of people with dementia, their carers and families and ultimately decrease the impact of dementia on society.

The consultation is open to Member States, UN agencies and other non-State actors such as relevant
nongovernmental organizations, private sector entities, philanthropic foundations, and academic institutions.

More information can be found here: http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/

7 September: WHO announces first WHO Global Ambassador for Non-Communicable Diseases

The World Health Organization (WHO) has announced the appointment of Mr. Michael Bloomberg, philanthropist and former Mayor of New York City, as the first WHO Global Ambassador for Non-Communicable Diseases (NCDs).

NCDs such as Dementia were included for the first time in the Sustainable Development Goals (SDGs) adopted in 2015 and in the newly created position, Mr. Bloomberg will provide support for achieving these goals. This will include health targets on premature mortality, tobacco control, universal healthcare and strengthening health finance in developing countries. It is hoped that he may also support action on dementia as a significant NCD affecting 47 million people worldwide, as the SDGs approach the mid-term review in 2018.

12 September: WHO Regional Committee for Europe 66th Session held

From 12-15 September the 66th session of the WHO Regional Committee for Europe was held in Copenhagen, Denmark.

High on the agenda was the ongoing work on Health 2020, the regional policy framework on health and well-being, and its links to the recently adopted 2030 Agenda for Sustainable Development and its global goals. During the 4 days the RC66 adopted the European strategy and action plan for refugee and migrant health and the European action plan for the prevention and control of NCDs.

Although there was no specific resolution on dementia on the agenda and during the conference there were few references to dementia. The new “Action plan for the prevention and control of non-communicable diseases in the WHO European Region” does mention dementia. For the first time, it recognizes the impact of shared risk factors and co-morbidities such as oral, musculoskeletal and mental health, and identifies air pollution and infectious diseases as risk factors. The Action plan focuses on a balance of prevention and treatment to reduce premature mortality, and acknowledges the contributions of vaccinations and relevant communicable disease control, treatment and secondary prevention.

Of most relevance to Alzheimer Europe is the announcement of a “zero draft” for the development of a draft global action plan on the public health response to dementia.

Other items on the agenda included:

Day 1 RC 66 opens – health central to the 2030 Agenda for Sustainable Development

- Eliminating communicable diseases
- Technical briefing on aligning the monitoring framework for Health 2020 with the SDGs
- Report of the Twenty-third SCRC
- The life-course approach to health and the Minsk Declaration
- WHO reform: progress and implications for the Region
- Events prior to the opening of RC66
- Briefing on the WHO Health Emergencies Programme and accelerating implementation of the IHR
- Briefing on preparations for the Sixth Ministerial Conference on Environment and Health
- Briefing for NGOs

Day 2 RC66 –adopts European strategy and action plan for refugee and migrant health

- Health in the 2030 Agenda for Sustainable Development and a midterm progress report on Health 2020 implementation
- Framework for action on integrated health services delivery
- European strategy and action plan on refugee and migrant health
- European action plan for sexual and reproductive health and rights

Day 3 highlights: agreement on women’s health strategy and action plans for HIV and viral hepatitis

- Discussion on WHO/Europe’s work in emergencies
- Strategy on women’s health and well-being in the WHO European Region
- Action plan for the health sector response to HIV in the WHO European Region
- Action plan for the health sector response to viral hepatitis in the WHO European Region

Day 4 RC 66 –adopts European action plan for the prevention and control of NCDs

- Proposed WHO programme budget 2018–2019
- European action plan for the prevention and control of NCDs
- European action plan to strengthen the use of evidence, information and research for policy-making
- Closing of RC66.

Policy Officer Vanessa Challinor attended on behalf of Alzheimer Disease International (ADI) and Alzheimer Europe.
20 September: Portugal moves a step closer to a national dementia plan

Portugal seems to be edging closer to a national dementia plan, following the launch of a new working group by the coordinator of the Integrated Continuous Care National Network, Professor José Manuel Lopes. The aim of the group is to prepare, as swiftly as possible, recommendations for the government on the main priorities to be included in the future plan.

The group's kick-off meeting took place on 20 September, with the participation of about 20 experts - mainly doctors and researchers, as well as two representatives from Alzheimer Portugal: psychologist Catarina Alvarez, coordinator of the Memory Cafés project and Maria do Rosário Zincke dos Reis, a lawyer dedicated to the legal rights of people with incapacity and also a member of the Alzheimer Europe Board.

Ms Zincke dos Reis had the opportunity to inform the group about the work done and documentation made by Alzheimer Europe over the past few years, highlighting as main issues and priorities for a Portuguese National Dementia Plan: The definition of care pathways for people with dementia and their carers, with special focus on the role of primary care and communication between general practitioners and specialists; Specific training on dementia for professional and family carers; The promotion of the legal rights of people with incapacity and also a member of the Alzheimer Europe Board.

In December 2015, a two-day conference took place in Lisbon about the National Dementia Plan, organised by the Directorate-General of Health and with the participation of various British experts, but not much had happened afterwards, until now.

The main conclusions reached by experts at the December 2015 meeting were:

- The Plan must necessarily be designed as broad guidelines and will not have many details, in order to allow for the specificities of the very different geographical areas: rural and urban, coastal and inland, northern and southern and to take account of the already existing facilities, where specific care for people with dementia is assured.
- The idea is to adapt already existing structures, promoting better articulation among them and the sharing of good practices with a deep investment in professional and family training.
- The Plan is being prepared in the framework of the Mental Health Programme, which recognises the heavy impact of dementia on mental health but does not neglect the neurological origins of many forms of dementia, nor the need to keep in mind the social, economic, ethical and legal impacts.
- In what concerns the legal impact, the Social Security Institute draws special attention to the need to change the current guardianship legislation, mainly to protect people with no family support (the need for professional guardians, for instance).

The next meeting of the new working group will be 11 October and the deadline to send expert contributions is 4 October.

Alzheimer Portugal sees this as a positive step and is hopeful that Portugal is moving slowly closer to having a National Dementia Plan.

26 September: Denmark launches new national action plan on dementia

On 26 September, Sophie Løhde, Minister for Health and the Elderly, officially launched Denmark’s new national action plan on dementia. The plan will run until 2020 with a budget of DKK 470 million (EUR 63 million) and has three main objectives:

- Make Denmark a dementia-friendly country, so that people with dementia and their carers can live a safe and dignified life.
- Develop person-centred treatment and care programmes, based on the needs and values of each individual, with a focus on prevention and early intervention.
- Provide support and encourage active involvement for family members and carers.

Most importantly, the aim of Denmark’s new national action plan on dementia is to make a real difference in the everyday life for all persons affected. Ms Løhde specifically cited the development of more care facilities, an increase in dementia diagnoses and a reduction in the use of antipsychotic medicines.

Alzheimerforeningen, the Danish Alzheimer association, has been actively involved in developing the new plan. Amongst other activities, the association hosted a series of meetings where persons living with dementia had the opportunity to directly address Ms Løhde and members of the national parliament. The participants specifically requested more support with transport and access to more meaningful daily activities – and both of these initiatives are included in the national action plan on dementia.

26 September: MEP Ole Christensen praises new Danish national action plan on dementia

On 26 September, Ole Christensen, MEP (Denmark) provided the following statement on the launch of the new Danish national action plan on dementia:

"As the living age of Europeans continue to rise to a yet unknown stage, the number of dementia patients is increasing as well. Sadly, we know that this disease has severe implications, not only on the lives of the persons diagnosed with dementia, but also on their families. In order to combat and prevent this disease we have to act and we have to act now.

Therefore, I am pleased that a majority of the Danish political parties are earmarking EUR 60 million over a 3-year period through the national dementia strategy."
With the help of the national dementia strategy, support will be provided to families, money will be earmarked for improving research on Alzheimer and other forms of dementia, and a stronger focus on prevention will be provided. These are major improvements.

I sincerely hope that the Danish dementia strategy will show capable of creating better lives for many of those patients who suffer from this terrible disease.”

Alzheimer Europe is very grateful to Mr Christensen and all the other members of the European Alzheimer’s Alliance for helping to make dementia a public health priority in Europe.

28 September: Meeting takes place at the EP on the rights of older persons

The meeting was co-organised by Age Platform, Help Age International and the European Network of National Human Rights Institutions (ENNHRI) and hosted by MEP Lambert van Nistelrooij. Whilst the rights of older people are embedded in international human rights conventions, existing human rights mechanisms have failed to adequately protect and promote their rights. Delegates at the meeting were informed about the activities of the Open-Ended Working Group on Ageing.

This working group was set up by the UN General Assembly in 2010 with the purpose of strengthening the protection of the human rights for older persons. The working group is composed of UN Member States, civil society and other stakeholders. The task of the group was to evaluate the current international human rights framework for older persons, to identify gaps and to consider the possibility of additional instruments and measures.

The suggestion is to develop a new international convention on the rights of older people, so that all people enjoy their human rights in older age, and on an equal basis with others.

In 2014, an Independent Expert on the rights of older persons was appointed by the UN Human Rights Council. This independent expert has assessed how existing international human rights instruments have been implemented in relation to older people’s rights, and has reported on good practices and implementation gaps. Johan ten Geuzendam, Advisor from the Directorate D. Equality. DG Justice and Consumers, emphasised the high financial cost of implementing and monitoring the Convention, and advocated for a better used of existing human rights mechanisms and to strengthen the mainstreaming of the rights of older people. MEPs Heinz K. Becker, Ivo Vajgl and Jean Lambert and Mrs Darja Bvađal Kuret from the Ministry of Foreign Affairs of the Republic of Slovenia also contributed to the discussions and showed their support to the Convention.

Ana Díaz, AE Project Officer attended the meeting.

Science – behind the headlines

27 September: Is there a link between air pollution and Alzheimer’s disease? – Dr Tom Russ comments

Dr Tom Russ is an Intermediate Clinical Fellow and honorary Consultant Psychiatrist at the Centre for Dementia Prevention and Alzheimer Scotland Dementia Research Centre, both at the University of Edinburgh. His research focuses on geographical variation in dementia risk and environmental risk factors for dementia.

Find out more about Dr Russ here: http://edin.ac/29VyW0O

Dr Russ commented based on the following headlines, versus the findings of the study to which they refer: “Air Pollution Particles Linked To Alzheimer’s Found In Human Brain” (Sky News); “Alzheimer’s disease: Condition linked to exposure to air pollution” (Daily Express); “Toxic air pollution particles found in human brains” (Guardian)

Were the headlines right or were they misleading in some way?

This paper attracted a great deal of publicity. Their findings from examining brain tissue from 38 people are exciting and suggest that more attention be paid to the influence of the environment – particularly air pollution – on brain health.

In general, the reporting was appropriately circumspect, though some newspapers did lead with the potential link with dementia. This link is, in fact, an indirect one: magnetite is toxic to the brain and one of the ways it is toxic – by producing reactive oxygen species – has been linked to neurodegenerative diseases.

How important is this story/study for furthering dementia research? Should we be excited?

The researchers examined samples from Mexico City and Manchester using techniques to identify the magnetic content in the brain – being scrupulous to avoid ‘contaminating’ the samples magnetically when they were preparing them. They identified two types of magnetite (an iron ore) in their samples: (1) angular particles which are likely to have been formed in the brain (and which have been previously observed); and (2) rounded particles which resembled those seen in urban air pollution (e.g. from vehicle exhausts and other sources). The formation of such particles requires extremely high temperatures and so they must have been formed outside the body and made their way in, presumably by being inhaled.

We already knew from animal studies that inhaled particulate matter could get into the brain, but here is evidence from humans that air pollution can directly affect the brain. This is an extremely interesting finding but, as is often the case, requires further careful investigation at this early stage. However, this may be the first step towards clarifying exactly how air pollution could be detrimental to brain health.
What might be the impact of this story/study in the scientific community?

There are likely to be numerous environmental factors which increase the risk of developing dementia, including air pollution, exposure to excessive amounts of some trace elements, pesticide use, and vitamin D deficiency (which relates to sunlight exposure). However, several of these – including air pollution – are potentially modifiable and, if this were possible at a population level, it would really be worth pursuing.

Furthermore, the growth in the number of people with dementia in the coming decades is projected to take place predominantly in low-to-middle income countries. It might well be these places where legislation to reduce air pollution could have the biggest effect on health. For example, Mexico City has extremely high levels of air pollution which has been studied in detail by the senior author of this paper (according to the World Bank, Mexico is an upper-middle-income country).

Approximately a third of dementia risk remains unexplained; genetic factors and known modifiable risk factors (smoking, diabetes, hypertension and obesity in middle life, low educational attainment, a lack of physical activity, and depression) also explain roughly a third each. Environmental factors – including air pollution – might well explain a proportion of this unexplained risk. Therefore, we urgently need more research in this area.

What are the next steps?

As with all novel findings, they should be replicated. However, the evidence we already have from observational studies is consistent in its support for the association between air pollution and dementia so this move to elucidate the mechanism is exciting. However, one unanswered question remaining for epidemiology is when exposure to air pollution is most detrimental to brain health – is it a gradual accumulation of damage or are there sensitive or critical periods of exposure? This life course epidemiology perspective, combined with further mechanistic work, should help shed light on the origins of Alzheimer’s disease and other neurodegenerative conditions and lead us closer to our ultimate goal – preventing dementia.

Science watch

26 August: AD may trigger increased expression of lysozyme, which attempts to counteract amyloid build-up

New research suggests that Alzheimer’s disease (AD) may trigger increased expression of an enzyme called lysozyme, which attempts to counteract amyloid build-up in the brain.

Investigators in a study published in the FEBS journal (Federation of European Biochemical Societies) on 26 August found that the expression of lysozyme was increased in the brains of both transgenic mouse models and humans with AD. Furthermore, lysozyme had favourable effects when expressed in different fly models of AD.

The findings indicate that lysozyme may represent an important clinical marker of AD and also point to a new therapeutic strategy that may help slow the disease’s progression.


30 August: Study links antipsychotic use to higher pneumonia risk in people with AD

Antipsychotic medications are associated with an increased risk of pneumonia in persons with Alzheimer’s disease (AD), according to new research from the University of Eastern Finland. The risk of pneumonia was the highest at the beginning of antipsychotic treatment, remaining elevated also in long-term use. No major differences were observed between the most commonly used antipsychotics.

Pneumonia was listed as one of the leading causes of death in the FDA’s 2005 warning on the use of antipsychotics for the treatment of behavioural and psychological symptoms of dementia. Since then, antipsychotics have been linked to an increased risk of pneumonia in several studies, but studies among persons with dementia have been scarce. However, almost one third of Finns with Alzheimer’s disease (AD) use antipsychotic medication.

The association between antipsychotic medication and hospitalisations or deaths due to pneumonia in 2005-2012 was investigated in the nationwide register-based cohort study MEDALZ at the University of Eastern Finland. The study included 60,584 persons with a clinically verified diagnosis of AD. Those who had used antipsychotic medication or had pneumonia within one year before the beginning of the follow-up and those who had schizophrenia and bipolar disorder were excluded from the study. The results were compared to a matched cohort of persons without AD.

The age-adjusted pneumonia incidence during antipsychotic use periods was similar in the AD and non-AD cohort (9.5/100 person-years and 10.2/100 person-years, respectively) while the higher risk of pneumonia among persons with AD was more evident during non-use (4.8/100 person years in those with AD and 2.4/100 person-years in those without AD). Thus, antipsychotic use was associated with a two-fold risk of pneumonia in persons with AD and even a higher relative risk increase (3.43-fold) among those without AD.

The findings indicate that antipsychotic use is linked to a higher pneumonia risk regardless of age, applied study design, treatment duration, choice of medication or comorbidities. In addition, the study only included cases of pneumonia leading to hospitalisation or death, which means that the actual risk increase may be even higher.

Consequently, the risk-benefit balance should be carefully considered when antipsychotics are prescribed, and the
Once inside the cell, toxic amyloid beta disrupts it by interfering with its mitochondria—the compartments that make energy for the cell. The result is that the cell stops breathing and eventually dies.

Armed with the new information about beta sheets, the team now plans to follow what happens after amyloid beta crosses the cell membrane and proceeds to interfere with mitochondria.

One of the things they want to examine is the interaction between amyloid beta and the mitochondria membrane, and whether it is similar to the interaction between the beta sheets and the membrane of the cell.

"Another question we will ask is: Can we manipulate the uptake or formation of these structures so they cannot enter the cell? This may be a therapeutic strategy to help future patients with Alzheimer’s."

http://m.jbc.org/content/291/37/19590.abstract

14 September: BarcelonaBeta Brain Research Center opens its doors

The Pasqual Maragall Foundation has moved its headquarters and brought together all of its scientific activities under one roof, at its new BarcelonaBeta Brain Research Center. The pioneering centre for dementia research opened its doors on 14 September.

The new centre has a high-quality neuroimaging unit and facilities to conduct clinical trials and other cognitive research. It is located in Barcelona’s calle Wellington on the Ciutadella campus of Pompeu Fabra University.

Four of the centre’s seven floors are already taken up, hosting various research programmes for the prevention of Alzheimer’s dementia, including the Alfa Study and the European project EPADD.

There is also a dedicated room for the centre’s “Therapeutic Program Groups for Caregivers”, which houses support group sessions for caregivers of people with dementia, to help provide them with tools to improve their quality of life.

Jean Georges, Alzheimer Europe Executive Director attended the opening.

15 September: Report to help health services prepare for future dementia treatments published

Alzheimer’s research UK (ARUK) has published a report, “Treatments of tomorrow: Preparing for breakthroughs in dementia”, to help health systems prepare for the advent of tomorrow’s dementia treatments.

The report is largely written with the UK’s national health system (NHS) in mind, but provides some interesting insights and recommendations, which could be applicable for any health care system. It outlines some of the complex challenges to be considered and recommends a number of actions, including:
• Better “horizon scanning” to help forewarn the health system about new treatments and diagnostic tools in development.

• Early discussions about the possible impact of disease-modifying dementia treatments between regulators, health system decision-makers, the pharmaceutical industry and non-profits.

• Scope for pharmaceutical companies and the health service to agree early/conditional access to new disease-modifying treatments where appropriate, alongside ongoing “real world” data collection to understand longer-term effects.

http://www.alzheimersresearchuk.org/about-us/policies-reports/treatments-of-tomorrow/

21 September: INTERDEM publishes paper on cost-effectiveness of dementia case management

On 21 September, INTERDEM published a study on the cost-effectiveness of two different types of dementia case management, in the journal Plos One.

The study followed a group of 521 persons with dementia and a close relative with and without case management for two years.

The researchers observed a substantial societal cost saving of between 22% and 35%, depending on the form of case management.

Case management embedded in specialised organisations outperformed case management embedded in generic care organisations (e.g. social care, general practice, home care). Specialised organisations were also able to help maintain a better quality of life for people with dementia and relatives and appeared to be very cost effective as compared with controls and case management from generic organisations.

http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0160908

22 September: Lundbeck says Alzheimer’s drug fails in late-stage study

On 22 September, Danish international pharmaceutical company H Lundbeck A/S announced that its highly anticipated experimental Alzheimer’s drug idalopirdine has failed in a Phase III study involving people with mild to moderate Alzheimer’s disease (AD).

The Copenhagen-based company said both doses of idalopirdine showed a “weak efficacy profile” and failed to reduce cognitive decline measured on the ADAS-cog scale in its “Starshine” study. Lundbeck added that idalopirdine was safe and well-tolerated. The company was testing the drug in combination with donepezil.

Two other late-stage studies of idalopirdine would continue as planned and it expected results from them in the first quarter of 2017.

http://uk.reuters.com/article/us-lundbeck-study-idUKKCN115286

Dementia in society

31 August: Heathrow Airport aims to become more dementia friendly

Heathrow Airport is working with the Alzheimer’s Society (UK) to learn about dementia and offer the best experience it can to travellers living with dementia.

The programme, “Dementia Friendly Communities” is part of the Prime Minister’s Challenge on Dementia 2020, which encourages businesses to become more dementia friendly.

Heathrow has said all 76,000 staff will undergo training based on the Alzheimer’s Society course, to make sure they can provide the best help for passengers with dementia.

The entire frontline Special Assistance team are being trained as Dementia Friends during the month of September. Furthermore, a STAAR (Senior Trained Additional Assistance Role) team has been created, which contains PRM (Passengers with Reduced Mobility) staff. Members of this team receive extra training to support passengers with hidden disabilities.

There has also been work with the security guards at the airport, to help passengers with anxiety. Quiet lounge areas are also being provided.

Actress Carey Mulligan, was recently announced as the Alzheimer’s Society’s first Global Dementia Friends Ambassador. She made a special visit to Heathrow (pictured) with Secretary of State for Health Jeremy Hunt and delivered a Dementia Friends session to some of the airport staff.


22 September: Terry Jones of Monty Python fame has a variant of frontotemporal dementia

A statement published on 22 September on the website of the British Academy of Film and Television Arts in Wales, also known as BAFTA Cymru, said Terry Jones, one of the original members of British surreal comedy group Monty Python has been diagnosed with primary progressive aphasia, a variant of frontotemporal dementia, which is affecting his ability to communicate. Mr Jones is no longer able to give interviews, the statement said.

The statement was released to BAFTA Cymru on behalf of the Jones family.
Living with dementia

4 September: Helga Rohra Chair of EWGPWD writes about being patron of “Move for Dementia” event

On the 4th of September 2016 the event “move for dementia” took place.

It was organised by a community in Enger, Germany, with Mr Guenther Niermann and his team in charge.

As chair of the European Working Group of People with Dementia (EWGPWD) and being myself a person living with dementia, I was invited to be the patron.

The event was held to raise awareness and to show solidarity for people with dementia.

Eleven different European countries (Netherlands, Luxembourg, Belgium, Austria, Spain, Greece, Poland, Lithuania, Switzerland, Italy and Germany) took part in “move for dementia”. All generations from kindergarten to people in nursing homes were active - walking or jogging.

Helga Rohra, Chairperson, EWGPWD

14 September: Agnes Houston Vice-Chair of EWGPWD co-hosts Scottish Conference Gov.Connect

My name is Agnes Houston I am proud to be a founder member of the European Working Group of People with Dementia (EWGPWD) for the last two years.

I was asked to write an article about my experience co-chairing the Gov.Connect Scottish Conference 2016. The other co-chair was the Dr Sue Northrop Vice Chair of the British Psychological Society Scotland.

Let me tell you a little about Gov.Connect - it is a social enterprise dedicated to assisting the wide range of organisations in the UK & EU challenged with delivering health and social care policy they seek to, to ensure that the vision for health and care is delivered upon across all UK and European geographies and administrations.

This dementia Scotland 2016 conference had a wide range of delegates, speakers, sponsors.

It was called “a Human rights-based approach to care” and we followed the dementia language guidelines.

A lot of sharing learning and networking happened at this conference. The venue was a challenge for people with dementia but with some better signage and help it could have been a better experience. I spoke with one of the conference participants about making a signage package and conference guidance that conference organisers could follow so for me this was a good outcome.

Not only did I co-chair but I was asked to talk about the “Dementia and sensory challenges” booklet, which was well received and according to Life Changes Trust 15,000 Copies of the booklet and DVD are currently circulating around the world. Hammond Care has recently taken over the printing and distribution in Australia. This booklet has currently been translated into five other languages. People with dementia and their carers have taken it to General Practitioners audiologists, opticians to help explain their symptoms.

I spent the next two days resting and recovering from participating in this event but for me personally, I believe it’s by continually campaigning and challenging my brain, exercising, doing yoga and eating healthily that I can keep living as well as I can after ten years with a diagnosis of dementia of the Alzheimer type.

Agnes Houston, Vice Chair, EWGPWD

New publications and resources

21 July: Helga Rohra publishes Dementia Activist - Fighting for our rights

Helga Rohra, Chairperson of the European Working Group of People with Dementia (EWGPWD) published a book, “Dementia Activist - Fighting for our rights”, on 21 July.

Speaking about her diagnosis, day-to-day life and experience of advocacy, she shows that a dementia diagnosis is not the end. With helpful advice and practical tips, this book is a testament to living well with dementia.

1 September: Journal of Prevention of Alzheimer’s Disease (JPAD) published

This month the Journal of Prevention of Alzheimer’s Disease (JPAD) Volume 3, Number 3, 2016 was published.

JPAD publishes reviews, original research articles and short reports to help improve knowledge in the field of AD prevention including neurosciences, biomarkers, imaging, epidemiology, public health, physical cognitive exercise, nutrition, risk and protective factors, drug development, trials design and health economic outcomes.

http://www.jpventionalzheimer.com/current-issue.html


On 20 September, Alzheimer’s Disease International (ADI) launched its World Alzheimer Report 2016, “Improving healthcare for people living with dementia: Coverage, quality and costs now and in the future”.

The report argues that healthcare should be holistic and person-centred, treating the whole person
according to their values and preferences, not as a set of separate health conditions or problems.

The report uses economic modelling to analyse the cost implications of the way dementia care is organised, and how care pathways could be more efficient. The report also highlights a lack of research into the effectiveness of key components of healthcare for people with dementia.


Jobs opportunities

6 September: Senior postdoc sought to help develop and implement AMYPAD project

AMYPAD is a European project to establish the true value of amyloid PET in a diagnostic and prognostic setting. This five-year project is a collaboration between industry and academic partners funded by the IMI-2 programme.

Throughout Europe, AMYPAD will recruit 900 memory clinic patients and 3,100 preclinical or prodromal AD subjects from natural history cohorts. Up to 50% of subjects will undergo dynamic scanning and have repeat imaging, for a total of 6,000 amyloid PET scans.

Main study goals include:

- Diagnostic impact including patient-reported outcomes and healthcare resource utilization
- Prognostic value and enrichment of treatment trials, and
- Quantitative assessment of treatment effects.

In close collaboration with EPAD, the cohorts will be followed with careful longitudinal monitoring and MRI to determine (surrogate) outcomes of cognitive decline and neurodegeneration.

The consortium brings together a world-class team of highly synergistic partners to form a pan-European network including the most active PET sites. This will ensure effective access to patients and also maximise exposure to technical knowledge and disease modelling. In addition, AMYPAD will develop expertise in image data collection, including β-amyloid PET and MRI data from the EPAD project.

AMYPAD is currently looking for a (senior) postdoc that will help develop and implement the project in close collaboration with the project leader spanning from research to implementation.

http://ep-ad.org/2016/09/06/sister-initiative-imi-ampad-looking-for-postdoc/

15 September: Alzheimer Europe is looking to fill three Luxembourg-based positions

Alzheimer Europe is looking to fill the following Luxembourg-based positions:

1 Project Officer (m/f) (Full time) - On a permanent basis

As the Project Officer, you will:

- Collaborate with EU projects funded by the Innovative Medicines Initiative
  1. AETIONOMY: Developing a “mechanism-based taxonomy” of Alzheimer’s and Parkinson’s Disease
  2. AMYPAD: Amyloid Imaging to Prevent Alzheimer’s disease
  3. EMIF: European Medical Information Framework
  4. EPAD: European Prevention of Alzheimer’s dementia
- Help in the dissemination of EU funded research projects
- Develop and update the Alzheimer Europe database on clinical trials in Europe
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation’s newsletter and website

1 Project Officer (m/f) (Full time) - For a two-year contract with possibility of extension

As the Project Officer, you will:

- Collaborate with EU projects funded by the Innovative Medicines Initiative
  1. MOPEAD: Models of patient engagement in Alzheimer’s disease
  2. ROADMAP: Real-world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform
- Help in the dissemination of EU funded research projects
- Develop and update the Alzheimer Europe database on treatment guidelines in Europe
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation’s newsletter and website

For either of the two project officer positions, you should have the following experience and qualities:

- Completed university education in a medical or scientific field
Experience in a similar position (background in scientific communication will be considered as an advantage)
A detailed understanding of dementia research and/or clinical trials
A perfect knowledge of English (knowledge of other European languages will be a plus)
Excellent writing and communication skills including communicating scientific concepts in easy-to-understand language
Experience of social media
Good computer knowledge (Internet applications, Word)
A keen sense of responsibility, initiative and ability to work in a small team
Willingness to travel abroad for project meetings, scientific conferences and other networking opportunities

Administrative Assistant (m/f) (Part time) - On a permanent basis

As the Administrative Assistant, you will:

- Support the Alzheimer Europe Board by drafting minutes and preparing Board documents in collaboration with the Executive Director
- Collaborate with the Communication Officer by contributing to the AE newsletter and updating the AE website
- Draft the Annual Report of the organisation
- Proofread documents
- Keep mailing lists and publications database up-to-date
- Respond to general mail requests and deal with filing

You should have the following experience and qualities:

- Completed secondary education and experience in a similar position (education or background in communication or secretariat will be considered as an advantage)
- A perfect knowledge of English (knowledge of French and other European languages will be a plus)
- Good writing and communication skills
- Experience of social media
- Good computer knowledge (Internet applications, Word)
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad for Board meetings on a quarterly basis

Please apply by sending your CV, together with a cover letter (both documents in English), by 7 October 2016, to: Alzheimer Europe, 14, rue Dicks, L-1417 Luxembourg or via E-mail to info@alzheimer-europe.org.

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

Alzheimer Europe Board
Chairperson: Heike von Lützau-Hohlbine (Germany); Vice-Chairperson: Iva Holmerová (Czech Republic); Honorary Secretary: Charles Scerrí (Malta); Honorary Treasurer: Maria do Rosário Zincke dos Reis (Portugal); Members: Marie-Odile Desana (France), Sabine Henry (Belgium), James Pearson (UK - Scotland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Helga Rohra (Germany), Štefanija Lukči Zlobec (Slovenia).

Alzheimer Europe Staff
Executive Director: Jean Georges; Communications Officer: Kate Boor Ellis; Policy Officer: Vanessa Challinor; Project Officer: Ana Diaz; Director for Projects: Dianne Gove; Conference and Event Coordinator: Gwladys Gillory; Finance Officer: Stefanie Peulen; Director for Communication: Alex Teligadas; Administrative Assistant: Grazia Tomasini.

AE Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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</thead>
<tbody>
<tr>
<td>5-6 October</td>
<td>AETIONOMY Steering Committee (Barcelona, Spain)</td>
<td>Jean</td>
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<tr>
<td>10-11 October</td>
<td>AETIONOMY Steering Committee (Barcelona, Spain)</td>
<td>Jean</td>
</tr>
<tr>
<td>13-14 October</td>
<td>AETIONOMY Steering Committee (Barcelona, Spain)</td>
<td>Jean</td>
</tr>
<tr>
<td>14 October</td>
<td>International Awards Mano Amiga (Leon, Spain)</td>
<td>Ana and Helen</td>
</tr>
<tr>
<td>18 October</td>
<td>Lilly Alzheimer’s University (Barcelona, Spain)</td>
<td>Jean</td>
</tr>
<tr>
<td>19 October</td>
<td>3rd meeting of health and social care professionals on dementia (Liubos, Portugal)</td>
<td>Jean</td>
</tr>
<tr>
<td>20-21 October</td>
<td>SMARTAMO (Torremolinos, Spain)</td>
<td>Dianne, Ana and Kate</td>
</tr>
<tr>
<td>24 October</td>
<td>EU Lay Summaries Taskforce (London, United Kingdom)</td>
<td>Ana and Dianne</td>
</tr>
<tr>
<td>25-26 October</td>
<td>PredictND Management Board and Project Meetings (Amersham, United Kingdom)</td>
<td>Jean and Dianne</td>
</tr>
<tr>
<td>27-28 October</td>
<td>Workshop: The Road to 2025: Delivering next generation Alzheimer’s treatment (Lausanne, Switzerland)</td>
<td>Jean</td>
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<tr>
<td>30 October</td>
<td>European Working Group of People with Dementia (Copenhagen, Denmark)</td>
<td>EWGPWD and AE staff</td>
</tr>
<tr>
<td>31 October</td>
<td>INTERDEM Meetings (Copenhagen, Denmark)</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>31 October-2 November</td>
<td>AE Board meeting, AE Annual General Meeting and the 26th Alzheimer Europe Conference: Excellence in dementia care and treatment (Copenhagen, Denmark)</td>
<td>Members of the AE Board, and staff</td>
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## Conferences 2016

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>31 October-2 November</td>
<td>29th Alzheimer Europe Conference (29AEC) on &quot;Excellence in dementia research and care&quot;</td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>10-11 November</td>
<td>EDUCAL 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>
</tr>
<tr>
<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>
</tr>
<tr>
<td>2-5 February 2017</td>
<td>10th Panhellenic Conference on Alzheimer’s Disease and Related Disorders (PICAD) and 2nd Mediterranean Conference Neurodegenerative Diseases (MeCoND)</td>
<td>Thessaloniki, Greece</td>
</tr>
</tbody>
</table>
26th Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016

www.alzheimer-europe.org/conferences #26AEC

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