Welcome!

We have been working particularly hard on our Glasgow Declaration this month, with only a month left until our deadline, now. With your support we have reached 7,400 individual signatures so far, with almost 2,300 new signatures this month alone! We are slowly creeping towards our target of 10,000, but we are not there yet so please continue to sign and share. If you are in any doubt about how important this campaign is to people living with dementia, turn to our “Living with dementia” section and read the article by Helen Rochford-Brennan, Vice-Chair of the European Working Group of People With Dementia (EWGPWD), on why the group supports it and urges people to sign.

In mid-October, we learned of a new European Parliament cross-party Written Declaration on Alzheimer’s disease (AD), launched by 23 MEPs. This Written Declaration shares much common ground with our Glasgow Declaration and we wholeheartedly support it, and are asking MEPs to sign it. You can read more about it in this newsletter in the EU developments section and on the back page.

MEPs who sign our Glasgow Declaration automatically join the European Alzheimer’s Alliance (EAA) and we are delighted to welcome seven new members this month. I extend a warm welcome to them all and hope to see them at our lunch debate on 1 December.

We were also excited to be a part of a “call to action” published in this month’s Lancet journal, on behalf of INTERDEM, AE, ADI and 10 others. It asks the WHO and the World Dementia Council to support large-scale research investment into population-orientated trials and to work with national governments and research funding bodies, encouraging collaboration.

Speaking of action on dementia, there were many articles last month from our members all over Europe, about their World Alzheimer’s Day (WAD) celebrations, and I am delighted to see that in this month’s edition we have some more. Many thanks to our members for sharing with us and for all the great work they are doing to raise awareness and to support people with dementia and their families.

On a less positive note, we are very sorry to have to say goodbye to Rozel Snell - a member of our European Working Group of People With Dementia since 2012. Rozel is no longer able to participate in meetings and has withdrawn her membership. I would like to thank Rozel and her husband, Brian, for their contributions to the group.

Lastly whether you joined us in Ljubljana last month for our 25th Annual Conference (25AEC) or not, you might like to watch our conference trailer and take a look at the photos, either for a trip down memory lane, or to get a flavour of what it was like. These can now be found on our website, as can videos of the plenary speakers.

Have an excellent month, and here’s hoping I can write November’s editorial starting with how successful our Glasgow Declaration campaign has been!

Jean Georges
Executive Director
Alzheimer Europe

23 September: AE contributes to newsletter of Observatory for Socio-political Developments in Europe

On 23 September, the Observatory for Socio-political Developments in Europe published the second edition of its newsletter this year. The focus of the newsletter was on national dementia strategies in Europe, and specifically on best practices in Switzerland and Scotland.

Alzheimer Europe (AE) was one of the main contributors to the newsletter (pages 7 and 8), as were our members, Association Alzheimer Suisse and Alzheimer Scotland.


13-14 October: Two AE Board members attend Hungarian dementia conference

The first Hungarian conference on “Inter-professional Dementia Approach” (INDA) was held in Mátraverébél-Szentkút, Hungary, on 13 and 14 October. It was hosted by the Hungarian Roman Catholic Church Aid, as one of the outcomes of its INDA Programme. The conference was chaired by its director Dr. Agnes Egervári.

The conference programme aimed at contributing to the process of social inclusion of persons with dementia and their family caregivers, and to set up an inter-professional base for the foundation of the Hungarian Dementia Strategy.

Two members of the Alzheimer Europe (AE) Board were among the invited speakers. AE Honorary Secretary, Dr Charles Scerri presented the Dementia Strategy of Malta and AE Vice-Chair, Prof. Iva Holmerova spoke about the quality of the Czech Alzheimer Society’s dementia care certification system. Both AE Board members also introduced the activities of Alzheimer Europe, and expressed their hope that Hungary might also become a member of Alzheimer Europe.

Alongside Dr Egervári, they also invited participants to support and promote the Glasgow Declaration.

19 October: EWGPWD waves goodbye to Rozel Snell, welcomes Karin Gustafsson

This month, we received news that Rozel Snell will leave our European Working Group of People With Dementia (EWGPWD). Her husband, Brian, contacted us to let us know that Rozel will no longer be in a position to participate in meetings and will sadly bow out of the group as a result.

Rozel was born in 1944 in Southampton and grew up in Jersey. She was diagnosed with Alzheimer’s disease and Parkinson’s disease. She was one of the founding members of the EWGPWD in 2012. We would like to thank Rozel for her important contributions and Brian for supporting his wife at meetings.

On another note, we would also like to say welcome to new member, Karin Gustafsson from Sweden, who will join the group’s next meeting in December. Karin has dementia and lives with her husband Lars, who is her carer. They live in Göteborg in Sweden. Karin was nominated by Alzheimer Sverige.

Pictured: Rozel and Brian Snell, dancing together at the recent #25AEC gala dinner in Ljubljana, Slovenia.

23 October: Call to action by INTERDEM, AE, ADI and others published in Lancet journal

On 23 October, the Lancet journal published a letter, “Dementia prevention: call to action” from INTERDEM, Alzheimer Europe (AE), Alzheimer’s Disease International (ADI) and 10 others.

The letter, which appears in the “correspondence” section of the journal, draws the reader’s attention to the importance of research into dementia risk reduction, particularly “since development of a cure for dementia by 2025 is unlikely”.

The authors stress the “urgent need for large, definitive, multicentre, international randomised controlled studies” into lifestyle-based interventions, stating that “at present, recommendations are undermined by the absence of well designed, properly scaled clinical and population-based trials”.

The letters closes with a call to action, addressed to the World Health Organization (WHO) and the World Dementia Council, asking them to “support large-scale research investment into these urgently needed population-oriented trials and to work with national governments and research funding bodies to encourage collaboration towards a concerted objective.”

You can read the full letter in the Lancet online:

http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2815%2900528-0/fulltext

28 October: Photos, videos and trailer from 25AEC are on our website

Alzheimer Europe (AE) held its 25th Annual Conference (25AEC) in Ljubljana, Slovenia from 2 to 4 September 2015 under the motto “Dementia: putting strategies and research into practice”, co-organised with Alzheimer Slovenia (Spominčica).

Photos and videos from the conference are now available on our website:

http://alzheimer-europe.org/Conferences/Previous-conferences/2015-Ljubljana/Photo-Gallery-and-Videos

There is also a trailer of the conference available, which gives a flavour of what the conference was like, for those who were unable to attend, and serves as a nice walk down memory lane for those who were:

https://www.youtube.com/watch?v=6i29MRx31E&feature=share
29 October: Glasgow Declaration campaign gets closer to target, thanks to your support

The Glasgow Declaration campaign has had an excellent month, attracting almost 2,300 new individual signatures, making a total of 7,373 at the time of writing.

15 policymakers have signed since the start of October (making a total of 96, including 80 MEPs):

MEP Bogdan Wenta (Poland), MEP Eleftherios Symandinos (Greece), MEP Elissavet Vozemberg (Greece), County Executive Dariusz Stopa (Siedlce, Poland), MEP Roberta Metsola (Malta), MEP Therese Comodini Cachia (Malta), MEP Dominique Bilde (France), Mrs Lotta Ahola, Member of the Municipal Council (Finland), Mrs Ulla-Maj Salin, Member of Municipal Council (Finland), MEP Elżbieta Łukacijewska (Poland), MEP Krystyna Lybacka (Poland), MEP Jan Olbrycht (Poland), MEP Alfred Sant (Malta), MEP Miltiadis Kyrkos (Greece), Ivo Komisic, Mayor of Sarajevo (Bosnia and Herzegovina).

A whopping 47 organisations signed this month (making a total of 141):

- Lodz Alzheimer Association (Poland), COTEC Europe, European Union of Women (EUW) British Section, Alzheimer Albania, Udruženje AIR (Bosnia), Society of psychosocial research and intervention (S.P.R.I.-EPSE – Greece), Expertisecentrum Dementie Vlaanderen (Belgium), Polish Association of Long Term Care, Memory Consultation CH (France), A.M.A.T.A. Umbria (Italy), University of Bradford School of Dementia Studies (UK), Ogapp (Abteilung für Alterspsychiatrie und Alterspsychotherapie - Austria), Alzheimer Slovakia, Pasqual Maragall Foundation (Spain), BarcelonaBeta Brain Research Center (Spain), Across Limits (Malta), French Federation of Memory Centres (FCMRR), Find Me If You Care (Poland), Jämssän Muistihdystys ry (Finland), Helsingin Alzheimer-Yhdistys ry (Finland), Kanta-Hämeen Muistihdystys ry (Finland), Savonlinnan Seudun Muistihdystys ry (Finland), Pieksämäen Muistihdystys ry (Finland), Poljoksi-Karjalan Musti ry (Finland), Gerontologisches Zentrum (Austria), YoungDementiaUK, Dementia UK, AGE Platform Europe, NEIL Dementia Research Programme at TCD (Ireland), Association for Assistance to Persons with Alzheimers Disease and Other Mental Disorders in Elblag (Poland), Faculty of Old Age Psychiatry at the Royal College of Psychiatrists (UK), Wielkopolskie Stowarzyszenie Alzheimerskie (Poland), Małopolska Fundacja Pomocy Ludziom Dotkniętym Chorobą Alzheimera (Poland), Sociedad Española de Geriatría y Gerontología (SEGG - Spain), Neurology Clinic Pleven (Poland), Federación Española de Enfermedades Raras (Spain), Hearts and Minds UK, City of Sarajevo (Bosnia and Herzegovina), Faculty of Philosophy, University of Sarajevo (Bosnia and Herzegovina), Matia Fundazioa (Spain), Bydgoskie Stowarzyszenie Opieki Nad Chorymi z Otepieniem Typu Alzheimerowskiego (Poland), Norfolk Community Health & Care NHS Trust (UK), Janssen EMMA, Greek Dementia Society, Austrian Society of Geriatrics and Gerontology (ÖGGG), Alzheimer Catalonia (Spain), BANU Bosniak Academy of the Sciences and Arts (Bosnia and Herzegovina).

We are extremely grateful to all who are supporting this important campaign and most particularly to those individuals, policymakers and organisations who are helping us to spread the word – we couldn’t do it without your help!

We would also like to thank Alzheimer Slovakia and Nasjonalforeningen for folkehelse (Norway) for their translations of the Declaration this month. The Declaration is now available in a total of 18 languages, as is the online sign-up form.

The closing date for signatures is 30 November 2015.

#GlasgowDeclaration #dementiamatters

http://alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014

EU projects

1 October: AFE-INNOVNET promotes EU Covenant on Demographic Change on UN Older Persons Day

AFE-INNOVNET used this day as a platform to promote its upcoming EU Covenant on Demographic Change, via a press release and the use of social media.

The Covenant aims to gather all local, regional and national authorities, and other stakeholders, that commit to cooperate and implement evidence-based solutions to support active and healthy ageing as a comprehensive answer to Europe’s demographic challenge.

It will be launched on 7 December 2015 at the Committee of the Regions in Brussels.

http://afeinnovnet.eu/content/towards-covenant

1-2 October: PredicTND meets in Perugia to discuss progress with the project

Members of the PredicTND project met in Perugia (Italy) on 1-2 October.

The group discussed progress on all the work packages, the recent European Commission review and in particular the recruitment process for the prospective study and for the low-cost predictive tools study involving games and tests on a citizen portal. Dianne participated in this meeting.

3 October: DECIDE papers appear on a new open access platform

A new open access website called Zenodo will host many of the publications from the DECIDE project, which ran from 2010-2013.

This is part of a European Commission pilot action to fund open access peer-reviewed publications from finalised FP7 projects. FP7 was the EU’s 7th Framework Programme for Research and Technological Development that funded the DECIDE project.
DECODE, or “Diagnostic Enhancement of Confidence by an International Distributed Environment”, brought together 13 partners - including Alzheimer Europe - to develop and launch an e-service that allows the early diagnosis of Alzheimer’s and other neurodegenerative diseases.

Several of the project publications are already available on the website and more are expected to follow.

https://zenodo.org/collection/user-fp7-decide

3 October: PharmaCog researchers show progress at ECCN conference

The PharmaCog project was very well represented at ECCN, the 15th European Congress on Clinical Neurophysiology that took place in Brno, Czech Rep. during 30 September - 3 October 2015.

Susanna Lopez presented the following papers:

- “Auditory oddball event-related potentials cortical sources are related to cerebrospinal fluid (CSF) β Amyloid (Aβ) level in amnestic MCI subjects.”
- “Abnormal delta cortical sources of resting state eyes closed EEG rhythms correlate with cerebrospinal fluid (CSF) β Amyloid (Aβ) level in amnestic MCI subjects.”
- “EEG markers of motor activity in physiological aging and Alzheimer’s disease mouse models.”

Claudio Babiloni presented:

- "Of Mice and Men: impact of Alzheimer’s disease on cortical generation of EEG rhythms in mice and humans towards a true translational mode.”
- "Cortical Generation of On-going "Delta" and "Alpha" EEG Rhythms in Mouse Models of Alzheimer’s disease and Alzheimer’s disease Patients at Prodromic and Manifest Stages.”


14-15 October: Craig Ritchie spreads the word about EPAD in Australia

On 14 October, Professor Craig Ritchie (pictured), ambassador for the European Prevention of Alzheimer’s dementia (EPAD) Initiative, gave a lecture in Melbourne, Australia. The Wicking Trust Public Lecture is attended by various representatives of leading research bodies, policy think tanks, care providers, consumers and carers.

Prof. Ritchie’s primary goals were to share information about EPAD, enlist support for the project and get local scientists involved.

On 15 October, Prof. Ritchie continued his campaign on Australian radio. You can listen to what he said here: https://radio.abc.net.au/programitem/pge4GxlQnG?play=true


15 October: EPAD team members meet Princess Anne in Scotland

On 15 October, Luc Truyen (pictured) along with the University of Edinburgh team represented the EPAD consortium at a University event to launch the new offices for the Centre for Clinical Brain Sciences. They had the honour of introducing the project to Her Royal Highness, Princess Anne.

Alzheimer Europe networking

On 3 September (Ljubljana, Slovenia) Jean had an introductory meeting with representatives of Merck to explore areas of future collaboration.

On 4 September (Ljubljana, Slovenia) the Executive of Alzheimer Europe and Jean met with a delegation of Lilly to discuss the ongoing collaboration.

On 16 and 17 September (London, United Kingdom) Jean attended the Patients and Consumers Working Party of the European Medicines Agency.

On 28 September (Luxembourg, Luxembourg) Jean met with representatives of the European Commission to discuss EU priorities on dementia.

On 1 October (Dublin, Ireland) Ana attended the launch of the Alzheimer Society of Ireland Pre-Budget Submission for 2016.

On 1-2 October (Dublin, Ireland) Ana attended the In-MIND policy symposium.

On 1-2 October (Perugia, Italy) Dianne participated in the PredictND consortium and management meeting.

On 14 October (Brussels, Belgium) Vanessa participated in the Brain, Mind and Pain EP Interest Group meeting.

On 20 October (Brussels, Belgium) Vanessa participated in the Eurocarners EP Interest group meeting.

On 28-19 October (Brussels, Belgium) Vanessa participated in the EFPIA Health Collaboration Summit.

On 30 October (Brussels, Belgium) Vanessa participated in a European Patients’ Forum (EPF) working group on Access.
Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 122, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance:

**Austria:** Heinz K. Becker (EPP); Kappel Barbara (NI); Rübig Paul (EPP)

**Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE);

**Croatia:** Biljana Borzan (S&D);

**Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP);

**Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D)

**Estonia:** Urmas Paet (ALDE);

**Finland:** Liisa Jakonsaari (S&D); Anneli Jääteenmäki (ALDE);

**France:** Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP);

**Germany:** Angelika Diebler (EPP); Udo Voigt (NI);

**Greece:** Costas Chrysoyagos (GUE/NGL); Manolis Kefalogiannis (EPP);

**Hungary:** Ádám Kósa (EPP);

**Ireland:** Lynn Boylan (GUE/NGL);

**Italy:** Brando Benifei (S&D); Elena Gentile (S&D); Pier Antonio Panzeri (S&D);

**Lithuania:** Vilija Blinkeviciute (S&D);

**Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE);

**Malta:** Therese Comodini Cachia (EPP);

**Netherlands:** Esther de Lange (EPP);

**Poland:** Marek Plura (EPP); Ewa Kaczyńska (EPP); Wiola Gajewska (EPP);

**Portugal:** Euros António (S&D);

**Romania:** Cristian Silviu Busoi, MEP (EPP);

**Slovakia:** Miroslav Mikolásik (EPP); Anna Zábořská (EPP);

**Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D);

**Spain:** Sergio Gutiérrez Prieto (S&D);

**Sweden:** Johan Schumacher (S&D);

**Switzerland:** Guy Graf (S&D);

**United Kingdom:** Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

**Cyprus:** Eleftherios Synadinos (NI);

**Croatia:** Miroslav Mikolásik (EPP); Anna Záborská (EPP);

**Germany:** Angelika Deibler (EPP);

**Greece:** Costas Chrysoyagos (GUE/NGL); Manolis Kefalogiannis (EPP);

**Italy:** Brando Benifei (S&D); Elena Gentile (S&D);

**Lithuania:** Vilija Blinkeviciute (S&D);

**Malta:** Therese Comodini Cachia (EPP);

**Netherlands:** Esther de Lange (EPP);

**Poland:** Marek Plura (EPP); Ewa Kaczyńska (EPP);

**Portugal:** Euros António (S&D);

**Romania:** Cristian Silviu Busoi, MEP (EPP);

**Slovakia:** Miroslav Mikolásik (EPP); Anna Zábořská (EPP);

**Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D);

**Spain:** Sergio Gutiérrez Prieto (S&D);

**Sweden:** Johan Schumacher (S&D);

**Switzerland:** Guy Graf (S&D);

**United Kingdom:** Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

**Cyprus:** Eleftherios Synadinos (NI);

**European Alzheimer’s Alliance**

23 October: Seven MEPs join European Alzheimer’s Alliance in October

Alzheimer Europe is very pleased to welcome seven more MEPs to the European Alzheimer’s Alliance (EAA) this month. Each became an EAA member upon signing AE’s Glasgow Declaration, which calls for the creation of a European Dementia Strategy:

- MEP Bogdan Wenta (Poland)
- MEP Eleftherios Synadinos (Greece)
- MEP Eliassavet Vozemberg (Greece)
- MEP Krystyna Lybacka (Poland)
- MEP Jan Olbrycht (Poland)
- MEP Alfred Sant (Malta)
- MEP Miltiadis Kyrkos (Greece)

**EU developments**

17 September: Commission and WHO Europe increase their cooperation

On 17 September it was announced that the European Commission (EC) and the World Health Organisation’s Regional Office for Europe (WHO EURO) were renewing their joint commitment to work together towards their shared objective of better health in Europe.

EC Health and Food Safety Commissioner, Vytenis Andriukaitis and WHO EURO Director, Zsuzsanna Jakab met and outlined the objectives:

Both entities committed to scale up cooperation in the following areas:

- innovation
- health security
- health information
- health inequalities
- health systems
- chronic diseases


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**European Dementia Strategy: Glasgow Declaration**, which calls for the creation of a European Dementia Strategy. Each became an EAA member upon signing AE’s Glasgow Declaration, which calls for the creation of a European Dementia Strategy.
1 October: EPF launches Patient Empowerment Campaign video

In May 2015, the European Patients’ Forum (EPF) launched a major one-year campaign on Patient Empowerment. On 1 October, an official video was launched to complement the campaign, in which the EPF have asked patients to share their views on what patient empowerment means to them.

The aim of the campaign is to build the momentum for the real empowerment of patients in Europe and to promote the development and implementation of policies, strategies, as well as healthcare and social services, to empower patients to be involved in decisions about and management of their conditions.

#PatientsPrescribe

https://www.youtube.com/watch?v=RZaHrqn2RP4

1 October: Guido Rasi nominated Executive Director by EMA for 2nd time

On 1 October, the European Medicines Agency (EMA) nominated Professor Guido Rasi for the position of Executive Director.

Prof. Rasi, who was selected from a shortlist of candidates provided by the European Commission, previously served as Executive Director from 2011 to 2014, before he was forced to step down from the position due to a procedural issue.

His appointment is yet to be approved by the European Parliament.

1-2 October: The In-MINDD team hosts a policy symposium in Dublin

In-MINDD (INnovative, Midlife Intervention for Dementia Deterrence) (2012-2015) is an FP7-funded project which aimed at promoting long-term brain health and prevent or at least delay the onset of dementia by combining social innovation, multifactorial modelling and clinical expertise.

The policy symposium was attended by fifty dementia experts from across Europe. Insightful presentations were given by Dr Edo Richard, Jurgen Scheflein (EU Commission), Prof Alina Solomon and the In-MINDD team. Attendees were also invited to participate in several round-table discussions over the 2 days, examining how dementia prevention should be translated into policy.

Ana Diaz, AE Project Officer attended the symposium and chaired one of the break-away sessions.

6 October: AD features as a topic of Innovative Medicines Initiative 6th Call for proposals

On 6 October, the Innovative Medicines Initiative (IMI) launched its 6th Call for proposals under IMI 2.

One of the topics under the new Big Data for Better Outcomes programme is “Real World Outcomes Across the Alzheimer’s disease (AD) Spectrum (ROADS) to Better Care”.

The deadline for submitting short proposals under Call 6 is 12 January 2016.


12 October: European Commission invests EUR 16 billion in research

On 12 October, the European Commission programme, Horizon 2020 (H2020) Work Programme for 2016-2017 was adopted. It outlines the calls and funding opportunities available over the next two years, and offers a total budget of almost EUR 16 billion.

In line with Commissioner Carlos Moedas’ strategic priorities, “Open Science, Open Innovation, Open to the World,” the new Work Programme offers funding opportunities through a range of calls for proposals, public procurements and other actions covering nearly 600 topics.


12 October: MEPs launch Written Declaration calling for European Alzheimer’s disease strategy

23 MEPs have submitted a Written Declaration on Alzheimer’s disease which invites the European Commission and the Council to recognise Alzheimer’s disease and related diseases as a public health priority in Europe and to adopt a comprehensive strategy to meet the challenges presented by Alzheimer’s disease and to promote research aimed at developing sustainable treatment solutions and efforts to improve the efficient provision of information and support to carers.

Alzheimer Europe gratefully acknowledges this initiative launched by the following Members of the European Parliament:

- Philippe De Backer (Belgium, ALDE)
- Filiz Hysusmenova (Bulgaria, ALDE)
- Ivan Jakovčić (Croatia, ALDE)
- Ruža Tomašić (Croatia, ECR)
- Neoklis Sylikiotis (Cyprus, GUE/NGL)
- Dominique Bilde (France, ENF)
- Sophie Montel (France, ENF)
- Luke “Ming” Flanagan (Ireland, GUE/NGL)
- Brian Hayes (Ireland, PPE)
• Mara Bizzotto (Italy, ENF)
• Aldo Patriciello (Italy, PPE)
• Remo Sernagiotto (Italy, ECR)
• Valentinaz Mazuronis (Lithuania, ALDE)
• Rolandas Pakas (Lithuania, EFDD)
• Jaroslaw Kalinowski (Poland, PPE)
• Cristian-Silviu Busoi (Romania, PPE)
• Emilian Pavel (Romania, S&D)
• Ivan Štefanec (Slovakia, PPE)
• Patrizia Šulin (Slovenia, PPE)
• Romana Tomc (Slovenia, PPE)
• Ivo Vajgl (Slovenia, ALDE)
• Milan Zver (Slovenia, PPE)
• Enrique Calvet Chambon (Spain, ALDE)

A Written Declaration is a text of a maximum of 200 words relating exclusively to a matter falling within the competence of the European Union. A Written Declaration can be submitted with a minimum of 10 MEPs’ signatures from at least three political groups. They then have three months to present it to their colleagues for signature. For the declaration to get to the next stage and be forwarded to the EU institutions named in the text it must attract more than half of all MEPs’ signatures (376). If it has not been signed by at least half of the MEPs it will lapse.


14 October: Brain, Mind and Pain EP Interest Group hosts meeting

On 14 October, the European Parliament Interest Group on Brain, Mind and Pain, in partnership with the Interest Group on Mental Health, Wellbeing and Brian Disorders, hosted a meeting on “Tackling the Stigma of Brain, Mind and Pain Disorders”.

The meeting brought together patients and professionals for a discussion on stigma. Personal stories were presented from the points of view of: a person affected by chronic pain, the parent of a child affected by ADHD, and the daughter of a person affected by Dystonia.

Following these very personal accounts, three professionals presented evidence of stigma. Prof. Matilde Leonardi, Neurologist, Besta National Neurological Institute presented the findings of the European Federation of Neurological Associations (EFNA) Patient Experience Survey. Paul Arthe, Executive Director, GAMIAN-Europe presented the Pan-European Stigma Survey, and Joop van Griensven, President, Pain Alliance Europe presented Patient Pain Pathway recommendations.

The evidence presented showed that stigma is very real and needs to be addressed for those with mental illness to be more included in society, rather than isolated. One of the main issues raised was mental health in the work place. Many people felt opportunities were lost due to their illness, and it was difficult to disclose mental health issues to employer. In some cases, people even found it difficult to disclose to a health professional, whom they felt often lacked understanding, or made them feel even more stigmatised.

The question of how to address the gap in Mental Health Services and allow those living with mental illness to speak out and express their needs was raised. Brain disorders cost Europe twice as much as cancer, but mental health is still vastly underfunded. It was felt that the European Union should take responsibility for dealing with these issues and raising the profile of mental health issues.

In summing up, Michel Hübel, European Commission (EC) said EU actions have given greater recognition to mental health as a priority, but much more could still be done. He talked about the work of the current Joint Action on Mental Health which will end in January 2016 and said the EC is already looking ahead to the next stage. He also agreed that research needs to be looked at and said this had been discussed at the Luxembourg EU Presidency meeting of health ministers, with regard to dementia research.

The meeting was co-chaired by MEPs Marian Harkin and Nessa Childers, both from Ireland.

Policy Officer Vanessa Challinor attended on behalf of Alzheimer Europe.

20 October: Meeting of European Parliament Interest Group on Carers and Eurocarers network

On 20 October, the European Parliament (EP) Interest Group on Carers and the Eurocarers network organised an event on “Carers in the European Semester Process” in Brussels, Belgium. The objective was to highlight this European Semester’s focus on health and long-term care, and discuss how this channel could be used to place a stronger focus on carers.

Christoph Schwierz, European Commission (EC) Directorate General for Economic and Financial Affairs (DG ECFIN) gave a presentation, entitled “The European Semester: Is there room for carers?” Mr Schwierz spoke about how to advise Member States (MS) on health budgets and the fiscal sustainability of health systems, as well as how the European Semester could be helpful with country specific recommendations (CSRs) to MS, for addressing long-term care (LTC).

In light of the ageing population and coping with LTC, spending remains a major challenge and appropriate policy action needs to be taken in all health-related areas, including LTC. At present, there are no official statistics on informal care in the EU, but it is estimated that the split between formal and informal care could be about 50-50. Next on the agenda was Stecy Yghemonos, Director of Eurocarers, talking about promoting the needs and added value of informal carers at EU level. Mr Yghemonos stressed the importance of putting informal carers on the EU agenda and re-emphasised the ageing population and resulting increase in demand for LTC.

This event was chaired by MEP Marian Harkin and supported by MEPs Heinz Becker, Jean Lambert, Marian Harkin and Sirpa Pietikainen.

Panelists were Philippe Seidel, Age Platform Europe, Luk Zelderloo, European Association of Service providers for
People with Disabilities, and Paul De Raeve, European Federation of Nurses. All panelists agreed that carers play a fundamental and indispensable role in the provision of LTC and that they should be recognised for their important contributions and be more formally supported at EU level.

Policy Officer Vanessa Challinor attended on behalf of AE.

Follow us on Twitter

Members’ news

2 September: Alzheimer Slovenia volunteers participate in AE’s 25th annual conference

Alzheimer Slovenia (Spominčica), had a rich and eventful September. The association began the month with the launch of Alzheimer Europe (AE)’s 25th Annual Conference in Ljubljana’s congress centre, Cankarjev dom. The conference was attended by 560 delegates from Europe and further afield, as well as 160 lecturers from various fields associated with dementia.

Spominčica ran an interesting initiative for volunteer participation at the conference. These motivated and dedicated volunteers also took part in a training related to the association’s project, “Living with dementia at home”. They will help people with dementia and their families in their homes in the future. At the conference they helped delegates with dementia, by offering orientation support, assistance in the special “quiet room” for delegates with dementia and their carers, companionship and any other required assistance at the conference centre.

To celebrate the 25th anniversary of Alzheimer Europe’s Annual Conference, Spominčica also issued a commemorative postage stamps for Slovenia and foreign countries, as well as postcards in English and Slovenian (pictured).

14 September: Results of France Alzheimer survey of persons with dementia are surprising

In April this year, France Alzheimer launched a large national survey to gather opinions from people living with dementia in France.

The results were published on 14 September, some of which are surprising:

While 79% of respondents said they can no longer perform daily tasks themselves (eating, dressing, driving...) and 54% said they had mobility problems, only 22% felt that they were no longer “the same person”.

While 75% felt their families were there for them and taking good care of them, 66% said they felt unable to talk to their loved ones about their condition and feelings, for fear of upsetting them or hurting them.

It is also interesting to read that only 4% of survey respondents mentioned finding a treatment, when asked what they felt was needed for people living with dementia.

Some of the advice given to others living with dementia, by respondents was:

- Do what you enjoy
- Live one day at a time
- Accept help and support with daily tasks

More information about the awards, as well as the list of winners can be found here:


16 September: Results are in for 2015 Dementia Friendly Awards UK

The winners of the Dementia Friendly Awards 2015 were announced at a ceremony in London on 16 September. These awards celebrate and showcase the important work people across the UK have done over the course of 12 months, to create dementia-friendly communities and improve the lives of people living with dementia and their carers.

More information about the awards, as well as the list of winners can be found here:


24 September: Scotland’s Dementia Awards 2015

The winners of Scotland’s Dementia Awards 2015 were announced at an awards ceremony on 24 September 2015 at the Marriott Hotel in Glasgow, in celebration of World Alzheimer’s Day.

These awards provide an opportunity for professionals and communities, who are committed to enhancing the health, wellbeing and experience of people with dementia and their families, to have their work recognised and promoted.

The list of winners for 2015 can be found here:


28 September: “Blue Wave” Dementia Friends initiative launched in Turkey

The Turkish Alzheimer Association has started a Dementia Friends initiative, called “Blue Wave”, in the hope it will soon spread over the whole country like a wave.

The aim of the programme is to raise awareness among people of any age, gender, health or social status. In order to accomplish this aim, face-to-face meetings have begun, and an online system is being developed.

The subjects covered in these meetings are:

- The fact that dementia is not a natural part of ageing, is caused by diseases of the brain and is not just about losing memory;
• What happens as the disease progresses, what the initial symptoms are, who the risk groups are and what can be done to reduce the risks;
• That it is possible to live well with dementia, in dignity and that there is more to the person than the dementia;
• The services provided by the Association - all services are free of charge - more information through web, Facebook, Twitter and videos.

As a pilot, seven face-to-face meetings have been held since 28 September, and more than 250 people have participated in these meetings and received blue Alzheimer-Friend-bracelets.

The Association is now working on a portal and an app, in order to eliminate constraints of distance or time.

Intense networking efforts are being made to get more volunteer groups (local administrations, charity groups, other NGOs, hospitals, pharmaceutical companies, GSM companies, etc.) in the pool, to expand the coverage area quickly.

6 October: AMPA Monaco has a new website

On 6 October, the Association Monégasque pour la recherche sur la maladie d’Alzheimer (AMPA), our member in Monaco announced its new website http://ampa-monaco.com/fr/

7 October: Cyprus Alzheimer Association hosts an evening of musical memories

On 7 October, the Cyprus Alzheimer Association organised a musical event entitled “Memories” in the Presidential Palace in Nicosia. The event was held under the auspices of Ms Andri Anastasiades, First Lady of the Cypriot Republic.

In her welcoming speech, the First Lady praised the achievements of all the volunteers of the Association.

The event was attended by 250 people in the presence of the Minister of Health, the Commissioner for Children’s Rights and Law Commissioner, the Commissioner for Volunteerism and Non-Governmental Organisations, the Commissioner for Personal Data Protection and a representative of the Environment Commissioner.

Musical entertainment was provided by a talented pianist and three singers, who delivered a set of “golden oldies”, still beloved by all. This was symbolic as people with dementia often retain long-term memories of their favourite music. The President of the Cyprus Alzheimer Association, Mrs Noni Diakou emphasised the important role that music can play to improve the quality of life of people living with dementia.

9 October: Jeremy Hughes receives CBE from Queen Elizabeth II

On 9 October, Jeremy Hughes, Chief Executive of the Alzheimer’s Society (UK), received his CBE (Commander of the Most Excellent Order of the British Empire) for services to older people, from Her Majesty Queen Elizabeth II (pictured).

As previously reported by Alzheimer Europe (AE) in an article dated 12 June, Mr Hughes was awarded the CBE in this year’s Queen’s Birthday Honours list.

Speaking about receiving his award at Buckingham Palace, he said:

“I am honoured by this award and the recognition it gives to Alzheimer’s Society’s fantastic achievements. I am extremely proud of the advances we have made in increasing funding into dementia research...However, more still needs to be done”. Mr Hughes commented that while investment in dementia research has increased, it still sits at only 0.3 per cent of the overall economic cost of dementia.

“We must also address funding for our social care system, which is in crisis and failing many people”, he said.


12 October: Czech Alzheimer Society organises “Prague Days of Gerontology”

On 12 and 13 October the Czech Alzheimer Society organised the “Prague Days of Gerontology” (PDG), in collaboration with the Prague Council. New inspiration in care for persons with dementia was the theme of this 19th PDG: Two main plenary sections dealt with possibilities of improving quality of care in institutions, followed by a section focusing on family care.

Three parallel workshops opened the second day of the PDG, one of them convened in collaboration with the WHO office in Prague and chaired by its director, Dr Alena Šteflová, Vice President of Association of Hospitals, alongside Dr Fiala and Alzheimer Europe Vice-Chair Prof. Iva Holmerová. This workshop focused on pressing issues related to long-term care for persons with dementia.

The conference programme closed with a panel discussion on case management for persons with dementia. Panelists were Martina Mátlová, Dana Hradcová and Radek Carboch. Participants shared their experience and views on case management in the Czech republic and also some experience from abroad. The conference took place in the historic, gothic New Town Hall in Prague, Czech Republic.
12 October: UK Alzheimer’s Society announces partnership with the Scouts Association

In October, the Alzheimer’s Society (UK) announced the launch of “A Million Hands”, a new four year partnership with the Scouts Association (TSA), involving half a million Scouts and adult volunteers.

“A Million Hands” offers Scouts four areas to choose from, including dementia, to work towards their Community Impact badge, as well as contributing to other badges and awards.


15 October: Norwegians visit dementia-friendly Crawley to learn more

22 delegates from different municipalities in Norway visited Crawley, England, on 15 and 16 October, to learn about their dementia-friendly work.

The Norwegian Health Association arranged this study trip to show communities from Norway already working to become more dementia-friendly good examples of how it can be done.

The visit included, amongst other things, a trip to the bank, the bus station, and the library, as well as trying out Walking Football – an activity for people with dementia.

15 October: Alzheimer Austria reports good results from its self-help group of people with dementia

The desire for regular meetings and exchanging views was first expressed in a series of group interviews involving people with dementia. Those interviews were conducted for the purpose of Mag. Reingard Lange’s master thesis entitled “Networking as a resource for people with dementia”.

Austria’s first supported self-help group is organised by Alzheimer Austria in cooperation with Mag. Lange, following the concept of Michaela Kaplanek. Participants are exclusively people with dementia, who also determine the topics on the agenda, such as how to cope with forgetting. Upon request, volunteers accompany participants to the meetings.

Since February 2015, meetings have been held every two weeks. The participants are very active and have reported a clear benefit from exchanging views with other people with dementia. With personal assistance from Alzheimer Austria, members of the group have contributed to the Austrian Dementia Strategy and even appeared on TV, where they spoke about their diagnoses. As dementia is still extremely stigmatised in Austria, this “coming out” provoked a considerable sensation. Hopefully this will reach other people with dementia with the message that they are not alone.

It seems apparent that people with dementia still find it very difficult to contact organisations like Alzheimer Austria. The association is now searching for new ways to reach people with dementia, in order to strengthen them by the support self-help group.

16-18 October: Slovenia hosts conference on vascular dementia

From 16 to 18 October, the 9th International Congress on Vascular Dementia was held in Ljubljana, Slovenia, attended by 200 delegates. The conference was hosted by Alzheimer Slovenia (Spominčica) together with the Ljubljana Neurology Clinic.

Spominčica President, Stefanija Łukic Zlobec presented the association’s work.

23 October: The Panhellenic Federation reports on recent activities around Greece

The Panhellenic Federation of Alzheimer’s disease and Related Disorders reports on some of its members’ recent activities around Greece:

Running Team for Alzheimer Hellas and new Youtube channel (pictured, middle right) - On the occasion of the 4th Night Marathon in the city of Thessaloniki, the Greek Association of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas) had the idea to form and participate in the 5 km road with it’s own running team! After our campaigning in our 2 Day Care centers and through the association’s social media over 120 participants were registered to support Alzheimer Hellas and it’s efforts to promote the importance of the physical exercise and to raise awareness among the general public.

Alzheimer Hellas has also launched its new YouTube channel! You can find it by searching for “Alzheimer Hellas” on the YouTube website.

Award Nomination for the Athens Association of Alzheimer’s Disease and Related Disorders - At their joint meeting, the board members of the Hellenic Olympic Winners Association, Panhellenic Association of Physical Education and the Institute of International and Greek Team Sports Law, decided unanimously to award Athens Association of Alzheimer’s Disease and Related Disorders (AAADRD) the Apollonian Award for its important contribution to Science and Greek society. The nomination happened on 2 October, at the Faliro Olympic Hall on the occasion of the annual event “Arts-Sports-Science & Society Routes - Apollonian Awards 2015". The award was given to the President of AAADRD, Dr Paraskevi Sakka by Olympic Champion Petros Galaktopoulos.

Activities of the Day Care Center for Alzheimer’s disease of Chania on World Alzheimer’s Day "DO NOT FORGET ME..." - The Day Care Center for Alzheimer’s disease in Chania (Crete) carried out several actions in the community of the local area with the occasion of the World Alzheimer’s
Day (WAD), addressing mainly people aged 65+ (the age bracket in which the major symptoms of dementia are detected). The actions were also addressed to the general public with the main aim of informing and sensitising them by presenting information about the disease (symptoms, treatment and therapy), information on how the Day Care Center works (services, personnel, daily activities, team and individual programs).

In particular the following actions took place:

- Speeches by the social worker on "Symptoms, treatment and prevention of Dementia and Alzheimer’s disease".
- Kiosk at the Municipal Market of Chania providing information and distribution of leaflets for the local people about the Alzheimer’s Day Care Center in Chania.
- Free screening of the film “Still Alice” (a film concerning a woman with Alzheimer’s disease and the way she handled her illness) at the open cinema “Attikon”, co-organised with D.O.KOI.P.P (organisation, part of the Municipality of Chania). A conversation between the audience and the personnel of the Day Care Center took place at the end of the screening.
- 3 days of free screening of memory problems by trained health professionals took place. The cognitive tests used are reliable screening tests detecting difficulties even at an early stage. Patients found having difficulties were referred for further examination at the Day Care Center.
- Projection of an informative TV advertisement at the local TV station “Nea Tilerasi” during September.
- Citation of an article at the local newspaper “Haniotika Nea” concerning the services of the Day Care Center of Chania.

Anniversary educational seminar for Health Care Professionals and Carers - The Alzheimer’s disease and related disorders association “Solidarity”, which covers the Heraklion Prefecture on the island of Crete has contributed to dementia diagnoses and provided support for people with dementia, their caregivers and families, since it came into existence 10 years ago. Solidarity’s main objective is to inform, educate and sensitize the public and the state.

As part of this effort, and on the occasion of World Alzheimer’s Day, an anniversary seminar was organised for health professionals and caregivers of people with dementia on 25 and 26 September. The seminar was open to all interested parties (Greek and foreign).

New association in north-western Greece - The Kozani Association of Alzheimer’s Disease and Relative Disorders, “Agios Nikolaos” is a newly founded association (14 July 2015) that covers the Kozani Prefecture, in Macedonia, Greece.

The association was founded thanks to the efforts of the Kozani Pensioners Association and thanks to the help and encouragement of Professor Magda Tsolaki, President of the Panhellenic Federation.

The association already counts 42 members, who have all signed the Glasgow Declaration.

Its first activities: informing the local population, invitation - recruitment of volunteers, choir section for the elderly, foreign languages courses (Italian) for the elderly.

On the occasion of World Alzheimer’s Day, a lecture was carried out by the chairman of the association, Dr Christos Voucharas on “Acquaintance with Dementia”.

26 October: Sarajevo recognises dementia as a public health priority

As a result of lobbying done by Udruženje AiR – the national Alzheimer association in Bosnia and Herzegovina - the Glasgow Declaration was signed by the Mayor of the City of Sarajevo, Prof. Ivo Komšić. On the occasion of this month, Professor Komšić thus became the third mayor to sign and Sarajevo became the second European capital to support this campaign, fighting for the rights of people with dementia.

As a result of the round table on the occasion of World Alzheimer’s Day (WAD), which is organised by Udruženje AiR, the Dean of the Faculty of Philosophy at the University of Sarajevo, Prof. Salih Foco also signed the Glasgow Declaration on behalf of his Faculty. The Faculty has a department of psychology and a department of sociology, both with long traditions. Prof. Foco recognised the problem of dementia in society and supports the fight against dementia, through the institution of higher education.

Also on the occasion of WAD, Udruženje AiR took part in a lecture on Alzheimer’s disease. The lecture took place at the Faculty of Medicine in Tuzla (pictured), organised by the Swiss Red Cross. The Manager of the centre for dementia presented their work, objectives and results.

World Alzheimer’s Day

21 September: Federazione Alzheimer Italia celebrates World Alzheimer’s Day

There were numerous initiatives organised by the member associations of Federazione Alzheimer Italia (FAI), throughout World Alzheimer’s Month www.alzheimer.it/iniziat2015.html

In Milan, FAI, in collaboration with UNAMSI (National Union of Scientific Medical Information) and Fondazione Golgi Cenci from Abbiategrasso, organised a conference called “Remember Me - The last scientific research data in the light of the Dementia Friendly Community” on 16 September at the Palazzo Marino (Town Hall) www.alzheimer.it/programma2015-x.pdf

Stefano Govoni, Professor of Pharmacology at the University of Pavia spoke of “Research on dementia: the ethics of the labyrinth” comparing scientific research to a maze.

Claudio Mariani, Neurology Professor at the University of Milan, in a report on “Recent advances in early detection,” said that “recognising and treating early Alzheimer’s disease is one of the main objectives of the research.”
Antonio Guaita, Director of the Fondazione Golgi Cenci, in a report called "Today is already tomorrow: the options for patients with Alzheimer’s and other dementias" explained that it is important to implement strategies to ensure the well-being of people with dementia and for caregivers, starting with dementia-friendly community initiatives, that are beginning to be tested in many European countries. Michele Farina, a journalist from the Italian newspaper Corriere della Sera, who has experienced the disease in his family, traveled in Italy and Europe, and recounted the journey in his book, "When do we go home? My mother and my journey to understand Alzheimer’s".

Marc Wortmann, Executive Director of Alzheimer’s Disease International (ADI), presented ADI’s World Alzheimer Report 2015, as well as an overview of dementia-friendly community initiatives worldwide.

Marco Trabucchi, Professor of Neuropsychopharmacology at the University Tor Vergata in Rome, gave a speech called “People with dementia: can a supportive community bring relief?” He explained how to help people with dementia, to make them feel at home, and how to help families to open up and not be ashamed, creating a friendly atmosphere around them by forming "participating cities". Finally, Gabriella Salvini Porro, President of the FAI, and Francesco Brancati, President of UNAMS, presented five journalists with awards in the fourth edition of the prize "Alzheimer’s: inform to understand - Care, Research, Assistance".

21 September: Fundación Alzheimer España covers Madrid with lost “memories” to fight Alzheimer’s

Each year on World Alzheimer’s Day (21 September), Fundación Alzheimer España (FAE - the Spanish Alzheimer Foundation) makes a special effort to raise awareness of Alzheimer’s disease, of which 150,000 new cases are diagnosed in Spain each year. This year, FAE joined forces with McCann Madrid to organise an emotional campaign, which not only raised awareness but also sought to attract volunteer carers to help out at FAE’s daycare centre.

FAE and McCann decided to use memory sticks (USB sticks) for their campaign, with the idea in mind of a person diagnosed with Alzheimer’s disease wanting to protect their most important life memories. They shot videos of people living with disease talking about what they want to remember, and uploaded the video onto many USB keys, which were then literally lost - dropped all around Madrid in banks, train stations, bus stations, coffee-shops, with the hope that they would be found and returned to the address on the stick.

Unbeknown to those who found them and decided to return them in person, this was in fact the location of FAE’s offices. The idea being that those who took the time to return the USB sticks in person, had the “soul of a volunteer” and were asked if they would like to help further. After their initial surprise, participants were receptive and empathetic and some individuals indeed showed their interest in working with the Foundation.

At the time of writing, 65% of the memory sticks had been returned in person to the FAE offices and 21% by mail. They continue to flow in.

The visits to the Foundation’s website and Facebook have had increased traffic as a result of this campaign, and the number of people interested in becoming volunteers has also increased dramatically. Given the unusual and innovative nature of the campaign, it also attracted plenty of attention from the Spanish media, and was broadcast on major television networks and radio stations.

FAE said "our aim of this action was to open social dialogue and raise awareness of the need to fight this devastating disease for patients and their families, not only on World Alzheimer’s Day but, most importantly, throughout the whole year.”

https://www.youtube.com/watch?v=7oTReISjjyg

21-27 September: Helsinki celebrates World Alzheimer’s Day twice

World Alzheimer’s Day was celebrated in Helsinki, with two different occasions: the Alzheimer Seminar for health and social sector professionals on 21 September, and a charity concert the following Sunday, 27 September.

The seminar covered a variety of topics from the rights of the people with dementia, to recent research results and what happens after diagnosis, for both the person with dementia and their caregiver. The research was carried out by the department of neurology at the University of Eastern Finland. The Alzheimer’s Association of Helsinki also presented their work at the seminar.

The charity concert was held in the Tempeliaukio Church - a very special building made from rock. It was a heart-warming concert with four artists taking the stage: Tia Cohen, Mikael Konttinen, Tommi Läntinen and Petri Laaksonen (pictured). The audience enjoyed the concert very much and next year’s concert is already being planned!

21 September: CEAFA celebrates World Alzheimer’s Day in Spain

During the month of September and specifically on 21 September World Alzheimer’s Day (WAD), 305 CEAFA member associations held numerous events around Spain, with the aim of raising public awareness of Alzheimer’s disease. Fundraising dinners, popular racing and art exhibitions were but a few of the activities represented. In recent years, the visibility of the group has expanded, with the use of new technologies such as social networking, allowing them to raise further awareness about the situation facing people diagnosed with dementia, as well as their family caregivers.

CEAFA - an umbrella organisation that brings together 13 regional federations, 6 “Uniprovinciales” partnerships and
305 associations spread throughout the country - gave a press conference at the headquarters of the IMSERSO, in which it unveiled its plans for “World Alzheimer Day”: to achieve a comprehensive approach to Alzheimer’s disease. It also expressed the need for a census of patients, the advance towards timely diagnosis - as well as the professional training required to support this, recognition of the costs associated with the disease for the family, and the promotion of research into Alzheimer’s disease - both clinical and social.

This year, CEFA has also begun using social networks, via which it presented an awareness campaign. The main campaign message was to “Remember the fight against Alzheimer’s”, with the hashtag #HazQueEseGestoSePague. The basic idea was that, as people use “Post-it” notes to remember different things during their everyday lives, they should also take a moment to remember the thousands of people living with Alzheimer’s disease.

To do this, a video was launched, based on this idea, as well as a campaign via social networks. It asks people to write on a Post-it and use the hashtag on social media.

https://www.youtube.com/watch?v=KzDTtPcnXrc

21 September: Association Luxembourg Alzheimer organises Memory Walk

In the framework of World Alzheimer’s Day the 14th Memory Walk took place in Luxembourg City. This event is organized annually, by the Association Luxembourg Alzheimer (ALA), to raise awareness about Alzheimer’s disease and other dementias.

Participants in the guided Memory Walk express their solidarity with people living with and affected by dementia.

From 11am onwards, ALA staff and volunteers were available for questions, and offered coffee and cake in the “Alzheimer Café”. They gave information about ALA’s departments and dementia services.

The highlight of the day, the walk itself, began at 1pm, when the first groups left to discover this year’s theme: UNESCO world heritage sites. The various points of interest around the city were explained by LCTO (Luxembourg City Tourist Office) tour guides. Two more walks were started during the course of the afternoon.

This year, more than 40 people participated in the walk. Visitors had the opportunity to watch an ALA documentary, displayed on a big screen throughout the day – an insight into the daily work in its counseling centers as well as in its day-care centers and at its residential and nursing home, “Am Goldknapp”.

In addition, face-painting was provided for the entertainment of both young and old, as was a free concert given by local bands.

Despite low temperatures, the warm and friendly atmosphere at the various stalls made this year’s edition of the Luxembourg Memory Walk a complete success. ALA would like to sincerely thank all its volunteers, LCTO tour guides, sponsors and friends.

21 September: Ligue Nationale Alzheimer organises Memory Walk in Belgium

In honour of World Alzheimer’s Day (WAD), the Ligue Nationale Alzheimer (Belgian Alzheimer Association) organised several activities during the month of September, including:

- a campaign called “Memorepair”, to allow users to digitalise their memories. Watch the campaign video here https://www.youtube.com/watch?v=HieXjOBdn40 and read more about the campaign here http://www.memorepair.be
- an “Alzheimer Café Day” (pictured), which took place on 21 September in Brussels, on the Place de la Monnaie. Several activities were planned throughout the day: games, presentations, bowling, information distribution, and discussions. People with dementia, their friends and families, professionals and anyone who with an interest in dementia was welcome.

www.alzheimer.be

21 September: English School Astronomy Club in Cyprus holds “Make a Wish” event for WAD

On the evening of 21 September, World Alzheimer’s Day (WAD), the Cyprus sky was clear enough to allow students of the English School in Nicosia, their parents, friends, teachers, guests, and members of the Cyprus Alzheimer Association to look up to the night sky and see the planets through telescopes. They were there to “Make a Wish” for those living with Alzheimer’s disease. This unique and innovative event emerged from a collaboration between the young volunteers of the Cyprus Alzheimer Association and the students of the Astronomy Club of the English School.

Students worked enthusiastically to organise and advertise the event under the guidance of the teacher responsible for the Club, Mrs Katie Demetriou, with the full support of the Head of the Physics Department, Mrs Stavroula Kapou. The youngsters co-operated with members of the Astronomy Society, who kindly provided their professional telescopes for the event. One member of the Society, who had a parent with Alzheimer’s disease, even donated one of his telescopes to the school during the event, to help promote learning.

The event included presentations about the planets from the Astronomy Club students, as well as live music by another student, plus a fundraising event. The English School Parents’ Association gladly contributed to the bazaar and made donations to the Cyprus Alzheimer Association.

“As profoundly noted by one of the students involved in the setting up of the event, raising our wishes and hopes to
space is of the utmost importance to the fight against Alzheimer disease; presently experiments are under study by NASA in space trying to advance knowledge towards the cure of the disease”, commented Mrs Noni Diakou, President of the Cyprus Alzheimer Association.

Both Mrs Leda Koursoumba, Commissioner for Children’s Rights and the Law Commissioner - and Mr Yiannakis Yiannaki, Commissioner of Volunteerism and Non-Governmental Organisations, conveyed their congratulations to the students and teachers of the Astronomy club for their hard work and creativity.

Mrs Diakou expressed her deep appreciation to all who had contributed to the success of such a great and extraordinary event.

https://www.nasa.gov/content/station-experiment-may-hold-key-to-alzheimers-cure

21 September: Alzheimer Bulgaria marks World Alzheimer’s Day with press conference

Every year since 2004, Alzheimer Bulgaria has marked World Alzheimer’s Day with a press conference.

This year, the problems of families who care for a dependent in Bulgaria were discussed by Prof. Lachezar Traykov, prominent Bulgarian scientist in the field of dementia, and Dr Nadezhda Todorovska, Deputy General Director of the Bulgarian Red Cross.

For the first time, the day was also honoured outside the capital, in Varna city, with an event in the Sea Garden. Students and graduate students of Prof. Ara Kaprelyan from Varna Medical University explained the benefits of early diagnosis and timely treatment.

21 September: Ireland marks “World Alzheimer’s Awareness Month” with poignant exhibit of letters by people affected by dementia

To mark World Alzheimer’s Awareness Month, a poignant exhibit of letters written by people affected by dementia went on display in various locations around Ireland throughout the month of September.

The letters were penned by people living with dementia, including advocates with The Alzheimer’s Society of Ireland (ASi), the Irish Dementia Working Group (IDWG), as well as carers of people with dementia both living and passed on.

Among the letters is one written by IDWG advocate Kathy Ryan (SS) - who has Younger Onset Alzheimer’s - to her sons Andrew and Matt (pictured).

Mrs Ryan writes “The greatest curse of Alzheimer’s, for me, is how it’s going to impact you both. I have tried to plan things so that you can get on with your lives and that’s what I want more than anything. Please don’t let Alzheimer’s take any more from us than it absolutely has to. I want for you both to take wings and fly.”

Carer Helen Cashell Moran from Co Dublin, carer to her father Paddy, who has Alzheimer’s, writes: “All I can say with certainty is that, the day I no longer have to care for you, a part of me will be forever lost. Caring for you poses difficulties, both logistically and emotionally, but it has also created a special bond between us. I hate to see you being constantly confused, but my heart swells with love and pride when you turn to me and ask me to help you work out the answer to whatever you’re trying to determine. The sheer trust you place in me makes it all feel worthwhile. Alzheimer’s has left you a shell of the man you once were, but I can see glimpses of my old Daddy in there and I know you can sense it too.”

Tina Leonard, Head of Advocacy and Public Affairs with The Alzheimer Society of Ireland said: “The ‘Letters to Remember’ was a wonderful and poignant campaign aimed at raising awareness of how dementia impacts those both living with the condition and their carers and loved ones. The letters are both uplifting and heart-rending, and demonstrate the emotional toll this condition is having on families across the country. We are delighted that the voice of the person with dementia took centre stage in this exhibit, as we strive to raise awareness of what a valuable contribution the person with dementia can make to society, given the correct supports. The exhibit was just one of a number of events which took place across the country to mark September as World Alzheimer Awareness Month.”

Some of the letters from this exhibit can be found in the “Living with dementia” section of the Alzheimer Europe website:

http://alzheimer-europe.org/Living-with-dementia/Personal-experiences-of-living-with-dementia

Living with dementia

11 October: Agnes Houston writes about her “Dementia and Sensory Challenges” project

My name is Agnes Houston. I am one of the joint chairs of the European Working Group of People with Dementia (EWGPWD), a committee member of the Scottish Dementia Working Group (SDWG) and I serve as a board member of the Dementia Alliance International (DAI).

Since my diagnosis of dementia of the Alzheimer type I have been an advocate in raising awareness on what it’s like to live with a diagnosis of dementia and what you can do to assist us.

Dementia is more than Memory but it was all I was being asked about. Six years ago I started having sensory challenges, nothing was in place to help me cope with these changes. During campaigning I found other people with dementia were having these issues as well. So, with the help of my daughter Donna and funding from the Life
Changes Trust, the “Dementia and Sensory Challenges” booklet was written.

In September 2015, we had the privilege to present a poster and speak at this year’s Alzheimer Europe conference in Slovenia. I was overwhelmed by the positive response it received and so proud that the poster was voted as the best in its category. I would like to thank Anne Pascoe for believing in me, and the 25 people with dementia, whose words and lived experience of dementia and sensory challenges influenced the content of this free booklet. And thanks to all who voted for the poster.

If you would like a PDF copy of the booklet here is the link: http://www.lifexchangetrust.org.uk/sites/default/files/Leaflet.pdf

Alternatively go to the SDWG website http://www.sdwg.org.uk/

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

22 October: European Working Group of People with Dementia calls on people to sign the Glasgow Declaration

Helen Rochford Brennan, Vice-Chair of the European Working Group of People with Dementia (EWGPWD), on why the group thinks our Glasgow Declaration is so important:

Albert Einstein once said “In the middle of difficulty lies opportunity”. The European Working Group of People with Dementia works to create opportunities out of our difficulties. Together we have the courage to stand up and say dementia is a critical issue and it must have the attention it deserves. However, most importantly we want to be part of the solution. This is why the European Working Group is asking people to join with us and sign the Glasgow Declaration. We believe that dementia needs to be higher on the EU agenda and the Glasgow Declaration can make this a reality.

The Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. As members of the Working Group we know that where there are strategies in place in a country it can bring meaningful change to people’s lives. With the support of a European Strategy imagine the strides that can be made together.

The Declaration also calls upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia. We are the voice of people living with dementia and it is important that we are listened to so that we can influence others’ experiences of dementia now and in the future, but we need political will.

If you believe like we do that dementia must be a European priority please join us and sign!

Policy watch

15 August: Research volunteers boost UK government’s hope of curing dementia by 2025

The UK Government’s ambition to find a cure for dementia by 2025 is being boosted by a big rise in people volunteering to take part in research. Over the past year, almost 22,000 people have taken part in dementia research studies, which is a 60% rise on the previous year, according to figures from the National Institute for Health Research.

The increased participation in 100 dementia research projects across the UK will support scientists in their bid to find new treatments to prevent, treat and hopefully cure dementia.

Research projects include testing whether antibiotics slow cognitive decline, investigating the role of the immune system in dementia, identifying genetic risk factors and improving end of life care for people with dementia.


1 October: Alzheimer Society of Ireland launches Pre-Budget Submission

The Alzheimer Society of Ireland (ASI) launched a Pre-Budget Submission on 1 October at an event in Dublin. This submission called on the Irish Government to take meaningful action on dementia in their 2016 budget to enable people with dementia to live well at home for as long as possible. The launch event was very well attended, with 20 TDs (Members of Parliament) present or represented.

As part of this campaign ASI asked supporters and members of the public to send a letter to their local TDs requesting that they support the ASI’s submission. This resulted in approximately 1,400 letters being sent to political representatives around Ireland. A copy of the ASI Pre-Budget Submission is available here:


Government policy in Ireland has been to support people to age at home, yet the vast majority of state investment has been in long-term residential care. To understand more about the economics of home care services and to further highlight this issue, the ASI commissioned “An Economic Analysis of Home Care Services for People with Dementia”. This policy paper was independently prepared by Dominic
The UK Chancellor of the Exchequer, George Osborne, has announced that working grandparents are to be given a new legal right to take time off to help care for their grandchildren, in an extension of the system of flexible parental leave.

This, however, could also apply to people caring for a spouse or parent with dementia which is exactly what the Alzheimer’s Society (UK) are calling for.

Jeremy Hughes, Chief Executive of the Alzheimer’s Society, said:

“The Government has recognised the need to improve parents’ access to childcare to help people stay in work and maintain economic recovery. However, attention should also be given to supporting those in work caring for a spouse or parent with dementia.

“In the UK alone, there are 670,000 carers for people with dementia. An aging population and further cuts to social care are combining to create a perfect storm which could lead to tens of thousands of working people forced to give up their jobs to look after elderly relatives in future.”

20 October: The National Institute for Health and Care Excellence (NICE) publishes new guideline to reduce dementia risk

A new guideline, published by the National Institute for Health and Care Excellence (NICE), aims to help reduce dementia risk in mid-life, as well as reducing levels of disability and frailty in older people. It also recommends population-level initiatives and changes to services, to lower the risk of dementia.

The guidelines focus on five lifestyle factors that have been linked to an increased risk of dementia - smoking, lack of exercise, alcohol consumption, poor diet and being overweight.

The recommendations are aimed at professionals - including people working in public health, planning and housing, as well as employers - in an attempt to create a more joined-up approach to efforts to reduce dementia risk.


21 October: Global “dementia discovery fund” is officially launched

Six major pharmaceutical companies have teamed up with the UK Department of Health and the charity Alzheimer’s Research UK to launch the world’s first venture capital fund dedicated to finding new ways to prevent and treat dementia. The fund was launched in London on 21 October. The pharmaceutical companies involved are GSK, Johnson & Johnson, Biogen, Eli Lilly, Pfizer and Takeda.

USD 100 million (EUR 91.4 million) was raised prior to the official launch of the fund, which was born at the UAE dementia summit in London in December 2013. Funding is to be invested in early-stage, novel treatments for Alzheimer’s disease (AD), Parkinson’s disease and other forms of dementia.

The goal of the “dementia discovery fund” is to come up with early diagnosis and effective treatment by 2025.

[http://www.alzheimersresearchuk.org/100m-dementia-discovery-fund-launches-to-support-pioneering-research/]

12 August: Gene variant identified, linked to amyloid beta build up in AD

A study, published in the journal Brain on 12 August, has found an immune system gene associated with higher rates of amyloid plaque buildup in the brains of patients with Alzheimer’s disease (AD). The study was conducted by a multi-institutional team, led by scientists at the Indiana University (IU) School of Medicine in the US.

The research found that a variant in the IL1RAP gene was associated with greater amyloid plaque accumulation over two years and had an even bigger effect than the well-known APOE e4 allele, notoriously associated with AD.

Using positron emission tomography (PET) imaging in just shy of 500 individuals, the team assessed the levels of brain amyloid deposits during an initial visit, then followed up with another test two years later. A genome-wide analysis was then conducted to identify genetic variants associated with the rate of plaque accumulation. As predicted, APOE e4 was found to be associated with higher rates of plaque buildup. The investigators were surprised, however, to find that IL1RAP showed an independent and even stronger influence on amyloid accumulation.

"This was an intriguing finding because IL1RAP is known to play a central role in the activity of microglia, the immune system cells that act as the brain’s "garbage disposal system" and the focus of heavy investigation in a variety of neurodegenerative diseases,” said IU postdoctoral medical researcher Dr Vijay K. Ramanan.

The study found that the amyloid-associated IL1RAP variant was also associated with a lower level of microglial activity as measured by PET scans, greater atrophy of the temporal cortex (a region of the brain involved with memory), faster cognitive decline and greater likelihood among study participants of progression from mild cognitive impairment (MCI) to AD.

"These findings suggest that targeting the IL1RAP immune pathway may be a viable approach for promoting the clearance of amyloid deposits and fighting an important cause of progression in Alzheimer’s disease,” said Dr Andrew Saykin, Director of the Indiana Alzheimer Disease Center and the national Alzheimer’s Disease Neuroimaging Initiative Genetics Core.

Dr Saykin noted that there are available drugs that target the IL-1/IL1RAP pathway for rheumatologic and inflammatory conditions. There are also antibodies against IL1RAP that are being tested to treat certain types of leukemia. Those tools could be adapted for laboratory studies to evaluate their potential as AD therapies, he said.

[http://brain.oxfordjournals.org/content/138/10/1076]

15 September: Lack of dementia specialists threatens research progress in the UK, finds report

The Alzheimer’s Society (UK) recently commissioned a comprehensive review of the UK dementia research landscape.

The report found that too few researchers are choosing a career in dementia, with five times more choosing to work in the field of cancer. Of those that do complete a PhD in dementia, retention in the field is poor, with 70 per cent leaving the field within four years.

The reports also showed a critical lack of people from care and clinical professions focusing on dementia research, which the society comments “is likely to stifle innovation and progress in these sectors”.

22 September: Combination treatment may reduce agitation in AD

Research published in the journal, Jama on 22 September suggests that the combination treatment dextromethorphan–quinidine sulphate can help reduce agitation in people with probable Alzheimer’s disease (AD).

The research team conducted a preliminary 10-week trial, conducted at 42 sites in the US, found that patients who took the combination medication demonstrated fewer occurrences and less severity of agitation, compared with patients who received placebo.

Patients in the treatment group had a mean 50.7% reduction in agitation and aggression scores from baseline to week 10, compared with 26.4% for those who received only placebo. The combination drug was generally well-tolerated.

An editorial accompanying the study notes that "although the results of the study by Cummings et al. are encouraging, it will be important for future studies to carefully consider the mechanisms of action. Agitation is a broad syndrome, and specific symptoms may have different neuropsychiological substrates."


23 September: Nestle and AC Immune will collaborate to develop AD diagnostic test

On 23 September, global food group Nestle and Swiss biotech firm AC Immune signed a research collaboration agreement to develop an Alzheimer’s disease (AD) diagnostic test. The collaboration will develop a minimally invasive diagnostic assay for Tau protein.

http://uk.reuters.com/article/2015/09/23/us-nestle-alzheimers-idUKKCN0RN0ME20150923

23 September: Drug used to treat cancer appears to sharpen memory

A study published in The Journal of Neuroscience, on 23 September, has found that a drug used in the treatment of cancer – RGFP966 - may have a positive impact on memory and learning ability.

The study was led by Kasia M. Bieszczad, Assistant Professor in Behavioral and Systems Neuroscience in the Department of Psychology at Rutgers University, New Jersey, US. She and her team found that the drug made laboratory rats “more attuned” to what they were hearing, better able to retain information, and able to develop new connections that allowed memories to be transmitted between brain cells.

The drug administered in this animal study is among a class known as HDAC inhibitors – used in cancer therapies to stop the activation of genes that turn normal cells into cancerous ones. In the brain, the drug makes the neurons more plastic, better able to make connections and create positive changes that enhance memory. Researchers found that rats, taught to listen to a certain sound in order to receive a reward, and given the drug after training, remembered what they learned and responded correctly to the tone at a greater rate than those not given the drug.

http://www.jneurosci.org/content/35/38/13124.full?sid=397ad73f-ccfa-4bbd-b700-2c71b657ad08

29 September: Report looks behind the headlines around Brain implant for memory loss

In late September, a number of newspapers reported on a prosthetic brain implant, with the potential to help treat people with memory loss. These reports refer to a device being developed with funding from the US Defence Advanced Research Projects Agency (DARPA), to help soldiers with memory loss. The news reports, however, suggested it could also be used to treat people with dementia, who experience memory loss issues.

In theory, this implant would work by allowing signals to bypass the hippocampus – and area of the brain damaged in people with dementia, and which is essential to forming and retrieving memories - and be processed artificially into a signal that can be committed to memory.

On 29 September, the Alzheimer’s Society (UK) published a “behind the headlines” report into this particular story. It concludes that "whilst it is exciting that such cutting edge techniques are being applied to the problem of memory loss, it is important to realise that this research is still in its infancy and there is still a great deal that we don’t understand about memory formation."

The report stresses that it will take at least a decade (or more) for such an implant to be developed and tested, and that even if they were to work for people with dementia in terms of memory symptoms, they would not treat other symptoms of dementia and would not cure dementia nor stop the condition from progressing.


14 October: Potential new AD drug target identified

A protein called GPR3 could become a new target for Alzheimer’s disease (AD) drugs, conclude a study published on 14 October in the journal Science Translational Medicine.

Removing the GPR3 protein from four different AD mouse models reduced the number of toxic amyloid plaques in the brain. One of the mouse models also showed improvements in memory, learning and social behaviour after having the GPR3 protein removed.

Brain samples from people who died with AD had increased levels of the GPR3 protein compared to healthy brains - and levels of the protein increased as the disease progressed. GPR3 is a class of protein called G-protein coupled receptors which are common drug targets but there is not yet a drug to target this specific protein.

http://stm.sciencemag.org/content/7/309/309ra164
15 October: Traces of fungus found in AD brains raises questions

A five-member team of Spanish researchers has reported finding traces of fungus in the brains of patients with Alzheimer’s disease. The team found cells and other material from “several fungal species” in the brain tissue and blood vessels of 11 deceased patients with AD, but not in ten control cases (with no AD).

The study, published in Nature’s journal of Scientific Reports on 15 October, raises unanswered questions about whether the fungi were the cause, or rather a consequence of AD, due to weakening the internal barrier that protects the brain, thus making it more open to infection.

http://www.nature.com/articles/srep15015

20 October: Go “teetotal” to reduce dementia risks, UK health watchdog says

Guidance from the UK National Institute of Health and Care Excellence on how to reduce the risks of dementia now suggests that even drinking within Government “safe limits” can increase the risk of dementia.

The new guidelines warn “there is no safe level of alcohol consumption”. The best approach, they conclude, is to be “teetotal” – i.e. not to drink alcohol at all – especially in middle age. They also call on GPs to tackle patients in middle-age about lifestyle behaviours linked to the condition, since research has found that one third of all Alzheimer’s disease (AD) cases can be linked to lifestyle factors – such as exercise, obesity, smoking and alcohol.

Current UK government advice – which is under review - suggests women can drink two to three units of alcohol a day (one 175ml glass of wine) and men three units, without compromising their health.

The new advice says drinking any alcohol can increase the risk of dementia, disability and frailty, advising GPs that people should be encouraged “to reduce the amount they drink as much as possible.”

It suggests Britain’s “social norms” when it comes to alcohol should be challenged.


23 October: Virtual reality maze may help predict Alzheimer’s disease

Alzheimer’s disease (AD) can be detected decades before onset using a virtual reality test, a new study conducted in Germany concludes. Results were published in the journal Science on 23 October.

People aged 18 to 30 were asked to navigate through a virtual maze to test the function of certain brain cells. Those with a high genetic risk of AD could be identified by their performance, the study showed.

The research team, led by Lukas Kunz of the German Centre for Neurodegenerative Diseases in Bonn, says the “high risk” group navigated the maze differently and had reduced functioning of a type of brain cell involved in spatial navigation.

“Our results could provide a new basic framework for preclinical research on Alzheimer’s disease and may provide a neurocognitive explanation of spatial disorientation in Alzheimer’s disease,” they report.

http://www.sciencemag.org/content/350/6259/430.abstract?sid=bc4a44c5-3d56-40ce-a5fc-10de4a776f7f

27 October: Donepezil may help keep people out of care homes

Donepezil, a relatively inexpensive off-patent drug that relieves some symptoms of Alzheimer’s disease (AD) may help keep people at an advanced stage of the illness out of nursing homes, at least for a while, a study has found. The research, funded by the Medical Research Council and the UK Alzheimer’s Society, was published in journal The Lancet Neurology on 27 October.

Donepezil is usually withdrawn as a treatment for people with moderate to severe AD, as it had been thought to provide little benefit. In this study, the researchers wanted to see if this was too hasty a decision, so they carried out a randomised controlled study to look at the issue, following the progress of 295 people either continuing with donepezil, or put on placebo.

Lead researcher Prof. Robert Howard, from University College London, said: “Our previous work showed that, even when patients had progressed to the moderate or severe stages of their dementia, continuing with donepezil treatment provided modest benefits in cognitive function and in how well people could perform their daily activities.

“Our new results show that these benefits translate into a delay in becoming dependent on residential care”.

The findings are a follow-up of trial data after donepezil modestly improved cognitive scores in advanced Alzheimer’s patients in 2012.

NHS Choices comments, “this study cannot prove donepezil was directly responsible for keeping people from being admitted to nursing homes. It examined the effects of continued donepezil treatment on nursing home placement – not on cognitive function. But the researchers did speculate donepezil could help people with Alzheimer’s cope better with day-to-day tasks, such as dressing.”

NHS Choices also points out that in some cases, people may benefit from placement in a nursing home and be happier there. “It would be presumptuous to assume going into a nursing home automatically represented a failure in treatment.”

Dementia in society

6 October: Bayern München football legend Gerd Müller has Alzheimer’s disease

Legendary German footballer Gerd Müller, now 70 years old, is receiving treatment for Alzheimer’s disease his former club, FC Bayern München confirmed on 6 October. Mr Müller played for Bayern - Germany’s most successful club of all time - alongside another footballing great, Franz Beckenbauer. He was known as "Der Bomber" for being one of the most prolific goal scorers in the history of football, scoring 533 goals in 585 games for Bayern between 1964 and 1979, and helping the side to four Bundesliga titles, four German Cup wins and three European Cup victories in that time.

Müller also helped West Germany win the World Cup in 1974 and European Championship in 1972. Müller’s 68 goals in 62 appearances for West Germany was a national record only surpassed by Miroslav Klose in 2014. Klose needed 129 appearances to match him.

FC Bayern München said Mr Müller is being cared for professionally, with the support of his family.

Mr Müller’s doctor said he is being treated with great respect by Bayern, the fans and media “despite unmistakable signs of his illness”.

New publications & resources

15 September: SROI report published on peer support for people with dementia

On 15 September, the Health Innovation Network (HIN), the Academic Health Science Network for South London (UK) has published a report, “Peer Support for People with Dementia – A Social Return on Investment (SROI) Study”, emphasising the positive social value of peer support groups for people with dementia, their carers and volunteers. HIN also re-launched its “Peer Support Resource Pack”, developed for the voluntary, statutory and community sectors to promote and encourage the set-up of peer support opportunities for people with dementia.


24 September: FP7 project In-MINDD publishes autumn newsletter

On 24 September, the Innovative, Midlife Intervention for Dementia Deterrence project (In-MINDD), published its autumn 2015 newsletter.

In-MINDD is an EU FP7 project focused on promotion of long-term brain health and dementia prevention/delay.


29 September: Mental Health Foundation publishes paper on human rights and dementia

The Mental Health Foundation (UK) has published a paper on “Dementia, rights, and the social model of disability”, written by Grainne McGettrick, Research and Policy Manager at Acquired Brain Injury Ireland - and formerly of the Alzheimer’s Society of Ireland.

Ms McGettrick’s paper, published online on 29 September, describes the social model of disability in relation to dementia, as well as national and international law.

http://mentalhealth.org.uk/content/assets/PDF/publications/dementia-rights-policy-discussion.pdf

9 October: New JPND reports available on longitudinal studies

The EU Joint Programme - Neurodegenerative Disease Research (JPND) commissioned ten groups of experts, through a peer reviewed call for proposals, to address methodological challenges preventing current population and disease-based longitudinal cohorts being fully used for Neurodegenerative Disease (ND) research. A reports has been published by each of the ten groups, providing recommendations.

http://www.neurodegenerationresearch.eu/2015/10/new-jpnd-reports-longitudinal-cohort-studies/

Contact Alzheimer Europe

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## AE Calendar 2015

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<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>3-4 November</td>
<td>DSDC International Dementia Conference (Birmingham, UK)</td>
<td>Jean</td>
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<tr>
<td>3 November</td>
<td>Steering committee meeting of the AETIONOMY project (Barcelona, Spain)</td>
<td>Dianne</td>
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<tr>
<td>3, 5, 6 November</td>
<td>4 IFAD project focus groups as part of the consultation on “Approaches to the communication of Alzheimer’s disease risk” (Barcelona, Spain)</td>
<td>Ana</td>
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<tr>
<td>4 November</td>
<td>General assembly of the AETIONOMY project (Barcelona, Spain)</td>
<td>Dianne and Ana</td>
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<tr>
<td>4-7 November</td>
<td>Clinical Trials on Alzheimer's Disease (Barcelona, Spain)</td>
<td>Jean</td>
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<tr>
<td>10 November</td>
<td>Annual Health Care Summit (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>10 November</td>
<td>European Parliament Interest Group on Innovation in Health and Social Care (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>10-11 November</td>
<td>Start-up meeting of Sympathetic Dysfunction in Alzheimer Disease project (SyDAD), (Stockholm, Sweden)</td>
<td>Ana</td>
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<tr>
<td>19 November</td>
<td>EPF Policy Advisory Group Meeting (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>23 November</td>
<td>Meeting with Quintilis (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>24-25 November</td>
<td>CHRODIS Conference (Vilnius, Lithuania)</td>
<td>Vanessa</td>
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<tr>
<td>25 November</td>
<td>Launch of Centre for Dementia Prevention (Edinburgh, UK)</td>
<td>Jean</td>
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<tr>
<td>25 November</td>
<td>Training session for patients and consumers interested in EMA activities, London, UK</td>
<td>Ana</td>
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<tr>
<td>26 November</td>
<td>Patients and Consumers Working Party of European Medicines Agency (London, UK)</td>
<td>Jean</td>
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<tr>
<td>27 November</td>
<td>GSK Health Advisory Board (London, UK)</td>
<td>Jean</td>
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<tr>
<td>30 November-1 December</td>
<td>AE Board meeting</td>
<td>AE Board and staff</td>
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## Conferences 2015-2016

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>31 October-5 November</td>
<td>XXII World Congress of Neurology, <a href="http://www.wcn-neurology.com">www.wcn-neurology.com</a></td>
<td>Santiago, Chile</td>
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<tr>
<td>5-7 November</td>
<td>8th edition of our Clinical Trials for Alzheimer’s Disease (CtaD 2015), <a href="http://www.ctad-alzheimer.com/">http://www.ctad-alzheimer.com/</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>17 November</td>
<td>Improving Patient Care: Enhancing Quality and Experience, <a href="http://www.openforumevents.co.uk/">http://www.openforumevents.co.uk/</a></td>
<td>Manchester, UK</td>
</tr>
<tr>
<td>7-9 December</td>
<td>Covenant on Demographic Change Towards an age-friendly Europe, <a href="http://afeinnovnet.eu/event/launch-covenant-demographic-change">http://afeinnovnet.eu/event/launch-covenant-demographic-change</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>9-12 March 2016</td>
<td>14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy, <a href="http://www.ad-springfield.com">www.ad-springfield.com</a></td>
<td>Athens, Greece</td>
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<tr>
<td>17-20 March 2016</td>
<td>The 10th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtextmed.com/cony">http://www.comtextmed.com/cony</a></td>
<td>Lisbon, Portugal</td>
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<tr>
<td>24-28 July 2016</td>
<td>AAC Annual Conference, <a href="https://www.alz.org/aac/">https://www.alz.org/aac/</a></td>
<td>Toronto, Canada</td>
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<tr>
<td>31 Aug-2 Sept 2016</td>
<td>10th International Conference on Frontotemporal Dementias, <a href="http://www.chrif2016.de/">http://www.chrif2016.de/</a></td>
<td>Munich Germany</td>
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<tr>
<td>6-9 September 2016</td>
<td>2016 IPA International congress, <a href="http://www.ipa-online.org">www.ipa-online.org</a></td>
<td>San Francisco, USA</td>
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<tr>
<td>5-9 October 2016</td>
<td>Croatian Congress on Alzheimer disease with International participation (CROCAD 16), <a href="http://www.alzheimer2016.com/">http://www.alzheimer2016.com/</a></td>
<td>Tuzla, Croatia</td>
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<tr>
<td>31 Oct-2 November 2016</td>
<td>26th Alzheimer Europe Conference (26AEC) on “Excellence in dementia research and care”</td>
<td>Copenhagen, Denmark</td>
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<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>
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ALZHEIMER EUROPE THANKS THE ABOVE MEPS FOR LAUNCHING THE EUROPEAN PARLIAMENT WRITTEN DECLARATION N° 0057/2015 ON ALZHEIMER’S DISEASE

1. Alzheimer's disease is an incurable neurodegenerative disease of the brain tissue that causes progressive and irreversible loss of mental functions, including memory.
2. Six million people are affected by Alzheimer's disease or related diseases in Europe, and the number of new cases diagnosed each year continues to increase.
3. There is currently no curative treatment for Alzheimer's disease, but some drug treatments can help to slow the process and early detection can assist in better supporting patients and their carers.
4. The Commission and the Council are invited to recognise Alzheimer's disease and related diseases as a public health priority in Europe.
5. The Commission and the Council are therefore called upon to adopt a comprehensive strategy for meeting the challenges presented by Alzheimer's disease. Research aimed at developing sustainable treatment solutions and efforts to improve the efficient provision of information and support to carers should be promoted.
6. This declaration, together with the names of the signatories, is forwarded to the Council and the Commission.

Alzheimer Europe calls on all MEPs to sign the Written Declaration before 5 January 2016
Thank you

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.