Welcome!

April has been a great month in European policy terms, with Malta launching its National Dementia Strategy “Empowering Change”, written by our Honorary Secretary, Dr Charles Scerri. The Maltese strategy is the fifteenth national plan to be launched in Europe, but the first to include a dementia-friendly version.

At the start of the month, the Welsh government announced a new drive to improve the lives of people living with dementia. Wales launched its national dementia plan in 2011, but this recent development aims to do more still to ensure that the nation is dementia-friendly.

Also on the policy front, the World Health Organisation (WHO) published a new statement on the public disclosure of clinical trial results.

For our own part, we are delighted to announce the creation of our new Expert Advisory Panel. The aim is to improve the information we provide on scientific breakthroughs and to include a commentary on key developments. We are also delighted to say that all abstracts for the Alzheimer Europe annual conference, 25 AEC in Ljubljana in September have been reviewed and we will soon finalise the programme. The reduced “Early Bird” registration fees are only available until the end of May, so don’t forget to register!

We have also been busy with our Glasgow Declaration campaign. The declaration itself, along with the sign up system, has this month been translated into seven European languages and will soon be available in three more. We would like to thank our members for their help on this! We are also delighted to have received signatures from three more MEPs this month, two of whom are new members of our European Alzheimer’s Alliance. If you have not already done so, please sign using the buttons available in this newsletter.

On the European project front, there was a big kick-off meeting for the new project, MIAMI-MD at the end of the month, at which we presented our Communication and Dissemination plans, as the work package leader for that area. AE team members have also attended meetings with the NILVAD, INTERDEM and EPAD projects in which we are involved.

Our friends at Alzheimer’s Disease International (ADI) held their 30th annual conference in Australia, which we were unfortunately unable to attend, but which seems to have been a big success. The Chairperson of our European Working Group of People with Dementia (EWGPWD), Helga Rohra, however, was in attendance and gave a well-received presentation.

Other big stories in the media this month have been around a study linking the immune system and a nutrient called arginine to Alzheimer’s disease and a landmark US trial, which raised questions around dementia and sexual consent.

Lastly, we are delighted that our readers seem very satisfied with our newsletter, based on survey results. We would like to thank everyone who responded and we hope you continue to enjoy reading our newsletter!

Jean Georges
Executive Director
1 April: Alzheimer Europe announces new Expert Advisory Panel

Alzheimer Europe (AE) is pleased to announce the creation of its new Expert Advisory Panel (EAP).

The EAP was envisaged earlier this year, to improve the information AE provides on medical and scientific breakthroughs in its newsletter and magazine and to include a “scientific commentary” on key scientific developments.

The EAP will also be involved in the abstracts process for AE’s annual conferences and - since AE is more and more called upon to take part in scientific projects - will also provide scientific advice on which research programmes and projects to prioritise.

The panel is currently composed of 32 advisors from around Europe, appointed by AE for a period of 3 years (2015-2018).

http://alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Expert-Advisory-Panel

7 April: Ethics and professional dementia care experts start work on ethical dilemma guidelines

On 7 April, Alzheimer Europe’s ethics working group met in Luxembourg. This was the first meeting for this year’s ethics project which aims to develop guidelines for professional carers of people with dementia.

The final report will be a training resource for professional carers to explore ethical dilemmas they may encounter in institutional/residential care or the hospital setting. This work follows on from last year’s report which focused on ethical dilemmas faced by people with dementia and their informal carers.

Next year’s work will address those encountered by professional carers of people with dementia living at home. The group, which is comprised of experts in ethics as well as in the provision of professional care and dementia research, will meet again in September in Slovenia and the report will be available in December.

14 April: AE thanks you for your positive feedback on our newsletter

In the first part of 2015, we ran a survey on our monthly newsletter, to collect feedback on the quality of writing, topic areas, user-friendliness and aesthetics, among others.

We are delighted to say the results say our readers are extremely satisfied with all these areas.

Your support is much appreciated as are the suggestions some of you made regarding updating our email and PDF templates. We will certainly take this into consideration and may make some slight changes later in the year.

We would like to thank you for giving your valuable time to respond and we hope you continue to enjoy reading our newsletter!

19 April: The Irish Times reports on Helen Rochford Brennan and importance of friendship

On 19 April, The Irish Times published a story in its Life and Style - People section, about Helen Rochford Brennan, Vice-Chair of Alzheimer Europe (AE)’s European Working Group of People with Dementia (EWGPWD) and Chair of the Alzheimer Society of Ireland’s National Dementia Working Group.

The story relates the importance of Helen’s friendship with her childhood friend, Aggie Kosikowski. It is written from the persepctives of the two friends, with particular emphasis on the support and friendship Ms Kosikowski has brought Helen since she was diagnosed with early onset Alzheimer’s disease (AD) in 2011, at the age of 61.

“We are so close, there’s nothing I can’t tell her about: if I’m going through a bad day, I know I can talk to her and when I get off the phone I will be cheered up”, writes Helen.

“I’m not surprised that Helen has become a spokesperson for people in Ireland with Alzheimer’s. That’s Helen: she does this because she really wants to help people and put a face on Alzheimer’s at a young age. I am very proud of her”, writes Ms Kosikowski.


28 April: 25th Alzheimer Europe conference abstracts evaluated

Abstracts for the 25th Alzheimer Europe Annual Conference – taking place in Ljubljana, Slovenia from 2 to 4 September - have been reviewed during the month of April. Evaluations will be sent out shortly and the conference programme will be available soon after.

If you wish to register for our conference, the Early Bird registration fee is still available until end of May.

REGISTER NOW!
25th Alzheimer Europe Conference
30 April: Glasgow Declaration now available in several European languages

During the month of April, Alzheimer’s Europe’s campaign, the Glasgow Declaration – calling for the creation of a European Dementia Strategy and national strategies in every country in Europe – has been translated into several European languages.

The declaration and online sign-up form have been available in English on our website since 19 February but now, with the help of our members, we have also made it available in French, Greek, Italian, Portuguese, Slovenian and Spanish. Croatian, Czech and German will be available very soon.

You can find the currently available versions on our website:
http://alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014/Other-languages

Our Finnish member, Muistiliitto has also translated the Glasgow Declaration, which is available for signing via their own website:
http://muistiliitto.fi/tietoa-muistiliittoa/apunkohtaisa/kohde-eurooppalista-muistokalenteria/

EU Projects

9 April: EPAD project team holds meeting on dissemination activities

The members of EPAD’s communication team held a two day meeting in Barcelona on 9-10 April. They discussed the ongoing development of the project communication plan and dissemination materials, such as the website, the internal and external newsletters and the project brochure.

The partners also established dissemination procedures - including impact measures - for scientific publications and other communication items. Finally, they reviewed the agenda for the first EPAD General Assembly that will take place on 19-21 May in Edinburgh.

www.ep-ad.org

23 April: INTERDEM group works on new outcome measures for psychosocial interventions

A team of researchers from the INTERDEM group met in London on 23rd January to work on updating the important 2008 paper entitled “A European consensus on outcome measures for psychosocial intervention research in dementia care” and to consider new themes and concepts for psychosocial intervention outcome measures. This work is funded by JPND.

At the workshop, Alzheimer Europe presented the plans for the consultation with people with dementia and carers. The consultation will be carried out during the month of May and will involve three groups of people with dementia and carers in different European countries. The EWGPWD will also participate in the consultation.

AE’s Project Officer, Ana Díaz represented the organisation at the meetings.

23-24 April: MIAMI-MD project will create app designed to improve quality of life for people with dementia

On 23-24 April, the kick-off meeting for the MIAMI-MD project was hosted by project leader Anglia Ruskin University (ARU) at its Postgraduate Medical Institute in Chelmsford, UK.

The four year project will develop an app called Medical Intelligence for Assistive Management Interface - Mild Dementia (MIAMI-MD), designed specifically to help improve the quality of life of people living with mild dementia.

The app will be designed to help people with mild dementia adhere to treatment regimens as well as allowing them to share health-related data with their carers and doctors. Carers would also be able to use the same app to remotely monitor those they care for and share information about their own well-being with doctors. As well as giving people more control over their care, the aim is to slow cognitive and functional decline and to reduce pressure on carers as well as costs for healthcare providers, through use of the app. It will be piloted with 1100 volunteers from several EU countries.

As the work package leader for dissemination and communication, AE – represented by Communications Officer Kate Boor Ellis and Director for Projects, Dianne Gove – attended the meeting and presented the dissemination and communication strategy.

The MIAMI-MD project will soon have a dedicated website and logo – to be communicated in due course - while the Twitter hashtag #MIAMIMD is already in use for tweets about the project.

Project partners in attendance at the kick-off meeting were: Anglia Ruskin University (UK), Alzheimer Europe (Luxembourg), Athena ICT (Israel), Handle My Health (UK), Universidad Politénica de Madrid (Spain), SEPT (UK), Consorci Sanitaria de Terrassa (Spain), DEX Innovation Centre (Czech Republic), Servicio Andaluz de Salud (Spain), Blekinge Institute of Technology (Sweden) and Katholieke Hogeschool Limburg (Belgium).

The next full meeting will take place in Madrid in September.
28 April: NILVAD’s French partners and DISTALZ hold working day on methodological aspects of NILVAD sub-study

A team of researchers from NILVAD and DISTALZ met in Lille on 28th April to work on the development of the questionnaire and protocol that will be used in the study. This is a sub-study of the NILVAD trial, and will explore the participants’ experiences of taking part in the trial, including their satisfaction with how the trial was organised, their involvement in the trial and the challenges they may have faced during the 18 months that the trial lasts.

The study will be conducted in France, the UK, Ireland and Greece. NILVAD clinical trial kicked off in 2012 and has recruited 510 people with mild to moderate Alzheimer’s disease in nine European countries. The trial is investigating the potential of a drug called nilvadipine to slow the rate of disease progression.

AE’s Project Officer, Ana Díaz represented the organisation at the meeting in Lille.

Alzheimer Europe Networking

On 30 March (Brussels, Belgium) Annette joined the European Patients’ Forum “Access to Healthcare” working group meeting.

On 31 March (Brussels, Belgium) Annette had a teleconference with Karin Hellsvik from Biogen.

On 1 April (Brussels, Belgium) Annette met MEP Françoise Grossetête’s assistant.

On 2 April (via telephone, Luxembourg) Kate and Alex attended an informal communications network kick-off meeting, organised by the European Patients’ Forum.

On 7 April (Luxembourg, Luxembourg) the Ethics working group met.

On 9-10 April (Barcelona, Spain) Jean and Alex participated in a meeting about the EPAD project’s dissemination activities.

On 21-24 April (Tallinn, Estonia) Gwladys went to a Fam-trip to Estonia visiting several venues to possibly host AEC2016.

On 23 April (London, UK) Annette attended a workshop organised by Gail Mountain and Esme Moniz-Cook and funded by JPND to develop new themes and concepts for outcome measures in dementia care.

On 23-24 April (Chelmsford, UK) Kate and Dianne attended the kick-off meeting of the MIAMI-MD project.

On 28 April (Lille, France) Annette attended a working day organised by NILVAD and DISTALZ (University of Lille North).

On 29 April (London, UK) Dianne participated in a master class, looking at how dementia is framed as well as ethical issues, organised by the Dementia Services Development Trust (Stirling) within the context of the Dementia Festival of Ideas.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 106, 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 for the European Alzheimer’s Alliance:

Austria: Heinz K. Becker (EPP); Kappel Barbara (NI); Rübig Paul (EPP).
Belgium: Mark Desmeester (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tararabila (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE).
Bulgaria: Andrey Kovatchev (EPP).
Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECP).
Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovsky (EPP).
Danmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D).
Estonia: Uurmas Paet (ALDE).
Finland: Liisa Jaakkola (S&D); Anneli Jäätteenmäki (ALDE); Miaspetra Kumppula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP).
France: Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvyn (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargnaux (S&D).
Germany: Angelika Niebler (EPP); Udo Voigt (NI).
Greece: Kostas Chrysogonas (GUE/NGL); Manolis Kefalogiannis (EPP).
Hungary: Ádám Kósa (EPP).
Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP);
Iceland: Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP);
Mairead McGuinness (EPP); Liadh Ní Riada (GUE/NGL); Brando Benifei (S&D);
Netherlands: Esther de Lange (EPP); Lambert van Nistelrooij (EPP).
Poland: Elżbieta Łukacijewska (EPP); Małgorzata Kowalczyk (S&D); Marta Muszyńska (EPP); Niewiadomski Stanisław (S&D).
Portugal: Liliana Rodrigues (EPP); António Cardoso (ALDE); Ana Amélia Paiva Ferreira (EPP).
Romania: Cristian Silviu Bușoi (MEP), (EPP); Mihai-Andrei Sighireanu (S&D);
Slovenia: Franc Bogovšek (S&D); Tanja Fajon (S&D); Alojz Peterle (EPP);
Spain: Célia Pérez (EPP); Beatriz Sáez (S&D); Laura Ballesteros (S&D).
Sweden: Cecilia Wikström (S&D).
United Kingdom: Theresa Villiers (EPP); Richard Howitt (EPP); Richard Howitt (S&D)

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European Alzheimer’s Alliance

30 April: Three MEPs sign Glasgow Declaration, two join the EAA

During the month of April, four policy makers signed the Glasgow Declaration, three of whom are MEPs. The other is the Mayor of Ljubljana, Zoran Janković. This brings the total number of policy makers supporting the Declaration to 54, from 19 different European countries.

MEPs who have signed this month are (in order of signing): Linda McAvan, Theresa Griffin and Juan Carlos Girauta Vidal.

Two of these MEPs (pictured) are also new members of the European Alzheimer’s Alliance (EAA), bringing the number of EAA members to 106. They are (in order of joining):
- Theresa Griffin (S&D, UK)
- Juan Carlos Girauta Vidal (ALDE, Spain)

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

EU Developments

30 March: Meeting of the EPF Working Group on ‘Access to healthcare’ takes place

On 30 March 2015 (Brussels, Belgium), the European Patients’ Forum organised a meeting with members of its Working Group on ‘Access to Healthcare’. Besides Alzheimer Europe (AE), the following patient groups were represented on the day: the European Alliance of Neuromuscular Disorders Associations (EAMDA), Europa Colon, Lupus Europe, the European Haemophilia Consortium (EHC), the National Patients’ Organization (NPO), Pulmonary Hypertension Association Europe (PHA Europe) and the Coalition of Patients’ Organizations with Chronic Diseases (COPAC).

The aim of the meeting was to work on the draft paper circulated by EPF on defining and measuring access. This was followed by a presentation on EU indicators for access and health inequalities by Mr. Artur Carvalho, Policy Officer with Healthcare Systems Unit, DG SANTE, European Commission. Finally, an update on the Patient Access Partnership (PACT) and the EP Interest Group on access was given.

EU Public Affairs Advisor Annette Dumas attended the meeting on behalf of AE.

7 April: EU Commissioner for Health and Food Safety writes open letter to EU Ministers of Health

On 7 April EU Commissioner for Health and Food Safety, Vytenis Andriukaitis wrote an open letter to the EU Ministers of Health, sharing his thoughts on the challenges facing Health in Europe and expressing some of his ideas about collaborating to ensure better health for citizens across the European Union (EU).

“Our motto ‘this time is different’ applies to how we cooperate; how we seek to bridge inequalities in health outcomes and life expectancy across the European Union; and how we endeavour to make all policies work for better health”, writes Commissioner Andriukaitis. He also describes people’s health as “society’s greatest asset” and insists the health sector is “at the leading edge of research and innovation and is one of the biggest job creators in the EU”.

His priorities as laid out in the open letter are prevention, promotion and protection - preventing people from getting ill by addressing issues such as tobacco, alcohol abuse, nutrition and physical activity; promoting healthier living; and protecting people from contagious diseases, famine and pollution.

“We can no longer turn a blind eye”, he says, to the causes of a “mounting burden of chronic diseases”.

Commissioner Andriukaitis says he is ready to co-operate with all Member States and stakeholders at European level in a supporting role and suggests a possible report on the state of health in Europe as a regular method of measuring progress.


20 April: EC investment plan amended by EP to save research budget

On 20 April, the European Parliament (EP) approved European Commission (EC) President, Jean-Claude Juncker’s European Fund for Strategic Investments (EFSI) after much deliberation. Their approval, however, was only given on the condition that changes be made regarding the role of the institution in the oversight of the EFSI and the provision of the budget.

The EUR 315 billion fund - which exists to finance new infrastructures, green technology and IT projects - was to be provisioned by a starting pot of EUR 21 billion provided by the European Investment Bank (EIB) and the EC combined. The EC share (EUR 15 billion) was going to be filled by reducing research and transport budgets, but this lead to an outcry from scientific communities, among others, as a result of which, the EP requested that the EC find alternative resources to finance the fund.

The EP’s decision has been welcomed by transport and research actors.

The amended agreement will be voted in June, provided that the Council of the European Union follows suit.
31 March: The Alzheimer Society of Ireland runs “#still” dementia awareness campaign

In March, to celebrate the opening of the Oscar winning film Still Alice, which tells the story of Alice Howland, a linguistics professor at Columbia University who develops early onset Alzheimer’s disease, The Alzheimer Society of Ireland (ASI) ran a week long digital campaign called #still. The campaign asked members of the public to post pictures of themselves or their loved ones living with dementia on social media, tagging ASI and including the hashtag #still.

The response was overwhelming from people living with dementia, their family carers and people who have lost loved ones to the condition. The short campaign garnered a huge level of online engagement, with more than a quarter of a million people posting on ASI’s Facebook and Twitter accounts. These campaigns promote visibility of the person with dementia in line with ASI’s ethos of placing the person with dementia at the centre of everything they do.

ASI also organised a panel discussion, following a public screening of Still Alice, at the Irish Film Institute in Temple Bar in Dublin on 7 March which was very well attended. The panel explored issues raised by the film and also discussed the value of film and the arts for both awareness raising and therapeutic purposes for people living with Alzheimer’s disease and other dementias in Ireland.

The panel featured Tina Leonard, Head of Advocacy at ASI; Hilary Moss, Director of the National Centre for Arts and Health; Chair of the ASI Irish Dementia Working Group, Helen Rochford Brennan – who is from Sligo and was diagnosed three years ago with early onset Alzheimer’s disease - and Ronan Smith, who is a passionate advocate for the Irish Dementia Working Group.

1 April: Alzheimer Scotland announces Scottish Dementia Awards 2015

Alzheimer Scotland announced the opening of entries for Scotland’s dementia Awards 2015 on 1 April:

Scotland’s Dementia Awards celebrate creative approaches, innovation and best practice in all aspects of information, advice, care and support for people with dementia, their carers, partners and families.

If you work within the health, social care, independent or voluntary sectors in the support of people living with dementia, or if you are involved in education or training relating to this, then we want to hear from you!

For further information about Scotland’s Dementia Awards, including official entry form and booking form to attend the awards ceremony (24 September in Glasgow), please visit www.ScotlandsDementiaAwards.org.uk. We will be tweeting with #SDAs15.

If you have any further queries, do not hesitate to contact us on 0141 410 1072 or email ScotlandsDementiaAwards@alzscot.org.

There are six categories to enter in 2015 and we can't wait to hear about your projects and partnerships.

2-5 April: Turkish Alzheimer Association holds fifth National Alzheimer Conference

The fifth National Alzheimer Conference by the Turkish Alzheimer Association (TAA) was held in Dalaman-Muğla, from 2 to 5 April.

More than 200 participants including neurologists, geriatricians, psychiatrists, psychologists, international and local pharmaceutical industry members - and the members of the Turkish Alzheimer Association attended the Conference.

On the first day of the meeting the leaders of TAA’s 14 branches from across the country came together and shared their experiences, activities and discussed the current conditions and their future plans. It was encouraging to hear that all the branches spread throughout the country are working very hard to raise awareness of Alzheimer’s disease (AD) and that they feel confident their efforts are eliciting a good response from the public, said Füsun Kocaman, Secretary General of the Turkish Alzheimer Association. Ms Kocaman also said there was good news from three branches regarding preparations for their local administrations to establish new day-care centres, news which she said was “very heartening”.

Current concepts in the diagnosis, pathophysiology and the treatment of AD and other dementias were the main focus of the scientific program. Keynote speaker, Dr Natalie Ryan from University College London, UK gave a speech about new findings in the neuroimaging of AD.

Another keynote speaker, Dr David Wilkinson from Southampton University, UK summarised the current and future concepts in the non-cholinergic treatment of AD.

There were sessions focusing on geriatric and psychiatric issues in people living with dementia. A panel discussion on the risk factors, health, life-style and cognitive training in the disease reflected the various opinions of the panelists practicing in different regions of Turkey. In the last session of the second day, results of the ongoing EU-funded biomarker project were presented and standard procedures of CSF biomarkers were discussed by the panelists and participants.

The workshop on “Neuropsychological Evaluation of the Patients” attracted many participant, as did another session on the implementation of mobile technology in the care of people with dementia and elderly people.
which was sponsored by one of the leading mobile phone operators in Turkey.

On the final day, participants got the chance to meet experts and have interactive discussions, while the poster presentations - including original clinical and case studies - were topped by prize-winner, Dr Hale Alpsan.

4 April: Alzheimer’s in Morocco - a new project is initiated by the MAA

In the framework of the Mediterranean Alzheimer Alliance (MAA), the Association Monégasque pour la recherche sur la maladie d’Alzheimer (AMPA) and the Sud Maroc Alzheimer association collaborated together for concrete action in favour of the fight against Alzheimer’s disease in Morocco.

During the 25th edition of the Rallye Aicha des Gazelles, from 25 March to 4 April, 3 initiatives were carried out in partnership with Association Essaouira Mogador and Association Coeur des Gazelles:

- During the Rally, the Medical Caravan organised by the Coeur de Gazelles Association offered consultations for people living in the remote regions of southern Morocco. This year for the first time, there was an Alzheimer’s awareness campaign. 440 people were trained on awareness of Alzheimer’s disease. 101 neurology consultations were carried out by Doctor Chraa (pictured, bottom left) and Professor Kissani from the Sud Maroc Alzheimer Association. Several people were diagnosed with Alzheimer’s disease, stroke and Parkinson’s disease among others. AMPA also carried out a study on the general public, in which 210 people were questioned about their perceptions and knowledge of Alzheimer’s disease. This unprecedented study will reveal the level of information that the South Moroccan population have regarding the disease. The results will be published by the end of 2015.

- Kate Williams and Laura Bouganne (pictured, right) participated in the automobile Rally, flying the colours of AMPA and the Principality of Monaco. After an eventful and memorable experience, they finished 95th out of 150 teams in the overall ranking. Over 30 articles were published in the press (Monaco, France and international) giving the AMPA team excellent visibility to communicate on Alzheimer’s disease.

- After the official arrival of the Rally on 4 April, the first Moroccan Alzheimer Pilot Centre was opened in Essaouira in the presence of the Governor of the region and a number of Moroccan authorities. Thanks to the support of AMPA and the Association Essaouira Mogador, this centre will offer memory consultations and a day care centre for the Southern region of Morocco.

10 April: France Alzheimer launches survey of people with dementia

France Alzheimer has launched a large national survey to gather opinions from people living with Alzheimer’s disease and other dementias. Unprecedented in France, this survey allows people living with dementia to express their feelings about their daily lives and experiences, their relationship with their caregivers, how society seem them and their condition, but also about their hopes for the future. If you are a person living with dementia in France, France Alzheimer would like you to make your voice count by taking the survey.

France Alzheimer urges carers – while they are welcome to be involved in the process - not to respond to the survey in place of the person living with dementia, but rather to provide support only as and when it is needed, if at all. The survey closing date is 18 June.

http://www.sondagefrancealz.com/

17 April: Scottish Dementia Working Group members involved in Dementia Diaries project

Scottish Dementia Working Group (SDWG) members have been involved in an innovative new project, called “Dementia Diaries”. The Dementia Diaries Project is an initiative of On Our Radar, a small non-profit communications agency who work with marginalised groups.

At two training sessions run by Libby Powell, from On Our Radar, SDWG members were shown how to use 3D printed mobile handsets. The phones are linked to a dedicated voicemail and the recording is then sent via the internet to staff members who listen to the message, transcribe it and upload to the Dementia Diaries website.

The aim of the project is to allow people living with dementia to share their thoughts in order to increase understanding of what it is like to live with dementia on a daily basis.

New committee member, Anne MacDonald said “it is so important to hear our voices with facts, understanding and hope. Dementia is everyone’s business.”

http://dementia.onourradar.org/

18-19 April: The Romanian Alzheimer Society attends two local events

On 18 and 19 April, the Romanian Alzheimer Society attended two events in Bucharest.

Firstly on 18 April, Vice President Maria Moglan attended the “Grandparents Club” organised by “Vocea Sperantei Radio” (Voice of Hope Radio) in Bucharest. Ms Moglan (pictured) spoke about the signs of Alzheimer’s disease and about prevention.
On 19 April, The Society attended an event organised by the Jewish Community Center, part of the Jewish Community Federation of Romania (a member of Romanian Alzheimer Alliance, founded by the Romanian Alzheimer Society). “Closer than close” is a community performance in which some of the residents of the Moses Rosen retirement home along with some staff members, who are with them on a daily basis, come together on stage to reconstruct everyday rituals, dance, and reminisce about the weaker and stronger connections between them. “Closer than close” depicts everyday life in a retirement home.

http://www.artapolitica.ro/platforma2015/body.html

21 April: Finland reports on its successful election pledge campaign

The Alzheimer Society of Finland (Muistiliitto) and its 43 local branches managed to reach a third of all the parliamentary election candidates with their Muistiliitto (“Memory15”) campaign. The campaign highlighted the importance of political decisions towards building a dementia-friendly Finland and reminded the candidates to listen to the voices of the people with dementia and their families.

Of the 761 signatories, 71 were elected to the Finnish parliament for the next four years. 71 “memory friendly” members of parliament come from eight different parties and all around Finland. In future, Muistiliitto will keep the signatories and the rest of the 200 members of parliament informed about the interests and concerns of its members.

The signatures and messages from the candidates were collected through the www.muisti15.fi website. Local branches did active, grassroots work to convince the candidates and social media channels were also used.

Muistiliitto is proud to say that “Memory15” was one of the most successful election pledge campaigns organised in Finland this spring.

23 April: CEFAA publishes report with Lilly to advance national dementia policies in Spain

On 23 April a press conference took place in the Spanish Institute for Older People and Social Services (IMSERSO) in Madrid. At the press conference, CEFAA and Lilly presented a report to advance the development of national policies for Alzheimer’s disease in Spain.

The report is part of a collaboration between CEFAA and Lilly and includes more than 20 recommendations that could help to improve the diagnosis and the care and support provided to people living with dementia and their families.

The report emphasises the need to create a national census of people with dementia, to address the existing variability and inequalities in access to health care services and social support in Spain and to improve the coordination between health and social services systems.

Other relevant aspects highlighted in the report relate to timely diagnosis, the role of Alzheimer’s associations and the involvement of carers in the provision of care and support.

Mr Koldo Aulestia, Chairperson of CEFAA, Mrs Teresa Millán, Director of Corporate Affairs for Lilly and Mr César Antón, Director General of IMSERSO participated in the event (pictured).


27 April: Alzheimer Portugal’s “Memo” project raises awareness in schools

Alzheimer Portugal’s project, “Memo e Kelembra nas Escolas” (Memo and Kelembra in schools) arose from a need to sensitise and raise awareness among the population - particularly children, teachers and assistants - about Alzheimer’s disease (AD) and other dementias, as well as their implications for our society, in particular families.

The aim of the project aim is to innovate by promoting health-related knowledge via the medium of literature, among the younger population: What are the first signs of the disease? What is dementia? How do I deal with its characteristics? What is happening to my grandfather/grandmother? As a grandchild, how can I help? Alzheimer Portugal hopes that, by enabling children to answer these questions, creative, significant improvements in health and family care could lead to a reduction in the incidence of dementia, as well as increased well-being and quality of life for people living with dementia.

Information sessions start with a presentation from the project’s technicians and with a role-play of the bilingual Portuguese/English book “O Pequeno Elefante Memo/Memo the Little Elephant”. Following this, discussions take place around subjects such as old age, children’s feelings around vis-à-vis the story (taking into account their body language), caring for people with dementia, support for older people, relating the elephants’ family to the children’s own families, what should be done when someone is ill, etc. The sessions end with the “elephant dance”, to create a relaxed environment.

To date, such sessions have already taken place in 11 of the 18 districts of mainland Portugal, covering 19 schools and 3429 participants, for students with and without disabilities.
Policy Watch

1 April: As UK Care Act comes into force, Alzheimer’s Society warns social care must not fall victim to election campaigns

On 1 April, the Alzheimer’s Society (UK) wrote an article, urging that “social care must not become the victim of this election campaign”.

“Without sustainable funding the most significant piece of social care legislation for decades is at risk of becoming a wasted opportunity”, it charity warned.

On the same day the Care Act (2014) came into force in the UK, the Alzheimer’s Society urged all UK political parties to “commit sufficient funding to turn its provisions into a reality” and warned that playing party politics with the lives of the most vulnerable in society “will fundamentally undermine this progressive legislation”.

“The human and economic impact of dementia is truly staggering. It costs the UK in excess of GBP 26 billion (EUR 36 billion) a year, which equates to GBP 30,000 (EUR 41,500) per person with dementia every year. Most striking of all is that people with dementia, their carers and families shoulder two-thirds of this cost themselves”, commented George McNamara, the charity’s Head of Policy and Public Affairs.

Mr McNamara noted that while people with cancer or heart disease can “quite rightly” expect the care they need for free on the NHS, this is not the case for people with dementia. While the reforms in the Care Act are “a step in the right direction”, unless properly funded they will not alleviate the “enormous burden on unpaid carers”, he said.

A coalition of more than 75 of the UK’s leading charities has warned that the UK government’s flagship changes to the social care system are “built on sand”, without adequate funding for disabled and older people and their carers. The Care and Support Alliance, of which the Alzheimer’s Society is a member, said the Care Act was “a bold attempt” to reform the system but without more funding, “thousands of people will continue to be cut out of the care system and denied access to things as basic as getting up, getting dressed and getting out of the house”.

Research by the London School of Economics has shown that around 500,000 older and disabled people who would have received care in 2009 are no longer entitled to it, while the Local Government Association and the Association of Directors of Adult Social Services estimate a GBP 4.3 billion “black hole” in social care services by the end of the decade.


2 April: Malta launches National Dementia Strategy, including dementia-friendly version

On 2 April, Malta launched its National Dementia Strategy. The strategy is the fifteenth national plan to be launched in Europe, but the first to include a dementia-friendly version. Dr Charles Scerri, General Secretary of the Malta Dementia Society and Honorary Secretary of Alzheimer Europe wrote the document, “Empowering Change”, which is a nine-year plan aimed at enhancing the quality of life of people living with dementia.

At the launch, Dr Scerri highlighted that most of the EUR 63 million to EUR 96 million spent annually on the condition was on informal treatment at home, often putting people at risk of poverty. He also said that although the strategy was launched today, much work has already been done with carers being trained and the parliamentary secretariat issuing documentation to help raise awareness.

The strategy details 85 recommendations, including raising awareness, training professionals and carers to make a timely diagnosis, immediate aftercare once a diagnosis is made and psychological support for carers.

There are 6,071 people diagnosed with dementia in Malta, equivalent to 1.5% of the population. This number is expected to grow to 13,000 in 2050, equivalent to 3.3% of the population.


2 April: Wales unveils new plan for dementia care and sets diagnosis targets for 2016

On 2 April, the Welsh Government announced GBP 1 million (EUR 1.39 million) to help recruit new primary care support workers for people living with dementia and set a target to raise the rate of diagnosis to 50%, from the current 43% estimated by the Alzheimer’s Society.

The announcement was made as part of a new government drive to improve the lives of people living with dementia in Wales, with the aim of making Wales a “truly dementia-friendly nation”.

The plan includes:

- A new target for health boards to improve dementia diagnosis rate to at least 50% by 2016.
- Funding for 32 new primary care support workers, to provide face-to-face support, information and advice on accessing the right care and services for people diagnosed with dementia.
- New funding for four additional primary care link nurses to visit the 675 residential and nursing homes in Wales and provide staff training.
- Increasing the number of Dementia Friends in Wales, by ensuring funding for the next three years for the Dementia Friends campaign.
- Publishing a new guide on the steps people can take to reduce their risk of developing dementia.
- Encouraging more GP surgeries to take up government-funded dementia training.
- These announcements come just weeks after the Welsh Assembly vowed to become a dementia-friendly organisation (25 February), to help support the 45,000 people living with dementia in Wales.


Page 9 of 16
13 April: Study says UK dementia research is still greatly underfunded

Authors of a UK study, published in the journal BMJ Open on 13 April, say that research funding into stroke and dementia in the UK remains too low. Despite the UK government’s increases in funding and efforts, which have put dementia firmly on the political agenda and have narrowed the gap between budgets for these two conditions and cancer and coronary heart disease (CHD), the report says that the amounts being spent on research bear little relation to the conditions’ costs to health and social services, or their economic and personal impacts.

The researchers, from the health economics research centre at Oxford University, suggest that the high level of research funding by cancer charities compared with those for other diseases can be partly explained by the public’s preferences and even a form of ageism - linked to the misconception that dementia and stroke are inextricably linked with ageing.

Dementia and stroke need extra funding and greater understanding, the authors conclude.

http://bmjopen.bmj.com/content/3/4/e006648

14 April: WHO publishes statement on public disclosure of clinical trial results

On 14 April the World Health Organisation (WHO) published a new statement on the public disclosure of clinical trial results.

The statement re-affirms “the ethical imperative of clinical trial results reporting” as well as defining reporting timeframes. It also calls for the reporting of older but still unpublished trial results, as well as outlining steps to improve linkages between clinical trial registry entries and their published results.

This new statement updates and expands the WHO’s 2005 statement that “the registration of all interventional trials is a scientific, ethical, and moral responsibility”.


3 April: Ronald Reagan’s speech patterns may help in AD research

Scientists studying the speech patterns of former US President Ronald Reagan – once known as “The Great Communicator” - have detected subtle variations, which they say are linked to the early stages of Alzheimer’s disease (AD). The results of their study - which compared 46 unscripted news conferences given by President Reagan with 101 sessions held by President George H. W. Bush during his own time in office - were published in The Journal of Alzheimer’s Disease on 3 April.

The relevant markers in President Reagan’s speech - such as the repetition of certain phrases or forgetting them altogether - are detectable years before he was officially diagnosed with the condition in 1994, five years after he left office, according to the researchers, at Arizona State University in the US. They hasten to add, however, that this does not prove that President Reagan’s time in office was adversely affected.

Dr Visar Berisha, one of the study’s lead authors said that natural language processing and algorithms may be used in the future, to detect these subtle changes in speech, which occur with AD.


To investigate this in a hospital setting, the researchers followed 230 people with dementia during their stays in hospital. They found that only 39% of the participants reported pain at least once during their hospital admission. Meanwhile 57% were observed by the researchers to be in pain at some stage.

The presence of pain was strongly associated with behavioural and psychiatric symptoms of dementia (BPSD), such as aggression and apathy. This matches with what has been previously observed in care homes, but this is the first study to demonstrate the same in a hospital setting.

The researchers, led by Dr Elizabeth Sampson, reported:

“Some BPSD in the acute hospital may be due to under-detected and under-managed pain. This then leads to a cycle whereby behavioural problems and rejection of care by the person with dementia can lead to dysfunctional coping in staff, increasing care burden and further alienating staff from the person with dementia.”

About half of the participants in the study could use the standard pain scale to describe their level of pain although this varied strongly, from 80% of people with early-stage dementia to just 3% of those with advanced dementia.

“This illustrates how self-report may lead to underestimation of pain in people with dementia, and the importance of careful observation for pain at rest and during movement”, concluded the researchers.


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25 March: Study finds people with dementia may be experiencing undiagnosed pain

UK research jointly funded by the Alzheimer’s Society and the BUPA Foundation has found that people with dementia in hospital may be experiencing undiagnosed pain. The study was published in the journal Pain on 25 March.

“Pain is commonly under-detected and under-treated in people with dementia, as they may not easily be able to indicate that they are in pain”, the researchers commented.
8 April: Study says arts and crafts activities delay the onset of memory problems

A study published on 8 April has found that those who participate in arts, crafts, computer use and social activities can reduce the risk of developing Mild cognitive impairment (MCI).

The study, published in the American Academy of Neurology, focuses on MCI, a condition that in some cases precedes dementia. It involved 256 people with an average age of 87 who were free of memory and thinking problems at the start of the study. After an average of four years, 121 people developed mild cognitive impairment.

Participants who engaged in arts in both middle and old age were found to be 73% less likely to develop MCI than those who did not report engaging in artistic activities. Those who did crafts in middle and older age were 45% less likely to develop MCI. People who socialised in middle and older age were 55% less likely to develop MCI compared to those who did not engage in social activities. Finally, computer use in later life was associated with a 53% reduced risk of MCI.

https://www.aan.com/PressRoom/Home/PressRelease/1363

9 April: UK study on weight and dementia has surprising results

This month, the UK media reported that being overweight “reduces the risk of dementia”. The story emerged from a UK cohort study of nearly 2 million middle-aged (40+) adults, which concluded that being overweight or obese - based on Body Mass Index (BMI) - was linked to a lower risk of dementia up to 20 years later, as compared with people who were in the healthy BMI range. Underweight people on the other hand, were found to be at higher risk of developing dementia in later life.

The study, carried out by researchers from the London School of Hygiene and Tropical Medicine and OXON Epidemiology, was published in the journal The Lancet – Diabetes and Endocrinology on 9 April.

The NHS has described the results as surprising, given that it bucks the trend of previous research in this area and “contradicts the current consensus of opinion...that obesity may be a risk factor for some types of dementia”. The NHS emphasises that "It is important not to overlook the many serious health risks associated with obesity, such as heart disease and diabetes” and that “a single study is unlikely to lead to a change in clinical guidelines".

The researchers themselves are unsure about the implication of their findings and said: “The reasons for and public health consequences of these findings need further investigation.”

http://www.thelancet.com/journals/landia/article/PIIS2213-8587%2815%2900033-8/abstract

13 April: New Alzheimer’s disease drug candidate enters Phase 1 trials

On 13 April, Indian pharmaceutical company Suven Life Sciences Ltd announced that its Alzheimer’s disease drug candidate, SUVN-G3031 has begun a Phase 1 clinical study in the US, to evaluate safety and tolerability in humans. The drug will be tested in multiple doses on participants, having passed the single-dose stage.

15 April: Study says sleep apnea is linked with earlier cognitive decline

People with sleep apnea - breathing problems during sleep - develop mild cognitive impairment (MCI) a decade earlier, says a new study published on 15 April in the journal Neurology.

The medical histories of 2,470 people aged 55 to 90 taking part in the Alzheimer’s Disease Neuroimaging Initiative (ADNI) study were reviewed for the development of MCI or Alzheimer’s disease (AD). Participants were also asked to report whether they suffered from sleep apnea and whether or not they received treatment with a continuous positive airway pressure (CPAP) machine during the night.

On average, people with sleep apnea were diagnosed with MCI in their 70s, a decade earlier than people without sleep breathing problems. However, the relationship between having sleep apnea and the age of diagnosis of AD was not clear in the study.

Twelve people in the study who developed MCI reported treating their sleep apnea with a CPAP machine and, on average, they developed MCI at the same age as those who did not report any sleep breathing problems. These findings suggest that use of a CPAP machine should be investigated further as a way to delay the onset of cognitive decline in people with sleep apnea.

Dr Doug Brown, Director of Research and Development for the Alzheimer’s Society (UK) commented that “frequent, loud snoring could be a sign of sleep apnea”. Given that those who reported having sleep apnea in this study developed cognitive decline a decade earlier, this could be an area meriting further investigation, he said - particularly as “the small number of people who received treatment in this study did not experience early cognitive decline, suggesting treatment could be an effective way to preserve cognitive health for longer.”

http://www.neurology.org/content/early/2015/04/15/NNL.0000000000001566

15 April: Study links immune system and arginine to Alzheimer’s disease

A study, published in the Journal of Neuroscience on 15 April has linked the immune system and a nutrient called arginine to Alzheimer’s disease (AD).

Research was conducted at Duke University Medical Center, North Carolina, US.
Using AD mouse models, the Duke researchers set out to investigate what happens to immune system cells in the brain as AD progresses. They found that immune system cells called microglia cluster around amyloid clumps and produce an enzyme which destroys arginine, a vital nutrient. They believe that the depletion of arginine in some parts of the brain could be responsible for the death of brain cells.

The team went on to show that blocking the depletion of arginine with a drug called difluoromethylornithine (DFMO) can prevent the buildup of amyloid clumps in the brains of mice. The drug also stopped the development of memory impairments in the mice.

The Alzheimer’s Society (UK) commented on the media reaction to this study:

“Previous studies into the mechanism behind Alzheimer’s disease have focused on the formation and buildup of the amyloid clumps. Treatments that have been developed to prevent these clumps from occurring or that clear them from brain cells have so far been unsuccessful at stopping the disease from progressing. This study provides a potential new mechanism for the role of the immune system in Alzheimer’s development.”

“The drug DFMO targets this mechanism and is already being developed as a potential treatment for cancer. This means that DFMO can be entered faster into clinical trials to determine if it can help with treating or preventing Alzheimer’s disease.”

It should be noted that the research was carried out in mice not humans and further research is needed before any real conclusions can be drawn.

http://www.jneurosci.org/content/35/15/596

16 April: Large-scale PET scan study for dementia is announced in US

On 16 April, a new four-year research study, with an estimated budget of USD 100 million (EUR 904,000) was announced by the Alzheimer’s Association (US) and the American College of Radiology (ACR). The Imaging Dementia – Evidence for Amyloid Scanning (IDEAS) Study will determine the clinical usefulness and value in diagnosing Alzheimer’s disease (AD) and other dementias in certain situations of a brain positron emission tomography (PET) scan that detects a core feature of AD.

The IDEAS Study will assess the impact of brain amyloid PET imaging on a variety of patient outcomes. It is led by the Alzheimer’s Association and managed by the ACR and American College of Radiology Imaging Network (ACRIN).


21 April: Trial to start on diabetes drug as possible dementia treatment

Patients over the age of 50 in the early stages of Alzheimer’s disease (AD) are being recruited for a new clinical trial in Cambridge, UK after a previous study found the already widely used diabetes drug, liraglutide might help reverse some of the damage caused to the brain, in the later stages of AD.

In the previous study last autumn led by Lancaster University in the UK, late-stage AD mouse models given the drug performed significantly better on an object recognition test and their brains showed a 30% reduction in the build-up of amyloid plaques.

The new study, led by Imperial College London, will recruit more than 200 men and women in their 50s, with early onset AD, to a year-long trial during which their brains will be scanned and their memory function tested.

23 April: Air pollution may raise risk of dementia, US study finds

A study published in the journal Stroke on 23 April has found that living near congested roads with high levels of air pollution can cause silent strokes, which in turn increase the risk of developing dementia.

Exposure to fine particulate matter known as PM2.5 – which has previously been shown to cause lung damage and harmful changes in blood vessels and clotting - alters the structure of the brain researchers at Boston University School of Medicine said. PM2.5 is mostly caused by traffic fumes and factory emissions.

The study, by Beth Israel Deaconess Medical Center and Boston University School of Medicine, involved more than 900 people aged 60 and over, who did not have dementia or a history of strokes.

It recorded how far participants lived from major roads and used satellite imagery to assess their exposure to PM2.5.

The study participants’ brain matter was measured using MRI scans. The researchers found that increases in PM2.5 in towns and cities was linked with a 46 per cent higher risk of silent strokes.

‘Professor Sudha Seshadri, department of neurology, Boston University School of Medicine said the team now plan to look more at the impact of air pollution over a longer period, its effect on brain shrinkage over time, and other risks including stroke and dementia.’

http://stroke.ahajournals.org/content/early/2015/04/23/STROKEAHA.114.008348.abstract

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Dementia in society

10 March: “Still Alice” writer and director, Richard Glatzer dies

Richard Glatzer (pictured, standing), who wrote and directed “Still Alice” together with his husband, Wash Westmoreland, has died with Amyotrophic lateral sclerosis (ALS) - also known
as Lou Gehrig’s disease or motor neurone disease (MND). Mr Glatzer was 63 at the time of his death, on 10 March.

His death came less than three weeks after actress Julianne Moore won the best actress Oscar for her performance in the movie. She played Alice Howland, a Linguistics Professor with early-onset Alzheimer’s disease.

In addition to his husband, Mr Westmoreland, Glatzer is survived by his sister, Joan, her husband, David, his loving nieces and nephews and his daughter, Ruby.

18 March: Big Bang Theory stars attend Alzheimer’s Association benefit

On 18 March, stars of hit US TV comedy series, the Big Bang Theory (pictured) attended “A Night at Sardi’s” - an annual celebrity musical revue and awards dinner held to benefit the Alzheimer’s Association (US).

This year’s event, under the theme of “Broadway’s Best” was held at the Beverly Hilton Hotel in Los Angeles, California and welcomed more than 850 celebrities.

To date, “A Night at Sardi’s” has raised more than USD 25 million for the Alzheimer’s Association.

8 April: Gaelic conversations help native speakers with dementia in Scotland

On 8 April, BBC Scotland reported on a project taking place in Inverness, in the Scottish Highlands. The project brought local school children to a care home to speak Gaelic with some of the residents, all of whom are living with dementia and many of whom grew up speaking Scottish Gaelic as their native language.

As well as providing the school children with an opportunity to further their linguistic and social skills, the Gaelic conversations helped residents of the care home to remember things from their own youth, which the care workers said boosted their sense of wellbeing and “gave them back their identity”.

Scottish Gaelic is a Celtic language spoken by approximately 1% of the Scottish population aged over three. It is not an official language of the EU nor of the UK, but is classed as an Indigenous language under the European Charter for Regional or Minority Languages.

15-19 April: ADI 2015 conference in Perth celebrates 30 years of ADI

From 15 to 19 April in Perth, Australia, Alzheimer’s Disease International (ADI) held its annual conference, celebrating 30 years since the organisation’s beginnings in 1984 and celebrating global collaboration.

The conference opened with a screening of the Hollywood movie, Still Alice, about a Professor with early onset Alzheimer’s disease.

Some highlights from the conference were:

- Keiko Matsushima from Japan was announced as the winner of ADI’s Home Instead Family Carer of the Year Award;
- ADI announced that its 2015 World Alzheimer Report is due for publication soon and will focus on updating global dementia prevalence and cost data;
- ADI met with its members from around the world to strategise about activities for September, which it calls “World Alzheimer’s Month”;
- Glenn Rees was welcomed as the ADI Chairman;
- The Chairperson of Alzheimer Europe’s European Working Group of People With Dementia (EWGPWD), Helga Rohra gave a heartfelt and well-received presentation, emphasizing, “I am still valuable, I am me! – I don’t want to be a victim of dementia I want to be the victor!”

Tweets from the conference can be found under the hashtag #ADI2015

22 April: Landmark US trial raises questions around dementia and sexual consent

This month a jury in the US state of Iowa tried the landmark case of Henry Rayhons, aged 78 - a retired farmer and former state senator accused of raping his wife, Donna Lou Rayhons. The trial raised ethical questions surrounding sexual consent with dementia and between married partners.

Mrs Rayhons was living with dementia in an Iowa care home at the time of the alleged assault in May 2014. Mr Rayhons was arrested and charged shortly after his wife’s death in August of the same year following a complaint made by care home staff, who had previously advised Mr Rayhons that his wife was no longer capable of sexual consent, due to her dementia.

Mr Rayhons was acquitted on 22 April, but it seems this was because the prosecution had failed to prove that sexual intercourse took place on the day in question, rather than because Mrs Rayhons had been able to consent. The verdict therefore bypassed the ethical and legal questions raised around consent.

The Alzheimer’s Association (US) said it was not taking a position on the case but noted the importance of conversations about the capacity of people with dementia for decision-making.

New Publications & Resources

1 April: Irish dementia survey report published

1 April saw the launch of “An Irish National Survey of Dementia in Long Term Residential Care”, carried out by Dementia Services Information and Development Centre (DSIDC) and researchers from Trinity College Dublin. The research team was spearheaded by Professor Susanne
Cahill - DSIDC Director and member of Alzheimer Europe’s Expert Advisory Panel.

The survey – the first of its kind in Ireland - found very low numbers of dementia-specific care units (SCUs) throughout the country and identified large gaps in service provision, as well as excessive numbers of patients in individual housing units. It also underlined the need for a new funding model to further incentivise the private sector.


22 April: The University of Copenhagen opens registrations for dementia PhD course

The University of Copenhagen is giving a PhD course at the Danish Dementia Research Centre, in co-operation with the University’s Faculty of Health Sciences from 24 to 27 August 2015. The title of the course is “Alzheimer's disease and other neurodegenerative dementias”. All lectures and workshops will be in English. The deadline for registrations is 1 June.

http://phdcourses.ku.dk/detailkursus.aspx?id=98361

Contact Alzheimer Europe

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

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AE Calendar 2015

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<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>4 May</td>
<td>Meeting with cabinet of Health Commissioner Vytensis Andriukaitis</td>
<td>Heike and Jean</td>
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<tr>
<td>7 May</td>
<td>Meeting of the European Parliament Interest Group on Care: ‘Family vs state responsibility for long-term care across the EU - the feasibility of one model?’</td>
<td>Annette</td>
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<tr>
<td>8 May</td>
<td>Lilly Working Group on AD environment (Erl Wood, UK)</td>
<td>Jean</td>
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<tr>
<td>8 May</td>
<td>Luxmiske conference (Luxembourg, Luxembourg)</td>
<td>Gwladys</td>
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<td>13-14 May</td>
<td>4th General Assembly of the NILVAD project (Thessaloniki, Greece)</td>
<td>Alex</td>
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<tr>
<td>14-16 May</td>
<td>Meeting of the full EWGPAD (Brussels, Belgium)</td>
<td>EWGPAD, Dianne and Ana</td>
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<tr>
<td>19 May</td>
<td>European Patients’ Forum General Assembly Meeting (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>20-21 May</td>
<td>IMEX conference (Frankfurt, Germany)</td>
<td>Gwladys</td>
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<tr>
<td>20-21 May</td>
<td>General Assembly of EPAD project (Edinburgh, UK)</td>
<td>Jean and Dianne</td>
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<tr>
<td>20-20 May</td>
<td>European Patients Forum conference “Empowered patients are an asset to society” (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>21 May</td>
<td>Conference “Politiques publiques et Recherche Alzheimer: Influences et enjeux réciproques” organised by Alzheimer France</td>
<td>Ana</td>
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<tr>
<td>26 May</td>
<td>‘Breaking down the barriers - Call to Action: Access to employment for people with multiple sclerosis’ (Brussels, Belgium)</td>
<td>Annette</td>
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## Future Conferences 2015

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>5 May</td>
<td>Le démence à tous les âges : enjeux et spécificités, <a href="http://www.alzheimer.be">www.alzheimer.be</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>1-7 June</td>
<td>Dementia Awareness Week: Let’s talk about dementia, <a href="http://daw.dementiacotland.org/">http://daw.dementiacotland.org/</a></td>
<td>Scotland, UK</td>
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<tr>
<td>5-6 June</td>
<td>The Alzheimer’s Show London, <a href="http://alzheimersshow.co.uk/">http://alzheimersshow.co.uk/</a></td>
<td>London, UK</td>
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<tr>
<td>11-13 June</td>
<td>7th Kuopio Alzheimer Symposium “From mechanisms to prediction and intervention of Alzheimer’s disease”, <a href="http://www.uef.fi/kuopioalzsymposium">http://www.uef.fi/kuopioalzsymposium</a></td>
<td>Kuopio, Finland</td>
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<tr>
<td>17-18 June</td>
<td>Best Practice in Care and Support of Persons with Advanced Dementia, <a href="http://www.uws.ac.uk/pallianeproject/">http://www.uws.ac.uk/pallianeproject/</a></td>
<td>Prague, Czech Republic</td>
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<tr>
<td>20-23 June</td>
<td>1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/berlin2015">www.eaneurology.org/berlin2015</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>3-3 July</td>
<td>Summer Course on Ethics in Dementia Care, <a href="https://gbiomed.kuleuven.be/english/research/50000687/50000697/summer-course">https://gbiomed.kuleuven.be/english/research/50000687/50000697/summer-course</a></td>
<td>Leuven, Belgium</td>
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<tr>
<td>26-27 August</td>
<td>Alzheimer’s disease and other neurodegenerative dementias, <a href="http://www.vdenscenterfordemenes.dk">www.vdenscenterfordemenes.dk</a></td>
<td>Copenhagen, Denmark</td>
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<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>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>
</tr>
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</table>
25th Alzheimer Europe Conference
Dementia: putting strategies and research into practice
Ljubljana, Slovenia
2-4 September 2015
Mark the dates!

www.alzheimer-europe.org/conferences