



NEWSLETTER

February 2015

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Editorial



Welcome!

This month, we have been working hard on the launch of our online sign-up campaign for the Glasgow Declaration. Individual online signatures have come in to the tune of just over 900 since 19 February, which means we remain optimistic about reaching our target of 5,000 by 1 December, when we will present our results at the European Parliament, calling for the creation of a European Dementia Strategy and national strategies in every country in Europe, as well as more global action on dementia. Despite the campaign being in its infancy, I am delighted to say that we have been attracting a good number of signatures from policy makers, having received eight signatures from MEPs this month alone.

In the latter part of the month, we held a successful series of meetings in Luxembourg: an AE Board meeting, a meeting of the Board of the AE Foundation, a Company Round Table with some of our sponsors and members and a Public Affairs meeting to exchange ideas with our national member organisations. Following these meetings, we are delighted to be able to count on the support of our members in our Glasgow Declaration campaign and to have the approval of the Board of the AE Foundation to support people with dementia at the AE Conference in Ljubljana. On the conference front, I would like to remind you all that the call for abstracts is open until the end of March and the early bird fee for registrations is available until the end of May, after which the full fees will apply.

In AE publications news, the latest edition of our Dementia in Europe magazine came out this month and our practical guidelines for people with dementia on continence care became available on our website.

There has been a lot of emphasis on trying to achieve concrete global and EU action on dementia this month, with the final G7 Dementia Legacy event taking place in the US and a final Young Leaders event in the UK at the end of the month. Questions arising from these events are: What, concretely, can be taken from these initiatives? How can the momentum be maintained? and what happens next?

At national level, in Austria the process of developing a strategy for dementia was launched, while in the UK, the Prime Minister announced his new Challenge on Dementia 2020, including a number of new research initiatives and a huge increase in funding for these.

As for our member organisations, Alzheimer Portugal has produced a new Portuguese edition of our care manual, for which we are most grateful. Alzheimer Scotland has launched a national campaign called "Let's Talk about Dementia" and the Alzheimer's Society's Dementia Friends programme has passed the 1 million mark.

Last but not least, it is great to see dementia getting an airing on the world stage, via the Oscar-winning movie, Still Alice, starring Julianne Moore. Ms Moore was exemplary in her acceptance speech, highlighting the importance of raising awareness and understanding of dementia.

On that high note, I wish you all a successful start to the spring!

Jean Georges
Executive Director

Alzheimer Europe

1 February: Neuronews interviews Alzheimer Europe's director



On 1 February, Neuronews, the news blog of the European Academy of Neurology (EAN), published an interview with Alzheimer Europe's (AE) Executive Director, Jean Georges.

Mr Georges answered questions about the work AE is doing to make sure dementia is recognised as a European priority, about the development of national dementia strategies and greater collaboration between EU countries. On this subject, he appealed to the readers of Neuronews to sign the Glasgow Declaration.

Mr Georges also expressed AE's interest in collaborating with other organisations with an interest in dementia, such as EAN.

You can read the full interview, here:

<http://www.neuronews.org/?p=8242>

10-11 February: AE and Spominčica work on 25th annual conference



On 10 and 11 February, Gwladys Guillory, Event and Conference Coordinator for Alzheimer Europe (AE) travelled to Ljubljana, Slovenia to meet with Alzheimer Slovenija (SPOMINČICA) concerning the organisation of our 25th Annual Conference from 2 to 4 September this year.

With plans afoot and moving along nicely, we would like to remind people to send their abstracts in by end of March and to register.

We would also urge people registering to book hotels and flights as there is another major event happening in the city at the same time, which may limit options quite swiftly.

You can submit your abstract here: <http://alzheimer-europe.org/Conferences/2015-Ljubljana/Abstract-submission>



19 February: AE launches Glasgow Declaration campaign sign-up online

On 19 February, Alzheimer Europe (AE) launched the online sign-up campaign for the Glasgow Declaration, which calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

The declaration originated at AE's 24th annual conference in Glasgow on 20 October 2014, the same day it was adopted unanimously by delegates from 26 AE member organisations.

At the time of writing, the online campaign had already achieved 871 individual signatures, 32 organisations and 16 policymakers, making a grand total of 919 supporters.

AE is using the Twitter hashtags #GlasgowDeclaration and #dementiamatters for this campaign.

The deadline for signatures is 30 November 2015 and anyone, anywhere in the world is welcome to sign to show their support.

Please sign the declaration and share it with your network.



20 February: AE's practical continence care guidelines are online

As of 20 February, our practical guidelines for people with dementia on continence care at home are available on our website.

<http://www.alzheimer-europe.org/Living-with-dementia/Guidelines-for-people-with-dementia-on-continence-care-at-home>

23 February: Board of AE Foundation approves support for people with dementia at AE Conference in Ljubljana



The Board of the Alzheimer Europe Foundation met in Luxembourg on 23 February to approve the financial report for 2014. The Board was particularly grateful for the additional support of EUR 29,421.98 provided by Alzheimer Europe at the end of the financial year which will bring the financial reserves of the association to EUR 115,215.63.

At its meeting, the Board also adopted a memorandum of understanding outlining its collaboration with Alzheimer Europe and discussed a collaboration agreement with the Luxembourg-based Fondation Alzheimer.

The Board also approved to create five bursaries of EUR 1,000 to support people with dementia who wish to attend the Alzheimer Europe Conference and to provide four awards of EUR 500 for best poster presented at the AE Conference in Ljubljana.

23 February: Alzheimer Europe Board meets in Luxembourg



The Alzheimer Europe Board members held a meeting on 23-24 February in Luxembourg. The Board discussed various financial and operational matters, including

preparations for the 25th Alzheimer Europe Conference

that will take place in Ljubljana, Slovenia on 2-4 September 2015. The next meeting of the Board will take place on 29 June in Brussels.

24 February: AE hosts Company Round Table meeting in Luxembourg



On 24 February, Alzheimer Europe (AE) hosted a Company Round Table meeting in Luxembourg. Seven representatives

from six sponsor companies, ten representatives from AE member organisations, nine AE Board members and five AE staff members attended.

AE Vice-Chair, Iva Holmerová welcomed participants and introduced AE Executive Director, Jean Georges. Jean presented AE's recent and ongoing activities and projects, including the Glasgow Declaration campaign, the Annual Conference, AE's involvement in G7 legacy events and the JPND, the Dementia-Friendly Communities report, the EU Dementia Ethics Network, the new Alzheimer's Association Academy programme, as well as sponsorship opportunities in 2015.

AE Project Officer, Ana Diaz presented the ongoing Clinical Trial database project. Giving an overview of the project and its origins, Ana explained some of the difficulties encountered along the way. She presented two draft database templates, emphasising that decisions about these templates had been taken with the input of four members of the European Working Group of People with Dementia (EWGPWD) and three sponsor companies.

Ana also presented the ongoing Guideline Watch project and presented information on the 71 guidelines on the treatments and management of Alzheimer's disease that had been collected. She invited support for the translations still remaining to be done, which constitute the biggest hurdle in this project.

Jean closed the meeting with a presentation about the European Dementia Monitor, comparing EU country data around various aspects of dementia.

The next Company Round Table meeting will be in Brussels on 30 June.

25 February: AE holds Public Affairs meeting in Luxembourg



On 25 February, Alzheimer Europe (AE) held a Public Affairs meeting in Luxembourg. The meeting was attended by delegates from 15 of AE's member organisations, 1 representative of the European Working Group of People with Dementia (EWGPWD) and 5 AE staff members.

AE Executive Director, Jean Georges opened the meeting with a discussion on some of AE's ongoing projects: Clinical Trial Watch, Policy Watch, Dementia Monitor and the Alzheimer's Association Academy. A working group was set

to work on the further development of the Dementia Monitor project and there was a lively discussion on the topics that member organisations would like to see addressed during the Alzheimer's Association Academy. The Academy, a brand new AE project, will be held during the upcoming AE Conference in Ljubljana, Slovenia.

Annette Dumas (Public Affairs Advisor for AE), Alex Teligadas (AE Director for Communication) and Kate Boor Ellis (AE Communications Officer) followed Jean with presentations on the work with the new European Parliament and the further development of the Glasgow Declaration campaign and the European Alzheimer's Alliance (EAA). The group agreed on the structure of the communication stream to be used for the Glasgow Declaration campaign and on how to further involve the members of the EAA at a national level. Annette, Alex and Kate also presented Alzheimer Europe's Communication and Public Affairs strategies, highlighting the relevance of increasing the visibility of national member organisations in AE communications and on the possibilities for involving members in EU policy making.

The 2015 Dementia in Europe Yearbook, "Is Europe becoming more dementia friendly?" was introduced by Ana Diaz (AE Project Officer) and representatives from Belgium (Sabine Henry), the Netherlands (Julie Meerveld) and Scotland (Jim Pearson) presented their experiences on Dementia Friendly Communities in their country. In addition, Helga Rohra, Chair of the EWGPWD talked about her experiences, from the perspective of a person living with dementia and described various projects that are currently ongoing in her country (Germany). By the end of the session, the methodology, contents and timeframe for the 2015 Yearbook were agreed by the members.

To finish the meeting, each AE member representative provided an update on their national campaigning work.

The next Public Affairs meeting will be held in Brussels on 1 July.

27 February: AE publishes new issue of Dementia in Europe magazine



The latest issue of AE's Dementia in Europe magazine (DIE) was released on 27 February. DIE issue 19 is available for purchase on AE's website and includes the following articles:

• Alzheimer Europe members elect new Board

- MEP Keith Taylor hosts a lunch debate on dementia prevention
- AE presents the new Executive Board of the European Alzheimer Alliance
- The EWGPWD begins its second term
- Alzheimer Europe presents 3 new publications
- Luxembourg expands services for people with dementia
- Greek Parliament approves national dementia strategy
- France launches a neurodegenerative disease strategy
- Italian EU Presidency holds dementia conference

- European Commission reports on key dementia activities since 2009
- “Global action against dementia” completes 2014 agenda
- Birgitte Vølund takes the helm of the Danish Alzheimer Association
- Franco-German cooperation brings together people with dementia
- The Mediterranean Alzheimer Alliance members meet in Lisbon
- AE’s member associations commemorate World Alzheimer’s Day
- Raoul Grönqvist and Milja Ahola discuss movement recall and musical therapy
- AE Conference opens with a focus on rights and autonomy
- Highlights from the plenary sessions of AE’s Glasgow Conference
- AE members adopt the Glasgow Declaration
- Snapshots from Glasgow
- Charts and figures from the conference

<http://alzheimer-europe.org/Publications/Dementia-in-Europe-Magazines>

28 February: Japanese national newspaper publishes AE interview



On 28 February, the Yomiuri Shimbun, one of the five national newspapers in Japan published an interview with Alzheimer Europe (AE)’s Executive Director, Jean Georges.

Journalist, Mina Mitsui compares the Japanese situation with European data provided by Jean regarding national dementia strategies, diagnosis of Alzheimer’s disease, family carers and combatting stigma.

EU Projects

2 February: AETIONOMY is featured in Nature Reviews



The AETIONOMY project was recently featured in a short article in Nature Reviews entitled “Towards reforming the taxonomy of human disease”.

The article describes IMI’s 2012 call for proposals to establish mechanism-based taxonomies for both inflammatory and neurodegenerative diseases. The respective results were the PRECISEADS and AETIONOMY projects, both of which aim to identify disease mechanisms that can be attributed to distinct subgroups of people.

The author goes on to compare and contrast the strategies followed by the two project teams. In both cases, a successful result will lead to increased confidence in target selection as well as higher success rates in drug development.

This article appeared in volume 14 of Nature Reviews Drug Discovery.

www.nature.com/nrd/journal/v14/n2/full/nrd4537.html

12 February: EPAD partners hold first communication meeting



On 12 February, the members of EPAD’s work package 6 met in Barcelona to begin work on the project’s communication

plan and dissemination activities.

The agenda included a brief on the budget and partners’ commitments, but the main focus was a review of existing communication and dissemination activities from similar IMI projects. This allowed the partners to draw up priorities for both internal and external communication tools. The meeting was attended by Sandra Pla and Thiria Fellier (SYNAPSE), Lennert Steukers (Janssen), Sean Knox (Novartis), Jean Georges and Alex Teligadas (Alzheimer Europe).

The five-year European Prevention of Alzheimer’s Dementia project is a collaborative research initiative to improve the chance of successfully preventing Alzheimer’s dementia and to better understand early aspects of Alzheimer’s disease before dementia develops.

www.ep-ad.org



Alzheimer Europe Networking

- On 3 February 2015 (Brussels, Belgium) Annette attended the Discussion Group on Health with Elena Gentile, MEP.
- On 9 February 2015 (Telephone) Dianne participated in the PACE executive board telephone meeting of WP4 of the PACE project.
- On 9 February (Munich, Germany) Jean participated in a meeting organised by INSERM to discuss a project application under the new IMI 2 call for proposals.
- On 10-11 February (Ljubljana, Slovenia) Gwladys met with Alzheimer Spomincica in Ljubljana concerning the organisation of the 25 AEC.
- On 11 February 2015 (Webinar) Kate attended a communications webinar on Twitter Analytics.
- On 12-13 February 2015 (Barcelona, Spain) Jean and Alex attended a WP6 communications meeting of the EPAD project.
- On 19 February 2015 (Brussels, Belgium) Ana, Dianne and Alex attended a development meeting for a new H2020 project.
- On 23-25 February (Luxembourg, Luxembourg) AE Board and staff members attended an AE Board meeting, a Company Round Table meeting and a Public Affairs meeting.
- On 27 February (Brussels, Belgium), Dianne took part in the continence care meeting to develop an article for publication in a peer-reviewed journal.
- On 27 February (London, UK) Jean took part in the Young Leaders in Dementia meeting at the Foreign and Commonwealth Office.

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at 90, representing 26 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). **Belgium:** Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Eleni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). **France:** Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP). **Greece:** Kostas Chrysogonos (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); Brian Crowley (ALDE); Luke 'Ming' Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). **Italy:** Brando Benifei (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP). **Netherlands:** Esther de Lange (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Lukacijewska (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tănăsescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolášik (EPP); Anna Záborská (EPP). **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Soledad Cabezón Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Ernest Maragall (Greens/EFA); Pablo Zalba Bidegain (EPP). **Sweden:** Cecilia Wikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Glenis Willmott (S&D).

EU Developments

28 February: Eight MEPs sign Glasgow Declaration and three join the EAA



During the month of February, eight MEPs signed the Glasgow Declaration. Signatories are calling for the creation of a European Dementia Strategy and national strategies in every country in Europe. They are also calling on world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

MEPs who have signed their support this month are (pictured, top left to bottom right): Nessa Childers (S&D, Ireland), Ernest Maragall (Greens/EFA, Spain), Bart Staes (Greens/EFA, Belgium), Hilde Vautmans (ALDE, Belgium), Romana Tomc, (EPP, Slovenia), Frédérique Ries (ALDE, Belgium), Patricija Šulin (EPP, Slovenia) and Cristian-Silviu Busoi (EPP, Romania).

Three of the signatories were not members of the European Alzheimer's Alliance (EAA) prior to signing the declaration. Mr Maragall, Ms Vautmans and Mr Busoi join the EAA as a result of signing the declaration, bringing the number of members to 90 at the end of the month.

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



3 February: Elena Gentile, MEP, organises Discussion Group on Health

On 3 February (Brussels, Belgium), Italian MEP Elena Gentile chaired a discussion group on health to discuss 'Health in all policies in the European Union'. The event was organised alongside CPME, the Standing Committee of European Doctors. The aim of the meeting was to reflect on how the last Commission's decisions (the 'Junker Investment Plan') could have an impact the health of the EU citizens. She was adamant neither the health of the citizens nor the quality of the healthcare services could be a minor part of the Plan.

In her presentation, Dr Katrin Fjeldsted, CPME President, proposed the creation of a network that would look towards a better definition of the doctors' roles and responsibilities, better healthcare services for the benefit of the patients of Europe.

Martin Seychell, Deputy General for Consumer and Health, European Commission explained the role of the EU is to raise awareness, bring added value to the Member States actions and identify concrete areas where the EU can provide support and amplify the decisions taken at national level. The policy areas on which the EU will focus in the future are cross border health threats, health systems performance assessment, medical devices and pharmaceutical concerns. Better coordination between the different DGs will be an opportunity to include health in all policies. The underline thread of the new European strategy is that European economic recovery is dependent on its people and what they can add. These people need to be in good health to contribute to the economy. Annette participated in the meeting.

4 February: The EP Carers Interest Group discusses 'Carers and EU action in the field of social exclusion'

On 4 February (Brussels, Belgium), the EP Interest Group on Carers organised a meeting to discuss (Carers and EU action in the field of social exclusion. Heinz Becker (AU), Marian Harking (IE), Jean Lambert (UK) and Sirpa Pietikainen (FI) co-chaired the meeting.

Carers are at a risk of poverty and social exclusion and EU initiatives need to be checked for their impact on and relevance to carers as a specific risk group. This was clearly demonstrated by Clare Cairns, Coalition of Carers in Scotland, who talked about carers and social exclusion. She talked about the impact of caring on finances, the inadequacy of support to carers, the lack of respite care services and the lack of training, information and counselling in some EU countries. She presented the findings of a research in the UK showing that caring could lead to isolation, to the difficulty to maintain relationships and social networks because people do not understand the impact that caring has and to keep in touch with friends or family. Caring is also has a gender link with 2/3 of carers being women across Europe. Support to carers who try to combine employment and care varies across Europe. The research also showed that caring can have negative impact on physical health, mental health. This impacts on the quality of care as more anxious and depressed carers report more incidents of abuse.

Ms Cairns called for the need to move from the recognition of the contribution of carers to giving carers actual rights. She gave the example of Scotland, where a Carers Bill going through the political system will give carers new rights. She also called for policies which would include financial support to carers, flexible employment schemes.

Representatives from DG Employment Ralf Jacob (Head of Unit Social Protection and Activation Systems) and Sven Matzke (Team Leader, Social Protection and Activation Systems) talked about the place of carers in the EU initiatives on poverty and social exclusion. The Commission does not have a specific focus or initiative on caring but EU initiatives such as the 2013 Staff Working Document on long term care and the 2014 Social Protection Committee/EC report on Adequate social protection for long term care needs in an ageing society are relevant. The EPSCO Council in June 2014 adopted a set of key messages referring explicitly to the need for adequate social protection for long term care needs and the need for Member States to move from a reactive to increasingly proactive policy approaches. In the Europe 2020 strategy, the impact of caring responsibilities are relevant for achieving the employment and poverty targets. The 2013 Social Investment Package explicitly refers to the need to addressing the gender dimension and calls for social investment throughout the individual's life.

EU reconciliation policies and the possibility of a future Directive on carers' leave were also mentioned. In its Strategy for equality between women and men 2010-2015, the Commission had already announced its intention to assess remaining gaps in entitlement to family-related leave, including carers' leave, and the options for addressing them. However, it is not known yet if the new Commission will take an initiative in this respect. There are

important knowledge gaps about the breadth and depth of social protection coverage in the EU and the Commission will seek to address this by gathering data on carers and their situation. The Labour force survey (improve questions on impact of caring on employment), the EU-SILC survey (adding questions accessibility of long term care services), the MISSOC data base, a joint Project with OECD on 'Measuring adequacy of social protection for long-term care needs' will be used to yield evidence-based data. Annette attended the meeting.

10 February: President Juncker replies to health NGOs' letter of concern



In December 2014, following the move of the health technologies portfolio to the

Directorate General for Enterprise, several European health NGOs and other actors from the public health community in Europe co-signed a letter to the European Commission, emphasising their belief that the health technologies portfolio should remain with the Health Directorate General.

On 10 February, the European Patients' Forum reported that they had received a response from the President of the Commission, Jean-Claude Juncker, stating that he has "asked the Commissioner for Health and Food Safety and the Commissioner for Internal Market and Industry to work closely together on all matters concerning health related product."

See Mr Juncker's full response below:

<http://www.eu-patient.eu/globalassets/who-we-are/response.juncker.healthngosletter.shift.10022015.pdf>

12 February: The ESSC organises a hearing on 'Long-term care and de-institutionalisation'

On 12 February (Brussels, Belgium), the European Economic and Social Committee (ESSC) organised a hearing to inform the opinion it will produce on long-term care (LTC) and de-institutionalisation (DI). This follows a request from the Latvian Presidency of the Council seeking a civil society contribution to the implementation of healthcare reforms and improvement of LTC. Once adopted, the opinion will be presented at a Presidency conference in June on 'De-institutionalisation practices and further development of the European social care policy'. The aim of the meeting was to understand the situation in different Member States, examine the challenges and look at solutions.

Kristine Lasmane, Ministry of Health in Latvia, presented the Presidency priorities for the inclusion of persons with disabilities in society, Jan Jarab, Europe Office of the UNHR presented disability in the international legal context and the human right approach to disability, Marie-Anne Paraskevas from DG Employment in the European Commission presented talked about the use of European Structural and Investment Funds for the transition from institutions to community-based care. Civil society was represented by Lumos (a children foundation), the European Disability Forum, NUI Galway - Centre for Disability, Law and Policy, European Association of Services

Providers for Persons with Disabilities (EASPD), the Association of Long-Term Care Service Companies (AESTE) and the European Network on Independent Living (ENIL).

The Rapporteur of the opinion is Gunta Anca, from Latvia and José-Isaias Rodriguez Garcia-Carlo from Spain.

24 February: MEP Interest Group on Brain, Mind and Pain is launched



Pain Alliance Europe (PAE) in conjunction with the European Federation of Neurological Associations (EFNA) launched and will coordinate a Member of the European Parliament (MEP) Interest Group

on Brain, Mind and Pain.

Co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Octavia Sârbu, the group will explore issues of common interest to those affected by neurological and chronic pain disorders. These will include stigma, quality of life, research and patient involvement.

http://www.pae-eu.eu/?page_id=833&sf36544594=1



Members' News

31 December: Association Alzheimer Suisse encourages memories through classic movie music



At the end of 2014, Association Alzheimer Suisse brought out a cd entitled "Souvenirs Inoubliables" (Unforgettable Memories). The cd consists of a collection of 12 songs from classic movies, including Butch Cassidy and the Sundance Kid, Some Like it Hot, Dr No, The Pink Panther and Casablanca.

The free cd can be ordered here (sleeve available in French, German and Italian. Voluntary donations are greatly appreciated):

<http://www.alz.ch/index.php/186/z/livres-dvd-et-cd/val2/162/val/283.html>

12 January: Greek brain training game launched



A new brain training tool was launched on 12 January in Greece, to help detect mild cognitive impairment in older adults.

Researchers from the Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) were among the team developing the virtual supermarket game, which they believe to be as accurate as the standardised tests currently used.

The game was created as part of a project to discover how new technologies can be used to treat and support people with mild cognitive impairment.

Read more about it in the Journal of Alzheimer's disease:

<http://www.j-alz.com/content/virtual-reality-brain-training-game-can-detect-mild-cognitive-impairment-condition-often>

31 January: Guinness record-breaking cheese made in support of Spanish Alzheimer's society



On 31 January in Spain, a Valencia-based company made a giant cheese, weighing over 1,000kg. The freshly-made "Queso servilleta" ("napkin cheese") -

for which 8000 litres of goat's milk and 80 kilos of salt were used - was made in the streets of Feria de San Blas de Albal.

The cheese was split into 10,000 portions and sold, with all proceeds going to the Spanish Alzheimer's Society (CEAFA), to support them in their work, improving the quality of life of people living with dementia.

The company in question, Granja Rinya, had already developed a cheese weighing 980kg (pictured) in 2010 to raise funds for a cancer charity. They now hope that their giant cheese will be validated and published in the Guinness Book of World Records.

1 February: Alzheimer Hellas has cake and eats it



On 1 February Alzheimer Hellas had the pleasure of organising its annual cutting of the New Year Cake for employees, patients and their caregivers who come daily to the organisation's two Alzheimer's day care centres operating in Thessaloniki.

Guests at the event heard a speech by Professor Magda Tsolaki and were entertained with live music and dancing. The event, which was held in a large hotel in the city, was clearly a big success as evidenced by the smiling faces of the guests.

1 February: Alzheimer Scotland launches its Let's Talk about Dementia campaign



In February 2015, Alzheimer Scotland's began its Let's Talk about Dementia campaign, which asks the public to have difficult conversations:

The worry that someone, perhaps even you, might have dementia is one of the hardest issues any of us will have to face. However, having difficult conversations about dementia – with partners, with family and friends, or with medical professionals – can make a huge difference to someone's future quality of life.

Talking about dementia makes it more likely that someone will get a diagnosis, which in Scotland can open doors to support from the National Health Service, local councils and organisations like Alzheimer Scotland. This is especially relevant as Scotland has a guaranteed minimum of a year's post-diagnostic support from a named link worker.

Each day, our 24-hour Dementia Helpline, Post Diagnostic Support Link Workers, Dementia Advisors and the staff in our services across Scotland speak with hundreds of people who have dementia, are caring for someone with dementia, or who are worried that they or someone else may have dementia. One of the most common things

people tell us is how difficult it can be to talk about their concerns that someone they care about may have dementia. People tell us that raising their worries with the person, or with other family members, is very difficult.

Often the person, or other family members, may deny that there is anything wrong, refuse to talk, or agree to seek advice from a doctor. Not only can this be very physically and emotionally draining for all concerned, it can mean that other, unrelated, health conditions which may be causing the symptoms go untreated. It can also prevent people who might have dementia from getting an earlier diagnosis and accessing the post diagnostic support which can help them to live well with the illness for longer, reduce unplanned hospital admissions, and unnecessarily early moves to care homes.

Our "Let's Talk about Dementia" campaign provides tips to help start those difficult conversations and is intended to:

- encourage families and friends to talk more openly about dementia
- break down some of the barriers such as the fear of dementia, stigma, and the worry that nothing can be done to help
- encourage people to seek help
- raise better awareness and understanding of dementia.

Let's Talk about Dementia had a double page spread in Scotland's biggest selling Sunday newspaper, a two week advertising campaign on Scotland's biggest commercial radio stations and was covered on local television. The next wave of this campaign will take place during Scotland's Dementia Awareness Week, which in early June 2015.

3 February: Alzheimer Scotland welcomes "Living and Dying with dementia in Scotland" report



On 3 February, Alzheimer Scotland released the following reaction to the report Living and dying with dementia in Scotland written by the UK-based charity, Marie Curie Cancer Care:

"Alzheimer Scotland - Action on Dementia has long recognised the need to address the complex and intensive experience of advanced dementia and end of life in Scotland. We very much welcome this report and are glad that Marie Curie are joining us in recognising that end of life care for people with dementia is such an important issue.

Alzheimer Scotland has been proactive in developing a model of integrated dementia-specific care and support for advanced dementia (including end of life care) which will address many of the issues raised in this report. We are now in a consultation phase to inform our new Advanced Dementia Model, which we plan to launch a report on in autumn 2015. We invite others to share their knowledge, expertise and experience by participating in this consultation process via our website - http://www.alzscot.org/campaigning/advanced_dementia_model. Ultimately, we want to achieve an integrated model of care and support for advanced dementia which delivers the best possible quality of life for people with dementia and family carers.

Alzheimer Scotland has worked in depth in recent years to identify and prioritise what is needed to help people to live well with dementia, including our development of a model of community-based, integrated support. This 8 Pillars Model of Community Support is currently being piloted across Scotland and the findings from this test period will have a clear influence on how care and support is delivered for people with advanced dementia and at end of life.

The Scottish Government has indicated that end of life care for people with dementia is will be a priority and they have begun discussions with Alzheimer Scotland in relation to our Advanced Dementia Model. It is important that we are able to continue to work in partnership with the Scottish Government, organisations like Marie Curie, and other stakeholders to make sure that people living and dying with dementia are able to have the best possible quality of life."

4 February: Spominčica President opens Still Alice premiere in Slovenia



On 4 February, "Still Alice" – the hugely successful Hollywood movie about a professor with early onset Alzheimer's disease - premiered in Koper, Slovenia. An introductory speech was delivered by the President of Spominčica, Štefanija Lukic Zlobec and all entrance fees for the screening were donated to the organisation.

22 February: UK surpasses target with 1 Million Dementia Friends



Over one million people have signed up in support of Dementia Friends, a campaign run by the Alzheimer's Society (UK) to change the public perception of the illness, surpassing the charity's original goal.

An ambitious new target of creating four million Dementia Friends by 2020 has now been set.

The programme was launched just over two years ago in a bid to increase awareness and challenge stigma.

23 February: Norwegian dementia research facilities to receive EUR 240,000 from Norwegian Health Association's annual collection



Funds from the collection conducted by Norway's Nasjonalforeningen for folkehelsen (Norwegian Health Association) in September 2014 will go to research, information and local activities for people with dementia and their caregivers. The

following research projects will receive funding:

- Marte Kvello: Young dementia in Trøndelag, NTNU Trondheim
- Maria Mastrangelopoulou: Does impairment of fast neuronal signaling expedite development or augment symptoms of dementia in neurodegenerative diseases? UiO
- Håkon Ihle-Hansen: Cognitive function and cardiovascular risk factors, Akershus Cardiac Examination 1950 (ACE 1950) Study, Vestre Viken HF, Bærum sykehus

The funding comes in addition to almost EUR 1.5 Million that will be distributed to research projects this year within the Norwegian Health Association's National Research Program For Dementia, financed by the telethon conducted in 2013.

26 February: Alzheimer Scotland is barking up the right tree with its Dementia Dog campaign



Hello I'm Alex 4 Paws

This spring Alzheimer Scotland launched a new appeal to raise GBP 30,000 (EUR 41,000) to complete the pilot for its Dementia Assistance Dogs project and report with great enthusiasm, "we're almost halfway there – so far!"

The face of the appeal is Alex 4Paws: the black-coated dog with a very big heart. Alex introduces the other two dogs, Kaspera and Oscar and shares the fantastic support they provide for their owners.

Kaspera and Oscar have been working as full-time Dementia Assistance Dogs since the pilot started in mid-2013. They receive special training to support people who have a diagnosis of dementia and their carers. They assist people with dementia to stay safe, remember things and feel more confident.

Dementia Assistance Dogs are good company for carers too, ensuring they feel less isolated and have help at hand when they need it. Dementia Assistance Dogs also encourage people living with dementia and their carers to be more active: to get out for walks, visit the shops or go to the hairdresser – everyday things that many of us take for granted. The pilot is scheduled to end in spring 2015 and it has been a truly life-changing experience for the couples involved.

"Kaspera is like Ken's shadow – he's never far away" Glenys is Ken's carer, and has watched the bond between Ken and Kaspera grow since they were partnered a year and a half ago. Kaspera has become more and more attuned to Ken's welfare, and Ken's confidence has also grown. Kaspera's presence makes him comfortable being at home on his own. Kaspera has been trained to bring Ken his medication and to nudge Ken in response to certain alarms which remind him to make food or put the kettle on. However, Kaspera now also does lots of things for Ken that he was never trained to do! He brings his paper through from the hall when it's delivered every morning. When Ken's walking down the stairs, Kaspera won't follow him until he's reached the bottom, so he won't knock Ken over on the way down. If Ken takes a nap, Kaspera will nudge him after 15 or 20 minutes, to make sure he's alright.

Kaspera often brings a small bag containing either medicine or a bottle of water to Ken. This will be useful as Ken's dementia progresses, to remind him to drink regularly through the day. Glenys says, "Kaspera's like two different dogs: he's friendly and boisterous with most people, but with Ken he's so gentle and patient."

Oscar helps Maureen in many ways on a daily basis: waking her up every morning and ensuring she takes her medication. Maureen's carer, Frank, says, "Oscar is a very playful dog, but he knows when he has his jacket on he is working. He reassures Maureen and makes her feel more comfortable – especially when we're out and about." Oscar is a watchful and comforting presence by Maureen's side when they leave the house.

It's not been all plain sailing with Oscar, who can be mischievous. He chews his way through a new tennis ball every fortnight and has been known to jump on fresh bed sheets with muddy paws! However, Frank is adamant that he wouldn't be able to manage without Oscar in the home.

<http://www.dementiadog.org/>



Policy Watch

6 February: US association publishes report on "Changing the Trajectory of Alzheimer's Disease"



The Alzheimer's Association (US) launched a report in early February, highlighting the savings that could be made if a new treatment for Alzheimer's disease (AD) were to be discovered. The Association estimates in this report, Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars, that USD 220 Billion (EUR 200 Billion) could be saved within five years if the target of finding a treatment by 2025, as stated in the country's national dementia plan, is met.

The report calls for the government to invest USD 2 Billion per year into dementia research, as recommended by the scientific community.

http://www.alz.org/alzheimers_disease_trajectory.asp

11 February: Final G7 Dementia Legacy event held in US



The fourth and final G7 Legacy event was held in the US on 11 February, following a two-day conference on the state of the science at the National Institutes of Health in Bethesda, Maryland (near Washington DC).

The event was a half day meeting and included updates from the World Health Organization on its research prioritisation project for which the first results will come out this March, as well as from the Organisation for Economic Development and Cooperation (OECD) on big data and on dementia research budgets from the G7 countries. The US has the largest budgets, but these are still far behind other major disease areas.

The G7 countries and the European Union gave updates as well. Canada, Japan and the UK are now planning big cohort studies looking at multiple chronic diseases - including dementia - and their risk factors.

The Canadian government reported having launched a Dementia Friends programme with the Alzheimer Society of Canada, using the experiences of Japan and the UK to work from. France reported on the launch of their new plan for neurodegenerative diseases: Alzheimer's disease and other dementias, Parkinson's disease, MS, ALS and Huntington's disease.

Germany started local dementia alliances in September 2014 and more than 1000 local info sites are now enrolled. They are also implementing Dementia Care Managers who serve as a link between patients and the health care system. The new centre for neurodegenerative diseases (DZNE) has a budget of EUR 80 Million per annum and has created partnerships with other European countries, Canada and the US.

The US Alzheimer's Association released a report on how much money could be saved if dementia onset can be delayed by 5 years - a massive amount (see article in this section, dated 6 February).

Italy launched its national dementia plan in November 2014, despite the challenge with the role of its regions. National plan areas are prevention, network of services, integrated care, research, ethics, fight against stigma and integrated services.

Japan also launched a new "Orange plan" on 27 January. They calculated two estimates: one with stable prevalence rates and another with increases in diabetes rates. The new plan has 7 pillars and aims for people with dementia living with dignity.

Finally, the UK is working on a number of initiatives and partnerships. One is "Join Dementia Research", a database where people can register to be part of research (see article in this section, dated 24 February).

The European Union is spending an impressive amount on research through its programmes, JPNP (Joint Programming on Neurodegenerative Diseases), Horizon 2020, Human Brain Project and IMI. Patient organisations are now involved in policy making.

In the afternoon the World Dementia Council met to talk about the future of the G7 Dementia Legacy initiative. The outcome is not entirely clear, but the hope is that there will be some future initiatives.

Simultaneously, the Alzheimer's Association (US) and ADI hosted a meeting with non-profit organisations who fund research in the US and Europe.

11 February: Austria launches process for developing dementia strategy



On 11 February, the process of developing Austria's Strategy for dementia was launched by Health Minister, Sabine Oberhauser (pictured) and Minister for Social Affairs, Rudolf Hundstorfer during

an international conference.

Keynote speakers at the conference included Volker Hirscher (Germany), who gave an overview of different dementia strategies throughout Europe and Verena Hanselmann, who talked about the national dementia strategy in Switzerland. The conference delegates also broke out into six working groups entitled "participation, removal of taboos and health support", "research and data", "professional care and support", "coordination and cooperation", "informal care and support services for living at home" and "quality and expertise".

During the development of the strategy, Antonia Croy and Monika Natlacen - both from Alzheimer Austria - will join two working groups that are due to meet during the month of March. Alzheimer Austria is also seeking the active participation of people with dementia from its "Supported Self Help Group" in the process of developing the national dementia strategy.

In January 2015, the Ministries of Health and Social Affairs released the "Austrian Dementia Report 2014", which will serve as the foundation of the national strategy. The report can be downloaded below or seen at

www.goeg.at/de/GOEG-Aktuelles/Neu-Oesterreichischer-Demenzbericht-2014.html

21 February: UK launches Prime Minister's Challenge on Dementia 2020



On 21 February the Prime Minister launched the government's five year vision for the future of dementia care, support and research, which follows on from the existing Prime Minister's Challenge on Dementia, launched in March 2012.

The Prime Minister's Challenge on Dementia 2020 "celebrates achievements to date and includes strong ambitions to boost dementia research, train more health and care staff, follow up timely diagnosis with greater access to help, advice and support for people with dementia and their carers, increase public awareness and create more dementia friendly public and private organisations and communities".

The overall target by 2020, is for England to be:

- The best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases.

Read the Prime Minister's Challenge on Dementia 2020 document in full here:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/406076/Dementia_vision.pdf

24 February: New national website aims to empower public to take part in dementia research



Following a successful pilot of the website, Join Dementia Research (JDR) in July 2014 in the North Thames area of the UK (see AE article dated 22 July 2014), the service was launched as a nationwide online and telephone service on 24 February.

JDR promises to accelerate the pace of dementia research by allowing people with and without dementia to register their interest in studies, helping researchers find the right participants at the right time. It is a collaboration between the National Institute for Health Research (NIHR), Alzheimer's Research UK, Alzheimer Scotland and the Alzheimer's Society (UK) and has been funded by the Department of Health. Its development in Scotland has also been supported for the past year by the Scottish Dementia Clinical Research Network (SDCRN).

<https://www.joindementiaresearch.nihr.ac.uk/>

27 February: Young Leaders in dementia event held in London



On 27 February, the UK Science and Innovation Network (SIN) organised the last in a series of four Young Leaders events on Dementia,

following similar events in Canada, Japan and the US. The UK brought together 45 young delegates from 18 countries at the Foreign and Commonwealth Office in London. It was held under the auspices of SIN France and SIN London and was also supported by the European Research Joint Programming Initiative on neurodegenerative disease (JPND) and Alzheimer Europe (AE).

The event was opened by the Head of SIN and Climate Department and FCO Deputy Chief Scientific Adviser, Andrew Jackson. Presentations were made by Philippe Amouyel, Chair of JPND and member of the World Dementia Council (WDC); Jean Georges, Executive Director of AE; Lee McGill, Private Secretary to the World Dementia Envoy and Secretariat to the WDC; Hilary Doxford, Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and the first WDC member living with dementia; and Mario Rivero-Huguet, from SIN Canada.

Delegates' ensuing discussions focussed on solutions to four main themes: Care, Cure, Research and Awareness. Awareness-related discussions highlighted the importance of adequate education and promoting caring as a career. Care-related discussions focused on early entry into clinical trials, standardisation for data and resource sharing. Delegates also debated the harmonisation and centralisation of research, guidelines, regulations, data platforms, global registry of projects (past, current and future) and a better mechanical understanding of dementia.

The resulting recommendations by the Young Leaders are now being drafted as an EU communiqué. Together with those from Canada, Japan and the US, they will be known as the "Young Leaders declaration" and will be presented at the WHO Ministerial conference in Geneva on 16-17 March. One of the EU delegates from this event will also join three representatives from Canada, the US and Japan at the conference.

<http://blogs.fco.gov.uk/nicollearbour/2015/03/04/the-youth-engaged-in-dementia-the-eu-young-leaders-against-dementia/>



Science Watch

28 January: Hops may help against Alzheimer's disease



On 28 January in the American Chemical Society's (ACS) Journal of Agricultural and Food Chemistry, a study was published into a compound from hops and its potentially protective attributes against brain cell

damage.

Lead study author, Jianguo Fang and his colleagues noted that mounting evidence suggests that oxidative damage to neuronal cells contributes to the development of diseases that originate in the brain. If scientists could prevent this type of damage, they might be able to prevent or slow down Alzheimer's disease (AD), Parkinson's disease (PD) and other neurodegenerative conditions.

One compound found in hops, called xanthohumol, is being researched for its potential benefits, including antioxidation, cardiovascular protection and anticancer properties, so Dr Fang's team decided to test xanthohumol's effects on brain cells.

In lab tests, the researchers found that the compound could protect neuronal cells and potentially help slow the development of brain disorders. The scientists conclude xanthohumol could be a good therapeutic target in AD and PD.

It should be noted that many sections of the European media picked this story up, choosing to report that beer can fend off dementia. This is not the conclusion of the study and Dr Arthur Roach, director of research at Parkinson's UK, said:

"It certainly does not suggest drinking a pint a day could stave off the condition. This is a very early step, and only further work will indicate whether this could lead to new drugs for Parkinson's and other neurodegenerative diseases."

<http://pubs.acs.org/doi/abs/10.1021/jf505075n>

4 February: US scientists find more DNA and extra copies of disease gene in AD brain cells



Scientists at The Scripps Research Institute (TSRI) in the US have published a new study showing that brains with AD have many neurons with significantly more DNA and genomic copies of the APP gene than healthy brains. The results were published on 4 February in the online journal, eLife.

Lead study author Professor Jerold Chun of TSRI and its Dorris Neuroscience Center and his team have had a longstanding interest in genomic variation among brain cells, which produces "genomic mosaicism". In this new study, the team set out to analyse the overall DNA content in cells, comparing 32 post-mortem AD brains and 21 post-mortem healthy brains.

The researchers found that more than 90% of AD brains displayed highly significant DNA increases of hundreds of millions more DNA base-pairs, compared with control samples, showing that mosaicism was altered in the AD brain. These changes were not found everywhere but were most evident in the part of the brain involved with complex thought.

The researchers then used a technique called single-cell qPCR to determine the numbers of APP copies in 154 individual neurons from AD and healthy brains. They also tested the neurons using a technique called FISH as an independent method to assess APP copies using fluorescent probes.

The tests showed that neurons from patients with AD were four times as likely to contain more than the normal two copies of APP with some AD neurons containing up to 12 copies.

While genetic tests on blood samples can reveal if a person is prone to developing familial AD, most people who develop AD do not test positive. The new study suggests that such genetic signatures might be lacking in the blood of the majority of patients because the genomic signatures of AD occur within individual brain cells.

The team's future studies will investigate the relationship between mosaicism and disease, the causes of mosaicism and potential new disease drug targets present in the millions of extra base-pairs found in single, Alzheimer's disease neurons.

<http://elifesciences.org/content/4/e05116>

4 February: US research harnesses immune cells to clear AD-associated plaques



New research from US scientists at the Keck School of Medicine of the University of Southern California (USC) shows that the body's immune system may be able to clear the brain of toxic plaque build-up that is the hallmark of Alzheimer's disease (AD), reversing memory loss and brain cell damage. Their study, which appeared in the peer-reviewed scientific journal, *Neuron* on 4 February, identifies a possible new therapeutic target.

Professor Terrence Town, the study's senior author and his team used genetically modified mouse models to show that blocking a substance called interleukin-10 activates an immune response to clear the brain of the beta-amyloid plaques to restore memory loss and brain cell damage. AD mouse models in which the immune cells were activated behaved more like those without AD in various learning and memory tests.

Future studies will test the effectiveness of drugs that target interleukin-10 in genetically modified AD rats.

<http://www.cell.com/neuron/abstract/S0896-6273%2814%2901201-X>

5 February: Alzheimer's Society research commitment creates network of Doctoral Training Centres



A large research commitment was announced by Alzheimer's Society on 5 February, which will create a

new research hub at the University of Sussex and a network of Doctoral Training Centres at universities across the UK, which in turn leads to the creation of 53 new PhD studentships to research dementia. The aim being "to create the next generation of dementia researchers to develop new treatments and improve care".

A gene which increases the risk of Alzheimer's disease (AD) by up to 10 times will be the subject of the new research hub at the University of Sussex. The GBP 700,000 (EUR 965,000) partnership between the charity and the university will enable eight PhD students to unpick the role of the gene APOE4 in the risk of developing AD looking at how different forms of the gene affect the brain throughout life.

The funding will also create a network of Doctoral Training Centres at universities across the UK, hoping "to enable the best scientists to tackle some of the most pressing issues in dementia."

These centres will be split between biomedical and care research, recruiting 53 PhD students from a variety of academic and clinical backgrounds "to bring fresh perspective to dementia research."

- Scientists at four Scottish Universities (Edinburgh, Aberdeen, St Andrews, Dundee) will look at how heart health and high fat diets impact on the risk of dementia
- PhD students at the Universities of Nottingham and Worcester will explore the benefit of creative art activities for people with dementia and their carers
- Bradford-based researchers will study how to improve the transitions experienced by people with dementia between different care settings to improve quality of life
- At Newcastle University, researchers will collaborate on understanding the distressing non-cognitive symptoms of dementia with Lewy bodies
- Southampton researchers will explore how to enable people with dementia to take calculated risks in daily life, such as travelling on their own, in order to maximise control and independence while balancing safety concerns.
- PhD students at University of Exeter will study dysfunctional brain networks in dementia using a range of approaches from mathematical modelling to brain scans to experiments with brain cells in a dish.

http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2308

9 February: AB Science to continue masitinib Phase III trial for AD

Pharmaceutical company, AB Science announced the successful completion of a futility analysis related to a Phase III trial of the drug, masitinib for the treatment of mild to moderate Alzheimer's disease (AD) on 9 February. Based on these results, the Independent Data Safety Monitoring Committee (IDMC) has recommended the continuation of the study.

Masitinib is an orally administered tyrosine kinase inhibitor that targets mast cells and macrophages, important cells for immunity, through inhibiting a limited number of kinases.

9 February: Karolinska Institutet announces promising results in small-scale AD therapy study

Scientists at Karolinska Institutet, Stockholm, Sweden, have evaluated a new Alzheimer’s disease (AD) therapy in which the patients receive an implant, stimulating growth of a certain type of nerve cell. The results of the small-scale study involving six patients with AD were published in the journal, *Alzheimer’s & Dementia* on 9 February.

Cholinergic nerve cells in people with AD undergo a selective and early breakdown. These cells require a specific nerve growth factor (NGF) to function. As NGF levels decline, the cholinergic nerve cells begin to degrade and the patient’s condition slowly deteriorates.

In an attempt to curb the breakdown of the cholinergic nerve cells, researchers at Karolinska Institutet’s Centre for Alzheimer’s Research and their colleagues at Karolinska University Hospital’s neurosurgery clinic and at the Danish biotech company, NsGene introduced NGF directly into the brains of patients with AD.

To gauge whether the NGF release had any effect on the cholinergic nerve cells, the researchers assayed the presence of specific markers of functioning cholinergic cells. This cell system communicates using acetylcholine, which in turn produces an enzyme called ChAT, found both inside and outside the cells. The team therefore developed a method enabling them to measure ChAT in the cerebral spinal fluid.

“Our results show that when the patients received NGF, there was a significant increase in ChAT in the CSF,” says Dr Taher Darreh-Shori, one of the researchers involved in the study. “The patients that exhibited this increase were also those that responded best to the treatment. Our PET scans also showed an increase in cholinergic cell activity and metabolism in the brain.”

In addition, the researchers were able to detect a slowing of memory impairment over time. While all this suggests that cholinergic functionality improved in the patients with AD who had received NGF therapy, the team adds that far-reaching conclusions should not be drawn at this stage.

<http://www.alzheimersanddementia.com/article/S1552-5260%2815%2900007-2/abstract?cc=y>

15 February: Boston University launches Phase II AD drug trial

Scientists at Boston University’s Alzheimer’s Disease Center and Boston Medical Center have launched a trial of their new Alzheimer’s disease (AD) drug candidate, T-817MA, a neuroprotective agent that acts on amyloid-induced neurotoxicity and memory deficits.

<http://www.nia.nih.gov/alzheimers/clinical-trials/noble-t-817ma-mild-moderate-alzheimers-disease>

16 February: NHS sets the record straight on “breakthrough” AD molecule discovery



A study carried out by researchers from the University of Cambridge, a trio of Swedish institutions – Karolinska Institutet, Lund University, and the Swedish University of Agricultural Sciences – and from Tallinn University in Estonia, has

brought to light a so-called “chaperone molecule” known as “Brichos”, which the researchers say helps prevent the clumping of toxic proteins leading to brain cell death. The results of this international study were published in the peer-reviewed journal, *Nature Structural and Molecular Biology* on 16 February.

The research studied purified amyloid protein fibrils under a variety of controlled conditions and results were used to better understand how the fibrils formed and how they catalysed other toxic reactions that could be causing damage to brain cells.

The study’s results, were hailed by the media as a “breakthrough” in AD research. The UK’s National Health Service (NHS) has responded to the media reports, however, warning that these are both “premature” and “somewhat overexcited”, given that the study was carried out using mouse models and lab-grown brain cells, not human subjects. The NHS also points out that while Brichos stopped damage occurring in a specific amyloid-related biological pathway, some of the damage associated with Alzheimer’s disease could still occur via other routes. It also emphasised that none of the experiments investigated whether Brichos could prevent symptoms of dementia or Alzheimer’s in mice or people as they were looking at chemical reactions, not symptoms.

The researchers themselves point out that Brichos would probably not be a suitable drug candidate, because of its composition, as it could be absorbed by the body before it reached the brain. The hope, rather, is that there may be more “chaperone molecules” out there that have the ability to cross the blood-brain barrier and help prevent brain cell damage.

<http://www.nhs.uk/news/2015/02February/Pages/Molecule-could-protect-against-Alzheimers-disease.aspx>

<http://www.nature.com/nsmb/journal/v22/n3/full/nsmb.2971.html>

16 February: New dementia research alliance launches in UK

A new network of research centres called the Drug Discovery Alliance (DDA), was launched on 16 February, funded by Alzheimer’s Research UK to the tune of GBP 30 Million (EUR 41.3 Million). The network aims to help with the search for an Alzheimer’s disease cure and consists of drug discovery institutes at Cambridge and Oxford Universities and University College London.

<http://www.alzheimersresearchuk.org/alzheimers-research-uk-launches-three-drug-discovery-institutes/>

24 February: Skin biopsies could help diagnose Alzheimer’s disease



A study, which will be presented this April at the American Academy of Neurology’s annual meeting in Washington D.C. has concluded that skin could be a biomarker for Alzheimer’s disease (AD) and Parkinson’s disease (PD).

The research team, led by Dr Ildefonso Rodriguez-Leyva at the University of San Luis Potosi, Mexico, reasoned that since skin has the same origin as brain tissue in the developing embryo, it might be a good window on what happens in the brain in later life, at a molecular level. Post-

mortem studies of people with PD had also revealed that the same protein deposits which occur in the brain with this condition also accumulated in the skin.

To test their theory in living subjects, the researchers recruited 65 volunteers - 12 who were healthy control subjects and the remaining 53 who had PD, AD or another form of dementia.

They took a small skin biopsy from behind the ear of each volunteer to look specifically for the presence of two proteins - tau and alpha-synuclein.

The 20 people with AD and the 16 with PD had raised levels of both these proteins in their skin compared to the healthy control subjects and the patients with other types of dementia.

Dr Rodriguez-Leyva, who will be presenting the findings in April said that more research was needed to confirm these results.

<https://www.aan.com/PressRoom/Home/PressRelease/1346>

27 February: Boehringer Ingelheim puts AD drug candidate on hold

Pharmaceutical company, Boehringer Ingelheim (BI) has placed a temporary clinical "hold" on a treatment for Alzheimer's disease (AD) that it has been developing together with another company, Vitae Pharmaceuticals (Vitae).

Unspecified skin reactions were reported to have been observed during a trial of BI's orally-administered (BACE) inhibitor, a potential AD drug candidate.

Vitae stated that depending on the outcome of the evaluation and on BI's decision, it expects either the BACE inhibitor or a trial-ready backup to be advanced.

<http://blog.ctnews.com/financialmines/2015/02/27/bi-puts-alzheimers-drug-candidate-on-hold/>

28 February: Scottish study says dementia rates are higher in the north



A recent study, aiming to estimate the magnitude of geographical variation in dementia rates has concluded that environmental factors, including a lack of sunlight, may increase the likelihood of dementia.

Scientists at Edinburgh University's Alzheimer Scotland Dementia Research Centre mapped dementia in Scotland among 37,597 people, all born in 1921 and among 27,680 Swedish twins.

In Scotland, the study revealed a substantial change in disease risk depending on where people lived as adults, but there was no change in risk linked to where they lived as children.

In Sweden, they found that twins living in the north were two or three times more likely to develop dementia compared with those in the south, after they accounted for factors such as age, gender and genes.

One environmental factor, which could help explain this disparity is vitamin D - previously linked to healthy brain function. Since humans mostly get their vitamin D from

exposure to sunlight, this could, in part, explain why people living in northern countries would be more at risk for developing dementia.

In conclusion, the researchers say that further work is required to confirm their findings and identify any potentially modifiable socio-environmental risk factors. They do believe, however, their results suggest that if these factors exist and can be "optimised in the whole population", that dementia rates could be considerably reduced.

http://journals.lww.com/epidem/Citation/2015/03000/Geographical_Variation_in_Dementia__Examining_the.21.aspx



Dementia in society

1 February: Scottish dementia play made into movie, Quiet Riot



A Scottish play about dementia, has been made into a short movie, "Quiet Riot" after the initial success of the stage version, "A Quiet Riot" in 2013-2014. The movie was recently screened for the first time at Creative Scotland's LUMINATE festival. The

Scottish Government's Joint Improvement team then became involved and the movie has since been used at the Dementia Champions Graduation Day and is soon to be screened at Glasgow Caledonian University's Podiatry Conference.

The play originated from a project embarked upon in late 2012, involving North Lanarkshire Council in Scotland and writer-director, Maggie Aitken.

"Quite apart from the complexities of lives affected by dementia and the hard work involved, there are tremendous personal, social and cultural pressures that land on the shoulders of those affected by the condition, their families and friends" said Ms Aitken.

The story looks at Bob, husband of Isobel, a woman living with dementia. The story unfolds as a well-crafted and true-to-life dialogue between Bob - a typical Scottish "bloke", with all his strengths and failings, the overriding one being stubbornness in the face of admitting defeat - and Bob and Isobel's daughter, Sarah. They discuss their hopes and fears about Isobel's future and touch on some of the awkward topics about her dementia and its impact on all of their lives. They await the visit of a potential home care worker with some trepidation.

For more information, please contact qurproductions@gmail.com or visit <http://qrmovie.wordpress.com>

4 February: CBBC broaches dementia in children's TV programme



On 4 February BBC children's television channel, CBBC aired a new documentary, "Mr Alzheimer's and me". The half-hour long programme aims to

help children to understand how their grandparent might be affected by dementia and how this might impact their family relationships. It was inspired by the reaction of filmmaker Natasha Dack's son to his 95-year-old great-grandmother's dementia.

Dementia is explored through the eyes of three children, Josh, Hope and Ella. They talk about with their very personal experiences with their grandparents, openly discussing topics such as the fear that they may be forgotten, other memory problems, concerns over "wandering" and falls and the toll that the role of carer is taking on their grandparent's partner and other family members.

While it is certainly sad to watch in parts, the documentary remains surprisingly upbeat, largely due to the positive attitudes of the children and the love of their grandparents. A three minute trailer of the half hour documentary is available here:

<https://www.youtube.com/watch?v=Ap-995wsbHg>

The full documentary can be viewed on BBC iPlayer (UK residents only):

<http://www.bbc.co.uk/iplayer/cbbc/episode/b0520tr8/my-life-series-6-3-mr-alzheimers-and-me>

22 February: Julianne Moore's Oscar acceptance speech shines a light on Alzheimer's disease



American actress, Julianne Moore won the Best Actress Oscar at the 87th Academy Awards ceremony (Oscars) in Hollywood on 22 February, for her starring role in the movie "Still Alice".

The movie, which has been taking audiences by storm since its release on 16 January and had already received accolades such as a Golden Globe among others, tells the story of Alice Howland (Julianne Moore), a 50-year-old professor of linguistics with early-onset Alzheimer's disease.

Ms Moore used her acceptance speech to raise awareness for Alzheimer's disease:

"I'm so happy, I'm thrilled that we were able to shine a light on Alzheimer's disease...So many people who have this disease feel marginalised. People who have Alzheimer's disease deserve to be seen so we can find a cure."

25 February: Marthe Mercadier talks publicly about Alzheimer's disease



French actress, Marthe Mercadier, aged 86, spoke out about her struggle with Alzheimer's disease in an interview with French radio network, Europe 1 on 24 February.

Accompanied by her daughter and carer, Véronique who announced her mother's diagnosis publicly in April 2014, Ms Mercadier was upbeat and engaged, if a little confused in her words at times during the interview.

Ms Mercadier professed wanting to speak out "without hesitation" and "without taboos", about her illness, to raise awareness of the disease and some of the difficulties she and her loved ones are encountering.

She was highly animated when talking about not wanting to go into a care home and said she would rather "commit suicide". Her daughter, however, was more philosophical on this point, stating that things were manageable thus far, but that she may need to call in help at a later stage in her mother's disease.

Ms Mercadier and her daughter realised there was "a memory problem" during filming for the French version of popular television programme, Dancing with the Stars in 2011. Since her diagnosis, she has been living with her daughter and granddaughter.

<http://www.telestar.fr/2015/articles/marthe-mercadier-raconte-son-difficile-combat-contre-la-maladie-d-alzheimer-82437>

New Publications & Resources

1 February: DAIZG publishes new frontotemporal dementia booklet



A new booklet on frontotemporal dementia (FTD) – one of the lesser known forms of dementia - is now available in German from Deutsche Alzheimer Gesellschaft (DAIZG). It provides information about the disease, diagnosis and treatment and care.

You can download the booklet as a PDF for free, or order a hard copy version via

<https://shop.deutsche-alzheimer.de/broschueren/18>

5 February: Nottingham-Worcester TAnDEM centre announced

On 5 February, the Alzheimer's Society (UK) announced the opening of a doctoral training centre, focussed on studying The Arts and Dementia. Intended as a national and international centre of excellence in training, education and research in dementia studies, the centre - a partnership between the Association for Dementia Studies at the University of Worcester and the Centre for Dementia, University of Nottingham - will be known as TAnDEM.

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2879

5 February: Professor June Andrews publishes new dementia book



Professor June Andrews, the Director of the University of Stirling's Dementia Services Development Centre in Scotland published a new book on 5 February. Titled "Dementia: The One-Stop Guide", it offers practical advice for families, professionals, and people living with dementia and Alzheimer's disease.

11 February: IMI launches new patient page on its website



On 11 February, the Innovative medicines Initiative (IMI) launched a new page on their website, dedicated to patients and patient organisations. The page, "IMI and patients - a partnership" gives information on how patients are involved in IMI's projects.

<http://www.imi.europa.eu/content/patients>

16 February: The Alzheimer’s society releases Dementia Guide on DVD

The Alzheimer’s Society (UK) has released its Dementia Guide on DVD. This guide is intended for anyone who has recently been told they have any type of dementia.

It aims to help the person with dementia, as well as close friends and family, who may be taking on a caring role.

The information on the new DVD is delivered by a range of experts, and people affected by dementia share their experiences of living with the condition. It includes subtitle and voiceover options in Bengali/Sylheti, Hindi, Punjabi, Traditional Chinese/Cantonese, Urdu and Welsh as well as British Sign Language.

It can be ordered via the Alzheimer’s Society’s [online publications form](#)

17 February: EPF announces workshops on Crossborder Healthcare

The European Patients’ Forum (EPF) has announced a series of workshops in March and April, with the objective of raising awareness and knowledge about the Crossborder Healthcare Directive and patients’ rights.

For further information, dates and sign-up links, see here: <http://www.eu-patient.eu/Members/Weekly-Mailing/workshops-on-crossborder-healthcare-opportunities-for-your-members/>

23 February: New Portuguese edition of AE Care Manual is available



Alzheimer Portugal has completed its second edition (1st in 1999) of our popular Care Manual in Portuguese, “Manual do cuidador”. We would like to thank Fondation Roger de Spoelberch for their support on this project.

The manual is available via Alzheimer Portugal.

<http://alzheimer-europe.org/Publications/Care-Manual>

Job opportunities

10 February: EPF advertises vacancy for PACT Coordinator



On 10 February the European Patients’ Forum (EPF) advertised a vacancy for a Coordinator for the Patient Access Partnership (PACT) in their newsletter. They are seeking an experienced person to coordinate the establishment of the Partnership in the coming months.

<http://www.eu-patient.eu/Members/Weekly-Mailing/coordinator-PACT/>



Contact Alzheimer Europe

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

Alzheimer Europe Board

Chairperson: Heike von Lützu-Hohlbein (Germany); **Vice-Chairperson:** Iva Holmerová (Czech Republic); **Honorary Secretary:** Charles Scerri (Malta); **Honorary Treasurer:** Maria do Rósario Zincke dos Reis (Portugal); **Members:** Marie-Odile Desana (France), Sabine Henry (Belgium), Gerry Martin (Ireland), James Pearson (UK - Scotland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Helga Rohra (Germany), Štefanija Lukič Zlobec (Slovenia).

Alzheimer Europe Staff

Executive Director: Jean Georges; **Project Officer:** Ana Diaz; **EU Public Affairs Advisor:** Annette Dumas; **Communications Officer:** Kate Ellis; **Director for Projects:** Dianne Gove; **Conference and Event Coordinator:** Gwladys Guillory; **Finance Officer:** Stefanie Peulen; **Director for Communication:** Alex Teligadas; **Administrative Assistant:** Grazia Tomasini.

AE Calendar 2015

Date	Meeting	AE representative
3 March	Meeting with MEP Nessa Childers and The Alzheimer Society of Ireland in the European Parliament in (Brussels, Belgium)	Alex
3-4 March	PredictND Project meeting and PredictND Board meeting (London, UK)	Dianne, Jean
4-5 March	Patients and Consumers’ Working Party of European Medicines Agency (London, UK)	Jean
5-6 March	AfE-Innovnet project consortium meeting (Brussels, Belgium)	Dianne, Ana
9-10 March	European Summit on Innovation for Active & Health Ageing organised by EIP AHA (Brussels, Belgium)	Dianne
12-13 March	Consortium meeting for the PACE project (Vollendam, Netherlands)	Dianne, Ana
16 March	General Assembly of the VPH-DARE@IT project (Rotterdam, Netherlands)	Alex
16-18 March	WHO Ministerial Conference on Dementia and CEOI Initiative Meeting on Dementia (Geneva, Switzerland)	Jean
19-20 March	Support at the meeting of the Executive of the European Working Group of People with Dementia (Luxembourg, Luxembourg)	Dianne
19-22 March	Symposium on IMI Alzheimer’s Platform and AD/PD Conference (Nice, France)	Jean
24 March	Presentation at the ESRC seminar series “Towards a European understanding of advance decision-making: a comparative, interdisciplinary approach” organised by the University of Leeds (Leeds, UK)	Dianne
24 March	EFPIA Think Tank meeting (Brussels, Belgium)	Annette
24-25 March	Roche Dementia Forum (Amsterdam, Netherlands)	Jean
27 March	PredictND Review Meeting (Brussels, Belgium)	Jean
30 March	EPF Access Working Group meeting (Brussels, Belgium)	Annette
7 April	Meeting of the ethics working group looking at ethical dilemmas (Luxembourg, Luxembourg)	Dianne

Future Conferences 2015

Date	Meeting	Place
9-10 March	European Summit on innovation for active & healthy ageing, http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=2015-summit-agenda	Brussels, Belgium
16-17 March	First Ministerial Conference on Dementia at the World Health Organization, www.alz.co.uk	Geneva, Switzerland
18-22 March	AD/PD 2015, The 12th International Conference on Alzheimer's and Parkinson's Disease, www2.kenes.com/adpd/pages/home.aspx	Nice, France
26-29 March	The 9th World congress on controversies in neurology (CONy), http://www.comtecmed.com/cony/2015/default.aspx	Budapest, Hungary
27-28 March	19th annual meeting of the German Society of Neurogenetics (DGNG), www.dgng.de	Bonn, Germany
15-18 April	30th International Conference of Alzheimer's Disease International, http://www.alzint.org/2015	Perth, Australia
14-17 May	9th Panhellenic Conference on Alzheimer's Disease and 1st Mediterranean Conference on Neurodegenerative Diseases, http://9thconference25.med.auth.gr/conference/gr/index.html	Thessaloniki, Greece
11-13 June	7th Kuopio Alzheimer Symposium "From mechanisms to prediction and intervention of Alzheimer's disease", http://www.uef.fi/kuopioadsymposium	Kuopio, Finland
20-23 June	1st Congress of the European Academy of Neurology (EAN), www.eaneurology.org/berlin2015	Berlin, Germany
1-3 July	Summer Course on Ethics in Dementia Care, https://gbiomed.kuleuven.be/english/research/50000687/50000697/summer-course	Leuven, Belgium
2-4 September	25th Alzheimer Europe Conference - "Dementia: putting strategies and research into practice", http://alzheimer-europe.org/Conferences/2015-Ljubljana	Ljubljana, Slovenia
31 October-5 November	XXII World Congress of Neurology, www.wcn-neurology.com	Santiago, Chile
9-12 March 2016	14th International Athens/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Athens, Greece

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

