



NEWSLETTER

November 2014

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Editorial



Welcome!

This month began with a trip to Tokyo, Japan, for the third G7 Global Dementia Legacy event. The three day event brought together dementia experts from around the world, to discuss "new care and prevention models". I was pleased to see there has been a slight shift in the approach and language being used. It seems that after feedback around the two previous events, calls for more focus on care rather than focussing entirely on a cure have been heard.

Then it was on to Lausanne, Switzerland for an OECD workshop on the 11th and 12th, which was hosted by the Swiss government. Possible measures to address a variety of issues surrounding dementia were discussed.

Our Honorary Secretary, Dr Charles Scerri travelled to Rome to attend the 2nd European Commission Working Group meeting of government experts on dementia as well as the Italian EU Presidency dementia conference. He represented AE and also gave a presentation on innovation.

AE colleagues have also been travelling all over Europe this month for a variety of conferences and project meetings. Alex and Ana attended a European Medicines Agency (EMA) training in London and a NILVAD steering committee meeting in Munich; Alex also participated in a Horizon 2020 workshop in Brussels, while Dianne and Ana travelled to Manchester for a PACE consortium; Dianne also travelled to a conference in Lisbon, organised by our friends from Alzheimer Portugal and the

Monegasque Association for Research on Alzheimer's disease (AMPA), at which she presented AE's work on the ethical implications of how dementia is perceived and portrayed.

The European Alzheimer's Alliance has grown in strength again this month, with two more MEPs joining: Therese Comodini Cachia (Malta) and Kostas Chrysogonos (Greece). This means we now have 86 members, from 26 European countries. We have re-introduced the table naming all current members of the Alliance to the newsletter, this month (page 5).

Great news in France this month, with President François Hollande announcing the launch of the much-anticipated neurodegenerative diseases plan for 2014-2019. The plan's three main areas of focus are on diagnosis, care and research.

In other policy news, government dementia initiatives in the UK have been under the microscope this month, with the recently introduced "cash for diagnosis" being discontinued as of next March, following fierce criticism by GPs and patient groups. There is also a scheme being introduced, under which GPs will offer their middle-aged patients a computer-based test, designed to show how their "brain age" compares with their biological age. News of the scheme has been met with mixed reviews in the public health sector and media.

Finally, we were pleased to learn, this month, that the World Dementia Council will shortly welcome a person living with dementia to its ranks.

On that high note, I wish you all a wonderful festive season!

Jean Georges
Executive Director

Alzheimer Europe

20 October: Apologies to Alicja Sadowska

We would like to apologise to Alicja Sadowska, Chairperson of the Polish Alzheimer's Association for accidentally omitting her name from an article in our last newsletter, dated 20 October. The article named the outgoing Board members and thanked them for their past contributions.

We thank Ms Sadowska sincerely for her past contributions on the Board and have amended the article accordingly, on our website.

<http://alzheimer-europe.org/News/Alzheimer-Europe/Monday-20-October-2014-AE-elects-new-Board>

5-7 November: Japan hosts third G7 Global Dementia Legacy event



From 5 to 7 November, Japan played host to the third in a series of four G7 Global Dementia Legacy events around the world. The first legacy event took place in the

UK in December 2013, the second in Canada in September this year and the final instalment will take place in the US in February 2015.

Dementia experts from around the world came together to talk about "New care and prevention models". Several people living with dementia were in attendance, as well as three members from the Alzheimer's Association of Japan's Dementia Working Group, who were speakers at the event.

Japanese Prime Minister Shinzō Abe highlighted the importance of dementia care provision and stressed the commitment of the Japanese government to take global action against dementia. His government's Health, Labour and Welfare Minister, Yasuhisa Shiozaki announced the launch of a new Japanese dementia strategy - an update to the 2012 "Orange Plan".

The Organisation for Economic Co-operation and Development (OECD) launched a dementia care report during the event, stating that dementia is the fastest growing cause of disability in the world today and emphasising the need to develop and implement policies to improve care and to share knowledge across the international community.

Jürgen Schefflein of the European Commission's Directorate General for Health (DG SANCO) presented results from the first European dementia action plan and was keen to emphasise the positive impact European collaboration has had on dementia care and research. A second plan will be prepared for 2015-2018.

Sessions on prevention and risk reduction highlighted intervention studies COGNICISE from Japan and THISCE from Taiwan, both combining physical exercise and cognitive training as well as other interventions combined to try to delay the onset of dementia. Alzheimer Disease International (ADI)'s Professor Martin Prince presented

the conclusions from this year's "World Alzheimer Report" on dementia and risk reduction.

The event also highlighted innovative care solutions using information and communications technology (ICT) to help support people with dementia and increase independence. The importance of person centred care was also emphasised by Professor Dawn Brooker from the University of Worcester and Professor Graham Stokes from Bupa (UK), who showed the link between high standards of care and a decreased need for antipsychotics.

In closing, Dr Saxena, Director of Mental Health, Neurological Disorders and Substance Abuse, speaking on behalf of the World Health Organisation (WHO), announced that the first WHO Ministerial Conference on Global Action Against Dementia would take place in Geneva, Switzerland in March of next year. Health Ministers from the 193 member states will be invited, along with various international organisations. The aim is to spread the work done by the G7 countries to the rest of the world.

To mark the event, UN Independent Expert, Rosa Kornfield-Matte also delivered a message on the full enjoyment of human rights by older persons.

Alzheimer Europe (AE)'s Executive Director, Jean Georges, attended the legacy event. Mr Georges reported that he was pleased to see there had been a shift, taking on board the calls for more focus on dementia care, rather than only talking about a possible cure. He noted, however, that it was apparent the G7 countries were still uncertain as to how to work together on this new area of focus and that there seemed to be more clarity around the core element of discussions, in terms of how to move forward. Perhaps combining age-friendly projects - Such as the WHO initiative on age-friendly environments or the European Innovation Partnership on Active and Healthy Ageing - with dementia-friendly communities and projects could be a useful direction to take, Mr Georges commented.

10 November: @AlzheimerEurope has 2,000 followers

On 10 November, Alzheimer Europe's Twitter account reached 2,000 followers.

At the time of writing, we had Tweeted 1647 times since our first Tweet on 21 June 2013, which amounts to an average of just over three Tweets per diem.



Follow us on Twitter

25 November: Alzheimer Europe staff attend EMA training



On 25 November, Ana Diaz (Project Officer) and Alex Teligadas (Director for Communication) attended a training day at the European Medicines Agency (EMA) in London.

The agenda provided a complete overview of how the EMA evaluates medicines for use in EU countries.

This process includes the scientific advice provided to patients and how they can contribute to the risk/benefit

discussion. Delegates reviewed the preparation of the European Public Assessment Reports (EPAR) and Patient Information Leaflets (PIL). EPARs are the basis of the PIL leaflets found in drug packages and thus part of the process of approving medicines for human use in the European Union.

The agenda also covered pharmacovigilance - the science concerned with the risks of medicines - and how the Agency deals with risks and incidents that could have a serious impact on public health.

Alzheimer Europe Networking

On 1 November (Brussels, Belgium) Alex attended a Commission workshop on "Health, Demographic Change and Wellbeing".

On 5-7 November (Tokyo, Japan) Jean attended the 3rd G7 Global Dementia Legacy event.

On 11-12 November 2014 (Lisbon, Portugal): Dianne attended the conference "Alzheimer and the Mediterranean: working together for a better understanding" organised by Alzheimer Portugal and AMPA.

On 11-12 November (Lausanne, Switzerland) Jean attended the OECD workshop on Alzheimer's disease research.

On 13-14 November (Rome, Italy) AE Honorary Secretary, Charles Scerri attended the 2nd European Commission Working Group meeting of government experts on dementia and the Italian EU Presidency dementia conference.

On 17-18 November 2014 (Manchester, UK): Dianne and Ana took part in the Consortium Meeting of the PACE project.

On 19 November (Munich, Germany) Ana and Alex attended the 4th NILVAD Steering Committee meeting.

On 25 November (London, UK) Ana and Alex attended an EMA Patient and Consumer Training Session.

On 28-29 November (Munich, Germany), Dianne attended the Integrated Care Workshop organised by Prof. Alexander Kurz.

On 1 December (Brussels, Belgium), Dianne attended the EIP AHA 3rd conference of partners: "taking stock and focusing on delivery".

On 1-2 December (Brussels, Belgium) AE staff and Board members attended an AE Board meeting and a Lunch Debate on dementia prevention.

EU Projects

11 November: European Commission holds Horizon 2020 project workshop



On 11 November, Alex Teligadas represented Alzheimer Europe at a European Commission workshop entitled "Health, demographic change and well-being:

perspectives from Social Sciences & Humanities (SSH) on research and innovation". The event was organised by the Directorate General for Research and Innovation, which processes and reviews applications for Horizon 2020 research projects. The main focus of the workshop was to improve understanding of the importance and scope of qualitative data in these projects.

This event stemmed from a relatively high failure rate of project applications for the Horizon 2020 programme. Reviewers were particularly concerned to see that applicants had misunderstood or misinterpreted a number of guidelines defined by the Commission. These mishaps were often related to qualitative research results from non-scientific studies and a frequent cause of project rejections.

The past several years have seen increases in the number of project partners with SSH backgrounds and also a growing body of qualitative research. Concurrently, strained budgets have led to additional criteria for project funding. For instance, Horizon 2020 applicants are required to include projections on the social impact of their projects.

This type of information is generally qualitative rather than quantitative, hence the need for a review of concepts and terms. The workshop delegates assessed and discussed many aspects of the methodologies and definitions that guide Horizon 2020 projects. They also held group clinics on four specific topics, returning with suggestions to improve understanding on both sides of the application process.

17-18 November: PACE holds consortium meeting in Manchester



On 17-18 November 2014 (Manchester, United Kingdom), the PACE project held a Consortium Meeting in Manchester. The PACE project, of which Alzheimer Europe is a partner, aims to compare the effectiveness of palliative care for older people, with and without dementia, in long-term care facilities in Europe. The work package partners discussed sampling issues, translations, ethics approval and piloting of one of the related studies in the project. One of the work packages involved mapping palliative care systems in long-term care facilities in Europe. This is almost complete and the results are expected to be ready for dissemination in January 2015. Please see the PACE website for more details:

www.eupace.eu

19 November: NILVAD holds Steering Committee Meeting



The NILVAD project partners held their fourth Steering Committee meeting on 19 November in Munich.

Brian Lawlor, Project Coordinator, welcomed the delegates and introduced the agenda. He was followed by Fiona Cregg, Scientific Project Manager, who gave a status update of the work packages. The meeting focused on the project's clinical trial of nilvadipine for mild to moderate Alzheimer's disease. Recruitment is progressing well and the target of 510 participants is expected to be reached by the end of March 2015.

Delegates also heard a proposal for a mini-study to document the experiences of trial participants and their carers. The study would examine motivations to participate, needs and expectations and how participating in a clinical trial may impact on wellbeing. If the study is approved, it will be led by Florence Pasquier (Centre Hospitalier Régional Universitaire de Lille) and Ana Diaz (Alzheimer Europe).

www.nilvad.eu

European Alzheimer's Alliance

25 November: MEPs Comodini Cachia and Chrysogonos join the European Alzheimer's Alliance

The European Alzheimer's Alliance is very pleased to welcome two new members as of 25 November 2014.

Therese Comodini Cachia, MEP (Malta) is a member of the European People's Party (EPP). She sits on the Committee

on Legal Affairs and is a member of the Delegation to the Parliamentary Assembly of the Union for the Mediterranean.

Kostas Chrysogonos, MEP (Greece) is affiliated with the Confederal Group of the European United Left - Nordic Green Left (GUE-NGL). He is the Vice-Chair of the Committee on Development and also a member of the Committee on Legal Affairs.

www.europarl.europa.eu/meps/en/124968/THERESE_COMODINI+CACHIA_home.html
www.europarl.europa.eu/meps/en/125061/KOSTAS_CHRYSOGONOS_home.html



Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at 86, representing 26 Member States of the European Union and all 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). **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 Grosselet (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:** Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkeviciute (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:** Elzbieta Lukacijewska (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL). **Romania:** Daciana Octavia Sarbu (S&D); Claudiu Ciprian Tanasescu (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); 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

14 October: Innovative Medicines Initiative has a new logo



On 14 October, The Innovative Medicines Initiative (IMI) released a new logo (pictured). The IMI is a public-private partnership aiming to speed up the development of better and safer medicines for patients.

11-12 November: Switzerland hosts OECD workshop on Alzheimer's disease research



On 11-12 November, the Swiss government hosted dementia experts at a two day workshop of the Organisation for Economic Cooperation and Development (OECD) in Lausanne, Switzerland. Participants discussed possible measures to address issues such as incomplete understanding of the disease, fragmented resources, challenges with the design and implementation of clinical trials and drug development processes.

The title of the workshop was "Enhancing Translational Research and Clinical Development in Alzheimer's Disease and other Dementia: The Way Forward" and it was organised in cooperation with The Global CEO Initiative on Alzheimer's Disease (CEOi) and Alzheimer's Disease International (ADI). Delegates shared ideas on how to improve drug and diagnostics development, with the aim of accelerating the translation of innovative research into effective therapies.

The workshop was a follow-up event to the OECD Workshop on "Better Health through Biomedicine: Innovative Governance", which took place in Berlin, Germany in 2010.

Organisers and participants made a commitment to keep the dialogue going and will reconvene to assess progress in a follow-up forum next year.

Alzheimer Europe's Executive Director, Jean Georges attended the workshop.

18 November: EPF states position on In Vitro Diagnostics Regulation



On 18 November, the European Patients' Forum (EPF) communicated its position on the most recent updates made by the European Parliament to the In Vitro Diagnostics Regulation.

Read the EPF's full position statement, including which key points it urges the Council to keep in or wants removed here:

www.eu-patient.eu/Members/Weekly-Mailing/IVD-position/

Members' News

19 October: Ireland's Helen Rochford-Brennan attends Alzheimer Europe conference



Helen Rochford-Brennan, Chair of the Irish Dementia Working Group has recently been appointed as a Vice-Chair to the European Dementia Working Group.

Helen travelled to the Alzheimer Europe Conference in Glasgow on 19 October 2014 for her first meeting with the European Working Group. Helen has played a leading role with the Irish Dementia Working Group to spread the message that people can live well with dementia. She is looking forward to working at a European level.

23 October: Scottish Dementia Working Group reports on 24th Alzheimer Europe conference



The Scottish Dementia Working Group (SDWG) was honoured to be involved in the largest ever dementia conference in Scotland. The focus of the conference was "Dignity and autonomy in dementia". Around 800 delegates were in attendance and there were representatives from 36 Alzheimer's Associations.

Our Chair, Henry Rankin, attended the conference with his wife, Anne. On Monday evening, Anne was proud to witness Henry address the audience at the opening ceremony and also sign the Glasgow Declaration.

Our members attended the Plenary Session on Tuesday morning and heard Health Secretary, Alex Neil share his personal experience of dementia.

Agnes Houston took part in a Special Symposium on Tuesday afternoon on behalf of the European Working Group of People with Dementia (EWGPWD). The session was titled "Snapshots of our lives" and was chaired by Helga Rohra, Chair of the EWGPWD. It was standing room only as Agnes delivered her talk "8 years on, here I am", to rapturous applause.

Our Chair, Henry Rankin spoke on Tuesday afternoon at the "Involving people with dementia" session which was chaired once again by Helga Rohra. Henry and researcher, Nick Jenkins from Edinburgh University presented "The Core principles for involving people with dementia in research", which was a warmly received subject resulting in many questions at the Q&A session.

On Wednesday, our members were up early to attend our workshop "The success and impact of the Scottish Dementia Working Group" which was chaired by Alzheimer Scotland's Deputy Director of Policy, Jim Pearson. David Berry from the Scottish Government and Patricia Howie from NHS Education Scotland (NES) joined six of our members on the stage. Each member gave an impressive speech, as always and our new member, Anne MacDonald finished the session by sharing her experience of her recent diagnosis.

Our member, Nancy was disappointed she could not attend the session as she was delivering a speech at the same time as part of the Highland Dementia Working Group. The speech, entitled «A purposeful life with dementia» was part of the “Involving people with dementia II” session.

Our members particularly enjoyed meeting delegates at our stand during the conference - handing out and discussing the leaflets they had produced on “Travelling with Dementia” and “The Core principles for involving people with dementia in research”.

23 October: Alzheimer Scotland gives three master classes after 24th AE conference



Following on from the 24th Alzheimer Europe Conference (20-22 October) in Glasgow, Alzheimer Scotland offered conference delegates the opportunity to extend their trip to Scotland by attending one of the three master classes taking place on Thursday 23 October. These offered a chance for a greater discussion and examination of some of the key subjects explored at the ‘Dignity & Autonomy in Dementia’ conference.

The master classes ran in Glasgow, Hamilton and Stirling, each with approximately 30 delegates in attendance and the following topics were explored:

Recent advances in dementia care; improving nursing home practice, hosted by the Alzheimer Scotland Centre for Policy and Practice, at the University of the West of Scotland:

Delegates took part in discussion groups considering what would best improve nursing home practice across Europe. A consensus was reached with the aim of producing an article for a quality peer-reviewed journal based on the interesting and wide-ranging discussions

Creating Dementia-Friendly Communities, hosted by the Alzheimer Society, at the Crown Plaza Glasgow:

The varying methods adopted across the UK and Europe were presented, including discussion around current programmes to support each of the dementia-friendly approaches. Delegates noted clear improvement, especially across the UK, in programmes being more greatly informed by the lived experiences of people with dementia and their carers. The afternoon sessions provided a great opportunity for groups to discuss and tackle specific areas focusing on: stigma/awareness, recognising progress, engaging businesses and organisations and involvement of people with dementia

International Ideas Lab; what we can learn from each other, hosted at Dementia Services Development Centre, at the University of Stirling:

Following a world-wide, open call which simply asked “Dementia in 2040 - what are the ideas today which will change the world of dementia tomorrow?” five very contrasting ideas from Australia, Canada, America, Denmark and the UK were selected. Delegates explored the next generation of ideas that will make a practical difference to people with dementia. Ideas included the power of social networks to improve the care of people with dementia, a model of one-to-one cognitive support, the practical use of gaming technology, the value of

rigorous quality of life indicators and a world-wide portal to support dementia-friendly communities.

<http://dementia.stir.ac.uk/ideaslab-2014>

1 November: The Alzheimer Society of Ireland launches Memory Ribbon Campaign



The Alzheimer Society of Ireland launched its Alzheimer’s Memory Ribbon Campaign on 1 November.

For the 48,000 people in Ireland today living with dementia, memories are especially precious and uplifting. ASI wants to celebrate those memories and all the special people who made them.

You can check out the campaign at www.memoryribbon.ie where you can create a memory and donate. You can browse, search and share your memories with friends and family online. Every donation will go directly to funding vital services in local communities around Ireland.

11 November: Germany’s DALZG selects research projects and pays tribute to volunteers



On 11 November, the German Alzheimer Society (DALZG) released a statement concerning two projects to which it has chosen to allocate funding received in 2014. The projects were selected from a pool of 43 research projects submitted by the technical advisory board of DALZG.

The first project will explore the benefits of tracking systems for people with dementia living at home and the second will look at assessing the capability of people with dementia to drive.

Research funding for the DALZG is awarded every two years. The overall amount of funding received in 2014 was almost EUR 200,000. Chairperson, Heike von Lützu-Hohlbein, had previously presented the projects on 25 October, at the association’s 8th annual congress in Gütersloh, Germany.

During the same congress, the association also paid tribute to eight of its voluntary workers, and awarded them with certificates of Merit for their unwavering commitment and hard work over the past ten years:

- Gudrun Andres (Alzheimer Gesellschaft Rheinland-Pfalz).
- Christa Dirks Isselmann (Alzheimer Gesellschaft Aufwind Brühl).
- Ingrid Fuhrmann (Alzheimer-Gesellschaft Berlin).
- Mathilde Greil (Alzheimer Gesellschaft Ingolstadt).
- Horst Laade (Alzheimer Gesellschaft Baden-Württemberg).
- Heide Römer (Alzheimer Gesellschaft Dortmund).
- Horst Schmikowski (Alzheimer Demenz Selbsthilfegruppe Hagen).
- Klaus Wudmaska (Alzheimer Gesellschaft Plauen-Vogtland).

11-12 November: Mediterranean Alzheimer's Alliance holds international conference



Alzheimer Portugal and the Monegasque Association for Research on Alzheimer's disease (AMPA) organised the International Conference "Alzheimer and the Mediterranean – working together for a better understanding" on 11-12 November 2014 at the Calouste Gulbenkian Foundation in Lisbon.

This event took place in the framework of the 4th Mediterranean Alzheimer Alliance (MAA) Workshop coordinated by AMPA and now brings together 14 Mediterranean countries (Cyprus, Croatia, Egypt, France, Greece, Italy, Lebanon, Malta, Morocco, Monaco, Portugal, Slovenia, Spain, Tunisia). The MAA is a network, composed of Alzheimer's associations, scientific experts and health care professionals from the Mediterranean region which not only aims to share and exchange knowledge and practices but also to make propositions on a local and international level.

With over 200 participants, this conference was a real success and a good opportunity to support Alzheimer Portugal in its national mobilisation for the fight against Alzheimer's disease. Each Mediterranean country was able to present its national initiatives and exchange on a wide range of topics: research, non-pharmacological interventions, care for people with Alzheimer's disease and government strategies also. For instance, Samia Abdul-Rahman from Egypt explained that there is no stigma attached to Alzheimer's disease in Egypt but that the normalisation of the disease is problematic and that the official term for dementia is rarely used as there is a general consensus that it is offensive; Leila Alouane from Tunisia gave examples of how to incorporate elements of a Mediterranean diet into one's daily life; Dianne Gove presented Alzheimer Europe's work on the ethical implications of how dementia is perceived and portrayed; Luis Amado, former Minister of Foreign Affairs for Portugal, drew attention to the economic and financial crisis, as well as to the geo-political environment.

Federico Palermi and Salomé Nicaise from AMPA presented the preliminary results of the "Alzheimer and the Mediterranean" Report which will be published in 2015 by the MAA. This Report will elaborate an update of these countries' needs and an analysis of the scientific, medical and social emerging issues in the Mediterranean region.

The conference reinforced bonds between the Mediterranean countries. There was a strong call for further initiatives to be made, both within the framework of the MAA and on a national level, in order to push governments to recognise Alzheimer's disease as a national public health priority demanding specific and real measures to promote quality of life. Two workshops are already planned in 2015, one in Greece on 14-17 May and one in Slovenia during the 25th Alzheimer Europe Conference from 2 to 4 September. This will be a great opportunity for new members to join the Alliance.

12 November: ASI raises awareness with Dementia Strategies Seminar



The Alzheimer Society of Ireland (ASI) held a seminar on 12 November, titled "Dementia Strategies - an opportunity to transform?"

With the imminent publication of Ireland's first National Dementia Strategy, the seminar aimed to raise awareness of what a dementia strategy can do for people with dementia and family carers in Ireland.

The seminar gave audience members the chance to learn about the experience in England on the implementation of their strategy, as the keynote speech was delivered by Professor Alistair Burns, National Clinical Director for Dementia in England. We also heard about the Scottish experience from Douglas Philips, Lead for Dementia with the Scottish Government Joint Improvement Team. Additional contributions were made by Helen Rochford-Brennan, Chair of the Irish Dementia Working Group, and Gerry Martin, CEO of The Alzheimer Society of Ireland.

13-16 November: Association Alzheimer Suisse attends health fair



Switzerland's national Alzheimer's disease association, Association Alzheimer Suisse (AAS) attended the first ever "Salon Suisse de la santé", from 13 to 16 November in Lausanne, Switzerland. Hospitals were represented as well as patient organisations and first aid services, among others. There were also several meetings held during the event.

The health system in Switzerland is subject to constant change and looking after oneself and one's health is an issue, which is fast becoming important for many people in the country. This was the reason behind the fair, which attracted almost 30,000 visitors.

The AAS aimed to put dementia on the fair's agenda by attending, as well as making visitors aware of dementia-related issues. The event, the organisation said, was "part of our ongoing efforts on providing information and support not only for people with dementia and their carers but also for the general public. In many ways and on as many occasions as possible."

www.planetesante.ch/Salon2

20 November: Jersey Alzheimer's Association runs art therapy sessions



Jersey Alzheimer's Association is passionate about 'person-centred care' and promotes meaningful activity, based on a person's wishes, ability and potential. One of the recent activities offered by the association is "Arts Exploration" – therapeutic art sessions, run by Lucy Blackmore. These take place in a local Community Centre and referrals from the Memory Clinic have ensured that good numbers have attended from the outset.

Lucy Blackmore writes:

"The aim of the sessions is for clients to lose themselves in the moment of creating. I am hopeful that through the process of using art as therapy, relationships are built, empathy fostered, anxiety lessened, and a sense of mastery or control over the group member's environment is developed. It's a matter of discovering new ways to express yourself and communicate. This enriching process aims to be life enhancing and fun. My initial hopes and aspirations for the group have exceeded my expectations. The group members are confluent with each other and supportive of one another's journey through this process.

www.jerseyalzheimers.com

20 November: Alzheimer Hellas holds various events in October and November



Here is an overview of events organised by Alzheimer Hellas during the months of October and November:

The Greek Association of Alzheimer Disease and Related Disorders (Alzheimer Hellas) with the support of the Association "Friends of Vafopouleiou Cultural Centre" hosted an art exhibition from 22 October to 20 November. The exhibition, entitled "Byzantine Vanguard", was implemented with the paintings of the Lord Hagiographer of the Ecumenical Patriarchate, Mr I. Mitrakas. There were also some parallel activities, such as a poetry reading and a speech. During these activities we had the chance to inform a large public group from our city about our NGO's actions concerning people with dementia and their caregivers.

On 15 October and 20 November, Alzheimer Hellas hosted two successful speeches of professors of psychology that were given during Alzheimer cafes in the city centre. Our patients had a perfect chance to be informed on issues that interest them, exchange ideas, talk to trained doctors and socialise. Therefore, education and relief of the disease burden was accomplished!

On 7-8 November, Alzheimer Hellas, with Prof. Magda Tsolaki (see photo) and our NGO's representatives Mrs Eleni Antoniadou and Mrs Xenia Maiovi, participated in the third Patients' Conference, "Patients in Power" hosted in the country's capital, Athens. The conference has shown that for yet another year, the problems of patients' organisations are similar and cooperation is much needed. During the workshop we also had the opportunity to train on strategic planning for NGOs.

Prof. Tsolaki gave speeches after Sunday mass in two churches and also at a church's advisory station. The speeches dealt with the specifics of the disease and the burden of caregivers. It is very crucial, bearing in mind that religion plays a great role in our culture, that priests and the church's flock are properly informed about dementia, the importance of prevention, early diagnosis and treatment fitted to each patient's needs.



20 November: Alzheimer Slovenia President receives several awards



The President of Spominčica – Alzheimer Slovenia, Štefanija L. Zlobec, recently received various awards for charity, nobility and humanitarian work. The awards were presented at the public event "People of Open Hands" which took place at the National Gallery of Slovenia on 20 November. The editor of the magazine Naša Žena and the secretary from the Ministry for labour, family, social affairs and equal opportunities presented the awards.

Štefanija has been working for the Slovenian Alzheimer Association Spominčica for more than five years. Štefanija has a University degree in economy and previously worked at the Ministry of Finance of the Republic of Slovenia. She started to work in the field of dementia when her husband was affected by Alzheimer's disease, before he even turned 50. He was a public person, a deputy in the Slovenian Parliament, a human rights activist, translator, poet and the Slovenian ambassador in Brussels.

Unfortunately, the diagnosis was established very late, because he was thought to be too young for such a disease. For the last two years, she has been the president of Spominčica – Alzheimer Slovenia and this year, became a member of the Board of Directors of Alzheimer Europe.

With her work and personal experience with dementia, she is trying to help others with this condition and raise awareness about dementia in the public domain.

24 November: EUR 21 million for Dutch dementia research



alzheimer nederland

The first 25 research projects of the Dutch "Delta Plan Dementia" were announced on 6 October and will start before the end of the year.

The studies vary in focus, from new treatments and prevention to better patient care and support. Results are expected in the coming years.

Gea Broekema-Prochazka, director of Alzheimer Netherlands said "We expect breakthroughs that are important for the patients that are faced with dementia today and for the patients of the future."

The 25 studies have received over EUR 21 Million in funding. The Dutch Government was the major contributor. Alzheimer Nederland was the major private investor with a contribution of over EUR 1 Million.

25 November: Norwegian lottery is the winning ticket for dementia research funding



The Norwegian Health Association has been awarded more than EUR 250,000 from the ExtraFoundation Health and Rehabilitation (Extrastiftelsen). The foundation's mission is to manage the profits from the state-regulated Norwegian lottery. Proceeds from the games go towards health projects administered by Norwegian NGOs.

EUR 119,000 goes to the Norwegian Health Association for ongoing research on user involvement and dementia, related to the use of medications. Two different local rehabilitation projects based on farm experiences for people with dementia, has received a total of EUR 112,000. The Norwegian academy of music has been given EUR 15,000 EUR to produce a handbook on music and dementia.

In total, 538 health projects related to research, prevention and rehabilitation have been granted a total of EUR 28,000,000 for 2015 by the ExtraFoundation.

Policy Watch

10 November: Pharmaceutical regulators meet for urgent talks on dementia

Pharmaceutical regulators from ten countries met in Geneva on 10 November, for urgent talks on ways of using existing laws and regulations to support dementia research and development. This was the first of three meetings, to take place worldwide.

This first meeting, led by the British government, brought together representatives from the Medicines and Healthcare products Regulatory Agency (MHRA) and regulators from the European Union, the United States, Canada, Japan, Switzerland, the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD). Their next steps will be to identify areas of focus for future collaboration and coordination.

Ms Hilary Doxford, Vice-Chairperson of Alzheimer Europe's European Working Group of People with Dementia (EWGPWD), attended these meetings at the invitation of the UK Department of Health.



18 November: France launches Neurodegenerative diseases plan



Marisol Touraine, Minister for Social Affairs, Health and Womens' Rights, Geneviève Fioraso, State Secretary for Higher Education and Research, and Laurence Rossignol, Secretary of State for Families, Older people and Autonomy, launched the new French neurodegenerative diseases plan for 2014-2019 on 18 November.

Announced by France's President Hollande, the plan has three main priorities:

1st priority – "Improving the diagnosis and management of patients":

- enhanced coordination between the attending physician and neurologist;
- better access to expertise, with the creation of 24 expert centres dedicated to multiple sclerosis, Parkinson consolidation of 25 specialised centres, in addition to existing reference centres for Alzheimer;
- 100 new devices specifically in support of better healthcare for older people;

- the development of therapeutic education for patients and their caregivers.

2nd priority – "Ensuring the quality of life of patients and their caregivers":

- increased home support, with 74 new teams specialised in Alzheimer's disease and behavioural experiments, to adapt this approach to Parkinson's disease and multiple sclerosis;
- more support for caregivers - 65 new support and respite platforms;
- support programs for patients and their caregivers as set out in the draft Health Act;
- priority given to maintaining employment and vocational rehabilitation for younger patients;
- digital solutions such as SMS alerts and smartphone and tablet apps, to improve patient autonomy.

3rd Priority – "Develop and coordinate research":

- recognition for centres of excellence in teaching and research will ensure France's place in European and international projects;
- improving knowledge tools will allow France to act more effectively on neuro-degenerative diseases.

[www.social-](http://www.social-sante.gouv.fr/IMG/pdf/Plan_maladies_neuro_degeneratives_def.pdf)

sante.gouv.fr/IMG/pdf/Plan_maladies_neuro_degeneratives_def.pdf

25 November: NHS England to discontinue "cash for diagnosis" scheme



NHS England's recently introduced "cash for diagnosis" scheme – so labelled by the media – was introduced in October, with the goal of increasing low levels of dementia diagnosis. The scheme, however, has been fiercely criticised by GPs and patient groups and will be discontinued after March 2015.

28 November: World Dementia Council will welcome member with dementia



On 28 November, the World Dementia Council announced that it will shortly welcome a new member, living with dementia. The decision follows the Council's third meeting, where they heard an address from Ms Hilary Doxford, Vice-Chair of Alzheimer Europe's European Working Group of People with Dementia (EWGPWD).

The Council feels that this kind of personal insight, provided by a person living with dementia, could help it to better reflect the experiences and needs of people with dementia. The name of the new member will be announced soon.

30 November: Norway holds open hearings on new dementia plan



The Norwegian government will develop a new plan to improve services for people with dementia and their carers: Dementia Plan 2020. People with dementia and their families will have a central role in the new plan and are invited to participate in open hearings.

The hearings are taking place in seven of the country's largest cities throughout November and December. The first meeting was held in Oslo with Health Minister Bent Høie present. On the same occasion, the Minister also published a letter in the largest newspaper VG:

"We want to listen to stakeholders in their efforts to create a new dementia plan. We have listened too little to those with dementia and their careers... It is one of the reasons why our services are not sufficiently facilitated for these group. There is still not enough knowledge about dementia in our society, both among victims and employees in health care services. It is one of the reasons that dementia is still shameful and why many try to keep the disease hidden."

The biggest challenges:

Norwegian Health Association is responsible for organising the regional meetings together with the Ministry of Health, the Directorate of Health and Ageing and Health and Ageing and Health - Norwegian Centre for Research, Education and Service Development. People with dementia, their families, volunteers, employees and managers of care services are invited.

The participants are invited to express what they see as the biggest challenges in dementia care today, and what users and their families need in order to live as good a life as possible, with dementia.

Science Watch

10 October: Thromboxane Receptor could be therapeutic target for AD



Scientists at Temple University School of Medicine, Philadelphia, US believe blocking the Thromboxane receptor in brain cells may play a major role in diffusing the biological consequences of Alzheimer's disease (AD). Their research was published on 10 October in the journal, *Neurobiology of Aging*.

By blocking these receptors with medication, thus stopping oxidative stress, the researchers were able to prevent some symptoms of AD - memory problems and accumulation of hyper-phosphorylated tau - in mouse models.

According to study author, Prof. Domenico Praticò, "besides the two major signature brain pathologies associated with Alzheimer's disease, amyloid beta plaques and the tangles which are formed from the phosphorylation of the tau protein, researchers have also known for a while that there is a signature from oxidative stress. But it has always been believed that oxidative stress was just a bystander and did not have an active function in the development of the disease."

The study's findings indicate that oxidative stress plays a possible role in Alzheimer's disease and also suggest that blocking oxidative stress and free radicals via the thromboxane receptor could be a new therapeutic target for AD.

The researchers continue to investigate additional compounds that could more efficiently block oxidative stress at the thromboxane receptor. Further research and eventual human studies are, of course, needed.

www.neurobiologyofaging.org/article/S0197-4580%2814%2900643-5/abstract

20 October: The syk enzyme regulates amyloid beta and tau hyperphosphorylation in AD

A new study shows that inhibition of the spleen tyrosine kinase (syk) enzyme can interrupt the neuroinflammation, pathological A β accumulation and tau hyperphosphorylation in Alzheimer's disease. The study authors also explain that nilvadipine is effective in stopping the activity of syk. Nilvadipine is currently being tested in a Phase 3 clinical trial in the NILVAD project.

www.jbc.org/content/early/2014/10/20/jbc.M114.608091
www.nilvad.eu

23 October: US scientists claim new dementia blood test is accurate



Researchers at the US National Institute on Aging (NIA) have created a new blood test, which they claim can detect Alzheimer's disease up to ten years before clinical diagnosis is possible.

The research team, led by NIA Neuroscientist, Dimitrios Kapogiannis, published its findings in the journal of the Federation of American Societies for Experimental Biology (FASEB), on 23 October.

The report claims this new blood test distinguishes between patients and healthy older people with 100% accuracy, however, it is still in the early stages of development and has only been evaluated in 174 individuals. The authors say that it will require a larger, long-term study before widespread use would be possible.

<http://www.fasebj.org/content/early/2014/10/23/fj.14-262048.abstract>

28 October: Researchers said to have identified new disorder, linked to AD

In a US study published on 28 October November in the journal *Acta Neuropathologica*, researchers report having identified a new neurological disease, which they say causes the same cognitive impairments as Alzheimer's disease but which has a different brain pathology.

The research team - led by Dr. Peter T. Nelson of the Sanders-Brown Center on Aging at the University of Kentucky, US and Dr John F. Crary of Mount Sinai Hospital in New York, US - found that unlike patients with Alzheimer's disease, who have both beta-amyloid plaques and tangles in the brain, those with the disorder they identified only have tangles, not plaques. They have chosen to name this disorder "primary age-related tauopathy" (PART).

Previous research has shown that some patients, while presenting with memory complaints, have no abnormal beta-amyloid in their brains, indicating that they would not develop the plaques, which are a hallmark of Alzheimer's disease. With this in mind, the team set out to

establish new clinical criteria for diagnosing PART - something they hope will lead to the development of better treatments for patients with varying types of memory disorders.

As yet, the researchers have said they are unable to determine how common PART is.

<http://link.springer.com/article/10.1007/s00401-014-1349-0>

3 November: UK doctors to offer brain tests to middle-aged patients



Doctors in the UK are set to offer middle-aged patients the opportunity to take a computer-based test designed to show how their “brain age” compares with their biological age. The aim is to encourage people to pursue healthier lifestyles.

The computer-based test, devised by Public Health England (PHE), will be piloted by General Practitioners (GPs) over the course of the next few months. The programme makes calculations based on patients’ answers to questions about habits such as exercise, alcohol intake, smoking and weight, combined with clinical data on blood pressure and cholesterol levels.

PHE dementia specialist, Mr Charles Alessi said the scheme will be entirely voluntary and would not amount to screening.

“We are offering people an opportunity to know exactly how risk factors can influence the rate of decline of their cognitive functions. Dementia is a whole group of conditions and we can manage some of the risks”, Mr Alessi said.

The Alzheimer’s Society (UK) - which is currently working with PHE and academic partners on tools to help people understand dementia risk factors - said the programme is still in the early stages of development and that more research is needed before finding a reliable risk calculator.

Dr Richard Vautrey, deputy chair of the British Medical Association’s GP committee, was more sceptical of the screening tool. “Giving someone’s brain age in relation to their natural age doesn’t necessarily mean they are likely to develop dementia any earlier,” he said. “We’d need to really look at the research evidence and understand if there is any basis for this supposition.”

4 November: Study says diabetes drugs look promising as AD treatment



Researchers at the University of Ulster, Belfast, Northern Ireland and at Lancaster University, England, say that two type 2 diabetes drugs, lixisenatide and liraglutide, may protect the brain from the effects of Alzheimer's disease (AD). Their animal study was published in the journal, *Neuropharmacology* on 4 November.

Both drugs investigated work by increasing insulin production, reducing blood sugar and helping food pass more slowly through the digestive tract. The study showed that daily injections of the drugs for 10 weeks

also reduced the levels of amyloid plaque in the brains of AD mouse models and improved their memories and recognition skills.

Previous studies have suggested that insulin may protect the brain and this new research suggests that it may also help repair neuronal damage.

The researchers hope that their findings may swiftly transform the treatment of AD, since the drugs are already available on the market.

The Alzheimer's Society, UK is excited by the promising results and is currently funding a clinical trial using liraglutide in people with early-stage Alzheimer's disease. Results are expected in 2015.

<http://www.journals.elsevier.com/neuropharmacology/>

5 November: Two scientists share German Alzheimer's Research Award



Two German scientists - Göttingen-based Professor Mikael Simons (pictured, right) and Munich-based Professor Stefan F. Lichtenthaler (left) – have been jointly awarded the EUR 100,000 Alzheimer's Research Award by Frankfurt’s Hans and Ilse Breuer Foundation.

The prestigious award was presented on 5 November for the tenth time and is the largest prize for Alzheimer's disease research in Germany.

Prof. Simons, born in Helsinki in 1970, was rewarded for his research, examining the electrical insulation of nerve fibers to reduce damage to the myelin sheath, which happens in multiple sclerosis (MS) and can lead to severe neurological disorders.

Prof. Lichtenthaler, born in Karlsruhe in 1968, was rewarded for his research on the function and regulation of proteins. His aim is to better understand the causes of dementias and to develop new diagnostic and therapeutic approaches and to better predict possible side-effects of medication.

www.breuerstiftung.de/

5 November: Antibodies can cross blood-brain barrier in primates



A study published in *Science Translational Medicine* on 5 November has shown that antibodies can cross the blood-brain barrier (BBB) in primates.

The BBB acts as a protective layer for the brain, by stopping some things from passing into it from the blood stream. This protection, however, can be a stumbling block for the development of drugs for the treatment of neurological conditions, including dementia.

Through the intravenous dosing of monkeys with anti-TFR/BACE1 antibodies, lead researcher, Dr Joy Yu and her colleagues were able to reduce levels of Amyloid beta (Aβ) both in cerebral spinal fluid and in brain tissue. They concluded they had achieved their goal and that it is, indeed, possible to “robustly and safely deliver

therapeutic antibody across the BBB in the primate brain.”

Dr Doug Brown, Director of Research at the Alzheimer's Society (UK), said that showing this process works in primates brings scientists “one step closer to using this technology for treatments in people”, but he stressed that more research is needed, “to see if this also works in the human brain, and whether the drug that makes it into the brain works as an effective treatment for people with Alzheimer's disease.”

<http://stm.sciencemag.org/content/6/261/261ra154.abstract?sid=21729187-e6a9-4802-a7d6-0fc54436a9f9>

12 November: Taking Vitamin B and folic acid may not help prevent dementia



A team of Dutch researchers, led by Dr Rosalie Dhonukshe-Rutten, from Wageningen University in the Netherlands, has completed a two-year study into the effects of vitamin B12 and folic acid on dementia. The study, published in the journal, *Neurology* on 12 November, concludes that these supplements did not cut the risk of developing dementia in healthy people.

In one of the largest studies to date - involving almost 3,000 people with high blood levels of homocysteine and an average age of 74 years – no difference was found in memory test scores between those who had taken the supplements for two years and those on placebo.

B vitamins have been linked to Alzheimer's disease for some years, and scientists know that higher levels of the body chemical, homocysteine can raise the risk of both strokes and dementia. Vitamin B12 and folic acid are both known to lower levels of homocysteine. This, along with studies linking low vitamin B12 and folic acid intake with poor memory, had prompted scientists to view the supplements as a possible aid in preventing dementia.

In this new study, however, results found no evidence of a protective effect: In four different tests of memory and thinking skills taken at the start and end of the study, there was no beneficial effect of the supplements on performance, despite a lowering of homocysteine levels in those taking the supplements.

The study concludes that the supplements “may slightly slow the rate of decline of global cognition, but the reported small difference may be attributable to chance.” Longer follow-up periods would be needed to see if vitamin B12 or folic acid could slow the severe memory decline associated with dementia.

The researchers stressed the results could not be extrapolated to people who already had cognitive problems and earlier research had suggested they may benefit.

www.neurology.org/content/early/2014/11/12/WNL.000000000001050

17 November: Advanced brain scanner could help Scottish scientists develop dementia treatments



The University of Edinburgh, Scotland reported on 17 November that it is to receive a new brain scanner, said to be the first of its kind in Scotland. The

Medical Research Council (MRC) has awarded GBP 6.8 Million (approx. EUR 8.5 Million) to support the programme. The scanner will be housed by the Clinical Research Imaging Centre at the university.

The system will let researchers track the movement of individual molecules within the brain's cells, combining magnetic resonance imaging (MRI) scans with positron emission tomography (PET) imaging to produce high-resolution pictures of the tissue of the brain.

Using the device should enable researchers to look in detail at what is going on inside the human brains and will also help doctors identify patients who are most likely to benefit from new therapies, as well as monitoring the effects of the treatment.

Professor Ian Deary, director of the University of Edinburgh's Centre for Cognitive Ageing and Cognitive Epidemiology, who led the bid, said: “Advanced brain imaging and stem cell research are likely routes to better understanding of the causes and progress of dementias.

Other organs of the body can also be studied with the device, enabling insights into diseases of the heart, blood vessels, lung and various types of cancer.

19 November: Study finds brain's “weak spot” for AD and schizophrenia



Scientists at Oxford University, England, have found a network of brain regions that appears to be more vulnerable than other areas to Alzheimer's disease and schizophrenia. Their study was published in the journal, *Proceedings of the National Academy of Sciences (PNAS)*, on 19 November.

The research team was led by Medical Research Council (MRC)-funded, Dr Gwenaëlle Douaud at Oxford University's Centre for Functional Magnetic Resonance Imaging of the Brain (FMRIB) and was an international collaboration between the University of Oxford neuroscience imaging team, neuroscience researchers from the University of Oslo and research clinicians from the University Hospital Basel, Imperial College London and the University of Oxford's Department of Psychiatry.

Magnetic resonance imaging (MRI) scans were used, to look at changes in the brain structure of 484 healthy people, between 8 and 85 years old.

The findings showed that, in healthy people, these parts of the brain are the last to develop and the first to show signs of neurodegeneration. The network in question, consisting of mainly 'higher-order' regions that coordinate information coming from different senses, doesn't develop until late adolescence or early adulthood and is associated with both intellectual ability and long-term memory. These mental abilities become significantly impaired in, respectively, people with schizophrenia or those with Alzheimer's disease.

Dr Douaud said: “Our results show that the same specific parts of the brain not only develop more slowly, but also degenerate faster than other parts. These complex regions, which combine information coming from various senses, seem to be more vulnerable than the rest of the

brain to both schizophrenia and Alzheimer's, even though these two diseases have different origins and appear at very different, almost opposite, times of life."

The MRC commented that the study "raises important issues about possible genetic and environmental factors that may occur in early life and then have lifelong consequences."

www.pnas.org/content/early/2014/11/19/1410378111.abstract?sid=3e673ca0-8975-4529-ba16-04ac39c0f423

24 November: Orexin protein may be new therapeutic target for AD



A new study, which appeared in The Journal of Experimental Medicine on 24 November, suggests an approach to preventing Alzheimer's disease (AD) may lie in targeting orexin - a protein that arouses the brain from sleep.

Researchers from the School of Medicine at Washington University in St Louis, US (WUSTL) came to this conclusion after they found that eliminating orexin in mouse models meant they slept longer, which significantly slowed the production of brain plaques, which in turn could help prevent AD.

Senior study author, Prof. David M. Holtzman, head of the Department of Neurology at the WUSTL School of Medicine said that blocking orexin to increase sleep in patients with sleep abnormalities, or perhaps even to improve sleep efficiency in healthy people, may be a way to reduce the risk of Alzheimer's disease. He concluded that orexin could be a new therapeutic target for Alzheimer's disease.

The study specifies, however, that orexin "only affects plaque levels when it also affects sleep": When the team altered orexin levels in only part of a mouse model's brain and not throughout, this did not alter the amount of time the animals slept for and neither did it reduce plaque levels.

Prof. Holtzman, said "we will have to think carefully about how to target it for Alzheimer's prevention. But the declines in plaque levels that we saw in the mice were very strong, so we're still very interested in exploring its potential for reducing risk."

The team is now looking at how sleep medication might affect the production of amyloid beta and the accumulation of plaques.

<http://jem.rupress.org/content/early/2014/11/18/jem.20141788.abstract>



Dementia in Society

22 October: History, Art and Alzheimer's at "Estimul'Art" in Barcelona

Estimul'Art is a cooperative effort between the Museum of History, Museum Frederic Marès and ACE Fundacio - the Catalan Institute for Applied Neuroscience. The goal is

to stimulate the memory and the cognitive capacities of people with Alzheimer's disease accompanied by their family or carers, through art and historical memory.

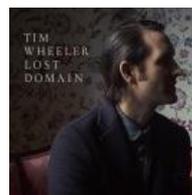


Twenty participants with mild or moderate Alzheimer's disease and users of ACE Fundacio day care centre took part in the first visit that took place on 19 September.

Ten monthly sessions are planned until June 2015. The visits are brief and focus on different art pieces. The first session focussed on 'Condestable', or Epiphany altarpiece (1464-1465), a work by Jaume Huguet in the chapel of Santa Agata in Barcelona.

The project will be subject to a qualitative evaluation after completion.

3 November: Tim Wheeler releases album about his father's dementia



Northern Irish musician, Tim Wheeler - frontman for the rock band Ash, whose hits include "Shining Light" and "Girl From Mars" - released his first solo album, "Lost Domain" on 3 November. The songs on this deeply personal album are all

about his father, George's dementia, prior to his death in 2012.

Mr Wheeler says he wanted to share his experience and his observations about what he and his father, a former district judge, were going through at that time. "It was a really hard time," he says. "but the closeness within my family made it a powerful bonding time as well."

A portion of the proceeds from the album is being donated to the Alzheimer's Society (UK). Mr Wheeler has worked closely with the charity since his father's death.

www.youtube.com/watch?v=EiAWJ0VKb-A&utm_campaign=Dementia+Friends+October+Newsletter&utm_source=emailCampaign&utm_medium=email&utm_content

6 November: OU helps large UK supermarket chain become more dementia-friendly



Staff from one of the UK's largest supermarket chains were given dementia training by The Open University (OU) on 6 November. The supermarket's designated "Community Life Champions"

received in-depth training, delivered by OU dementia specialists.

The supermarket staff members were taught skills they might need to help make the lives of customers with dementia easier, both in a shopping environment and also in other everyday situations within their local communities.

"Community Life Champions" will share what they learned with their colleagues to help make all of the supermarket's stores in Scotland more dementia-friendly.

19 November: “Integration You and Me” film festival highlights needs and potential of people with disabilities



The tenth "Integration you and me" film festival took place on 19 November in the European Parliament in Brussels, Belgium. Its host, MEP Marek Plura, who was born with a progressive muscular dystrophy, saw it as a great opportunity to raise the subject of the implementation of the European Disability Strategy 2010-2020.

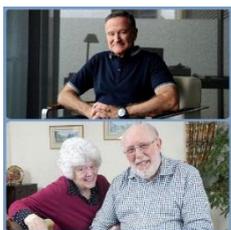
Over the past decade, the festival "has managed to pave the way for the subject of disability in media, culture and social space" Mr Plura said.

Three short films (Franco-Spanish, British and Polish productions, each one with English subtitles) were selected for the review in the European Parliament, due to both their theme and artistic value.

"I believe that the upcoming International Day of Persons with Disabilities [3 December], the beginning of the new term in the European Parliament as well as the first year of the Multiannual Financial Framework is the right moment to bring the needs of persons with disabilities and their great potential into light, but also the barriers they encounter", surmised Mr Plura.

Guests included representatives from various NGOs, the European Institutions, the education sector as well as diplomats and the media.

24 November: Peter Ashley says he knows what Robin Williams was going through



On 11 August this year, American actor and comedian, Robin Williams (pictured, top) took his own life at his home in California. He had struggled with drug addiction and alcoholism throughout his life and had also suffered bouts of severe depression. The autopsy report said he likely had dementia with Lewy Bodies (DLB), and his wife stated he had also been diagnosed with Parkinson's disease shortly before his death.

Mr Williams began his career as a stand-up comedian in the 1970s and rose to fame as the character, Mork in the TV series "Mork & Mindy", before going on to play lead roles in many Hollywood feature films, including "Good Morning, Vietnam", "Dead Poets Society" and an Oscar-winning performance in "Good Will Hunting" in 1997.

In recent years, although he continued to make movies, his depression was worsening, he was suffering from insomnia and his behaviour was - according to his family - increasingly strange. The likely cause being the hallucinations and paracusiae (auditory hallucinations) common in people with DLB.

Peter Ashley (pictured, bottom, with his wife, Ann) - one of the pioneers of the involvement of people with

dementia in Europe - was the first person living with dementia to speak at an Alzheimer Europe Conference (Maastricht, 2002) and an active member of Alzheimer Europe's working group on advance directives. Mr Ashley has Lewy Body Dementia and believes he understands better than most what Robin Williams was experiencing prior to his suicide. In an article published on 24 November in the UK's Telegraph newspaper, he said:

"I can understand the impact it must have had on him. You think that if someone is intellectually very competent, they can cope – but it's not necessarily true. I can well understand him experiencing depression from Lewy bodies and that driving him to the edge. I'll make no qualms about it – I've been to the edge. I've tried to commit suicide twice."

Mr Ashley, 78, began having hallucinations aged 63. He had been suffering from what he thought was an extreme bout of depression and spent some time in a psychiatric hospital before doctors diagnosed his underlying condition as DLB, a terminal illness that shares symptoms with Alzheimer's and Parkinson's diseases. DLB accounts for approximately 10% of the incidence of dementia.

www.telegraph.co.uk/health/11246934/Ive-been-to-the-edge-I-know-what-Robin-Williams-was-going-through.html

New Publications & Resources

5 November: Alzheimer's Society launches dementia risk factors resource online



On 5 November, the Alzheimer's Society (UK) announced the release of a new online resource, which pulls together the evidence on the following risk factors for dementia: Physical activity; High blood pressure; Diabetes; Smoking; Diet; Mental activity; Depression; Obesity; Alcohol and Cholesterol.

<http://alzheimers.org.uk/reducemyrisk>

20 November: “My Visitor Book” created by Alzheimer's Society

The Alzheimer's Society (UK) has created a resource called "My Visitor Book", to enable people with dementia to keep track of the professionals who visit them in their home. There is space for the person to include:

- the name of the professional
- organisation
- job
- contact number
- reason for their visit
- what they did
- when the next appointment is.

The aim is to provide a useful way of recording what happened and developing self-help strategies. It is intended as a resource "for the person with dementia themselves to refer to and use as is most appropriate for them."

www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2775&utm_campaign=General141114&utm_content=12351042902&utm_medium=Enewsletter&utm_source=Smart%20Focus

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 2014

Date	Meeting	AE representative
5 December	NILVAD: People with dementia experiences of participating in the clinical trial (Lille, France)	Ana
9-12 December	EMIF project meetings (Barcelona, Spain)	Alex
10 December	EFPIA Think Tank meeting (Brussels, Belgium)	Annette
19 December	Stakeholder Meeting to discuss and provide the on-going development of the next AAL JP Call for Proposals on "Living Active and Independently at Home"	Dianne

Future Conferences

Date	Meeting	Place
17-18 February 2015	11th International Update Conference on Clinical Neurology and Neurophysiology, http://www.isas.co.il/neurophysiology2014/index.php	Tel Aviv, Israel
18-22 March 2015	AD/PD TM 2015, The 12th International Conference on Alzheimer's and Parkinson's Disease, www2.kenes.com/adpd/pages/home.aspx	Nice, France
26-29 March 2015	The 9 th World congress on controversies in neurology (CONy), http://www.comtecmed.com/cony/2015/default.aspx	Budapest, Hungary
27-28 March 2015	19 th annual meeting of the German Society of Neurogenetics (DGNG), www.dgng.de	Bonn, Germany
15-18 April 2015	30th International Conference of Alzheimer's Disease International, http://www.alzint.org/2015	Perth, Australia
23-26 April 2015	9th Panhellenic Interdisciplinary Conference on Alzheimer's Disease and Related Disorders in combination with the 1st Mediterranean Conference on Neurodegenerative Diseases	Thessaloniki, Greece
20-23 June 2015	1st Congress of the European Academy of Neurology (EAN), www.eaneurology.org/berlin2015	Berlin, Germany
9-12 March 2016	14 th 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

