



NEWSLETTER

September 2013

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Editorial

There is a pleasant sense of anticipation in the office, as we're all quite keen to finally reach Malta for our flagship event. At this time of year, we sometimes feel that preparations for the Conference will never end, but our efforts have paid off and we are now as ready as can be.



We have also kept up our project work, including meetings with Mental Health Europe, EFPIA and the European Medicines Agency. There was an interesting conference of the WHO European region and we met with colleagues from the ethics working group and the EMIF project.

Two of our EWGPWD members distinguished themselves in September: Agnes Houston won a Lifetime Award for her work with the Scottish Dementia Working Group and Stig Atle Aavik was received by the King of Norway ahead of a major fundraising drive for dementia. If you are attending the Conference, you will soon notice that the group members are active in many different - and sometimes surprising - activities.

We are also pleased to report on the actions of our European Alzheimer's Alliance members for World Alzheimer's Day: French MEP Françoise Grossetête, Chairperson of the Alliance, issued a stirring message praising all those who voluntarily give of their time and effort to support people with dementia and their caregivers. Meanwhile, MEP Martina Anderson bravely took to the rainy streets of her hometown in Northern Ireland to complete a ten kilometre Memory Walk, on behalf of her mother who is living with dementia.

Tonio Borg, EU Commissioner for Health and Consumer Policy, also published an article that pays tribute to the challenges faced by people with dementia and their caregivers.

As every year, we are very glad to report on our members' World Alzheimer's Day activities. Cyprus opened the country's first day care centre for people with dementia. Greece held events during the entire month, including a novel demonstration of cognitive tests with members of the public. Memory Walks were very popular again this year - particularly in Portugal, which saw simultaneous walks in seven cities. Slovenia preceded its Memory Walk with an Alzheimer Café meeting, while Belgium organised a huge Alzheimer Café event featuring art therapy sessions. In Italy, there were conferences, concerts and award ceremonies, as well as a visit to the Vatican. TV viewers in the Netherlands were treated to a new documentary about dementia and Norway launched a unique fundraising drive that featured a royal audience.

Our deadline for this issue was quite tight, so we hope to continue our coverage of World Alzheimer's Day next month. All WAD activities will also appear in a future issue of the Dementia in Europe magazine.

At the time of writing, Conference registrations were still coming in and we now expect a total of 520 people. According to our sources, some very eager delegates have already arrived on the sunny island! We applaud their enthusiasm and look forward to joining them and the rest of our distinguished guests next week.

Jean Georges
Executive Director

Alzheimer Europe

19 September: Agnes Houston wins Lifetime Achievement award



Congratulations to Agnes Houston for winning the Lifetime Achievement award at Scotland's Dementia Awards 2013!

Agnes was cited for her work in the Scottish Dementia Working Group and honoured as a long-time campaigner on dementia rights and issues.

She is also a Vice Chairperson of the European Working Group of People with Dementia (EWGPWD), which she joined in 2012.

All the members of the EWGPWD and the staff and Board of Alzheimer Europe are very pleased for Agnes - we look forward to celebrating this achievement in Malta!



www.ScotlandsDementiaAwards.org.uk

AE Projects

1 September: EMIF launches project website



The EMIF (European Medical Information Framework) partners have launched a website that provides information on the activities and progress of the project.

EMIF is a five year project that aims to improve access to patient-level data by creating an environment that allows for efficient re-use of existing health data. A common information framework will link up and facilitate access to diverse medical and research data sources. The project includes two research topics that will help guide the development of the framework: the onset of Alzheimer's disease and the metabolic complications of obesity.

The Alzheimer's disease topic, known as EMIF-AD, aims to discover and validate biomarkers of AD onset in the preclinical and prodromal phases and also during disease progression. This will help to identify high-risk individuals and will facilitate drug development and clinical trial design.

Alzheimer Europe is a partner in the work packages "Sustainability and Outreach" and "Programme Management and Dissemination".

EMIF receives support from the Innovative Medicines Initiative Joint Undertaking (IMI-JU) under grant agreement n. 115372.

www.emif.eu

1 September: NILVAD reports on successful first period of project work



The NILVAD team recently submitted the first periodic report of the project to the European Commission. The report comprises all the deliverables and milestones of the first 18 months of the project.

NILVAD is conducting a Phase 3 clinical trial of Nilvadipine, a hypertension drug, for mild to moderate Alzheimer's disease. The main focus of the first period of work was to develop the set-up framework so that the trial could begin.

This huge task was successfully achieved and recruitment began in April 2013. As of 30 June, a total of 25 people have begun the trial at eight sites. A total of 500 participants in nine countries will take part in the double blind, placebo-controlled study.

If the NILVAD trial delivers a positive result there will be a significant impact from a treatment and quality of life perspective for the 5 million Europeans who suffer from Alzheimer's disease. There will also be a considerable socio-economic effect on the cost of care for people with Alzheimer's disease.

Another major aim of the NILVAD study is the creation of a cross-national network in Europe, which could be used to conduct future AD clinical trials. The current trial will also add to the existing body of information about Alzheimer's disease and will be another step forward towards developing an effective treatment for the disease.

The NILVAD project (2012-2017) has received support from the European Commission's Seventh Framework Programme.

www.nilvad.eu

European Alzheimer's Alliance

15 September: MEP Martina Anderson completes 10K Memory Walk



Alzheimer Europe wishes to thank Martina Anderson, MEP (UK) and member of the European Alzheimer's Alliance, for her support as she completed a 10 kilometre Memory Walk in her hometown of

Derry, Northern Ireland.

Ms Anderson was accompanied by several family members in what she called the "best turn-out yet for the Memory Walk in Derry." They endured the rainy conditions and completed the walk in support of her mother Betty, who has lived with Alzheimer's disease for nearly 14 years.

19 September: MEP Grossetête issues a message of hope on World Alzheimer's Day



On 19 September, Françoise Grossetête, MEP (France) and Chair of the European Alzheimer's Alliance, issued a statement to mark World Alzheimer's Day. The following is a translation of the original French-language statement.

More than seven million people are living with dementia in Europe - including over 850,000 people in France - and these figures are expected to double within 20 years. There is no cure and the last seven years have seen no new medicines to halt the disease.

However, the European Union is making significant financial contributions and there is a continuing effort to

foster collaboration among the best research minds and assets in every European country.

The new EU research programme will have more than EUR 80 billion at its disposal, of which over EUR 8.5 billion may be available for research into Alzheimer's and other neurodegenerative diseases in the period 2014-2020.

If we hope to meet the mounting challenges of dementia care, this type of initiative will have to become permanent policy rather than a time-bound project. This situation applies to EU institutions and also to national governments.

World Alzheimer's Day gives us the opportunity to express our appreciation for the efforts of patient associations and individual volunteers who strive to maintain and improve the quality of life of people with dementia and their caregivers. These efforts are an essential part of the fight against Alzheimer's disease and other forms of dementia.

As Chairperson of the European Alzheimer's Alliance, I call on each and every individual to take a moment to think about this disease and its challenges and consequences. I also heartily applaud the work of all the individual volunteers in all countries who are working together to raise awareness and increase our understanding of Alzheimer's disease.

The original French-language version is available on Ms Grossetête's website.

www.francoise-grossetete.eu/spip.php?article1601



21 September: MEP Griesbeck praises World Alzheimer's Day activities



Nathalie Griesbeck, MEP (France) and member of the European Alzheimer's Alliance, expressed her support to the French Alzheimer's disease community with a post on her website.

She pointed out that World Alzheimer's Day is an opportunity to stand back and reflect on the evolution of this disease that affects some three million people in France. This special day is also an opportunity to raise awareness about the support available to improve the quality of life of the people with Alzheimer's disease and their carers.

Ms Griesbeck gave particular praise to France Alzheimer for the association's unflagging efforts to provide better support for people with dementia - including the organisation of numerous events for World Alzheimer's Day. All of these events help to raise awareness and provide information to the public, but also serve as a call for solidarity toward people with dementia and their carers.

www.nathalie-griesbeck.fr/2013/09/journee-mondiale-contre-la-maladie-dalzheimer/#more-12028

22 September: MEP Anja Weisgerber is elected to the German Parliament



On 22 September, Anja Weisgerber, MEP (Germany) and member of the European Alzheimer's Alliance (EAA), was elected to the German Parliament and will therefore resign from the European Parliament.

Ms Weisgerber joined the EAA in 2006, one of the very first MEPs to join the European Alzheimer's Alliance. We wish her every success in her new position.

Alzheimer Europe Networking

On 2 September, Annette met Stefanija Lukic Zlobec of the Slovenian Alzheimer Association (Brussels, Belgium).

On 2 September, Gwladys attended a meeting with the AE Conference team (St Julian's, Malta).

On 11 September, Alex attended an EMIF project meeting (Brussels, Belgium).

On 16-18 September, Jean attended the WHO Regional Committee for Europe meeting as part of the ADI delegation (Izmir, Turkey).

On 17-20 September, Dianne attended the Université d'été "Alzheimer, éthique et société 2013" organised by the Espace National de Réflexion Éthique sur la Maladie d'Alzheimer" (Lille, France).

On 19 September, Annette went to an EFPIA Think Tank session (Brussels, Belgium).

On 25 September, Dianne attended a presentation at the Ambient Assisted Living Forum (Norrköping, Sweden).

On 25 September, Annette participated in the roundtable discussion on the pharmaceutical sector organised by J&J (Brussels, Belgium).

On 25-26 September, Jean attended the Patients' and Consumers' Working Party of the European Medicines Agency (London, UK).

On 30 September, Annette met Yves Brand, Mental Health Europe, to discuss the European Joint Action on Mental Health (Brussels, Belgium).

On 1 October, Annette attended the EPF official launch of its European elections political campaign (Brussels, Belgium).

On 2 October, Jean participated in the Innovative Medicines Lunch in the European Parliament (Brussels, Belgium).

On 3 October, Alex attended the EMIF WP15 workshop (Brussels, Belgium).

On 4 October, Dianne participated in the second meeting of the ethics working group on perceptions and the portrayal of dementia (Brussels, Belgium).

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at 70, representing 23 Member States of the European Union and all seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their continued support of the European Alzheimer's Alliance:

Austria: Becker K. Heinz (EPP), Werthmann Angelika (NI). **Belgium:** Demesmaeker Mark (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnoc Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP). **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). **Finland:** Jaakonsaari Liisa (S&D), Jäättelä Anneli (ALDE), Pietikäinen Sirpa (EPP). **France:** Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Juvin Philippe (EPP), Morin-Chartier Elisabeth (EPP), Pargneaux Gilles (S&D). **Germany:** Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP). **Greece:** Chountis Nikolaos (GUE-NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP). **Ireland:** Aylward Liam (ALDE), Childers Nessa (non-attached), Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP). **Italy:** Panzeri Pier Antonio (S&D), Toia Patrizia (S&D). **Lithuania:** Blinkevičiute Vilija (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Malta:** Cuschieri Joseph (S&D). **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP). **Poland:** Łukacijewska Elżbieta (EPP). **Portugal:** Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL). **Romania:** Antonescu Elena Oana (EPP), Busoi Cristian (ALDE), Sârbu Daciana Octavia (S&D), Tanasescu Claudiu Ciprian (S&D). **Slovakia:** Mikolasik Miroslav (EPP), Zaboriska Anna (EPP). **Slovenia:** Kleva Kekuš Mojca (S&D), Peterle Alojz (EPP). **Spain:** Badia i Cutchet Maria (S&D), Estaràs Ferragut Rosa (EPP). **United Kingdom:** Anderson Martina (GUE-NGL), Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), McCarthy Arlene (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

EU Developments

9 September: EP unveils its information campaign for the 2014 European elections

On 9 September, the European Parliament unveiled its information campaign for the European elections 2014 with the slogan "This time it's different".

The campaign logo, with the baseline "ACT.REACT.IMPACT." stresses that EU voters can exercise their power, through the ballot box, to determine the future shape of Europe.

The campaign began on 10 September and will continue beyond the elections, until the newly-elected Parliament in turn elects the next European Commission President. The campaign will have four phases:

- This phase began with the presentation of the baseline "ACT.REACT.IMPACT." It aims to explain the European Parliament's new powers and their implications for EU residents.
- The second phase will run from October 2013 to February 2014 and will highlight five key topics: the economy, jobs, quality of life, money and the EU in the world at a series of interactive events in European cities.
- Phase three, the election campaign proper, starts in February 2014. It will focus on the 22-25 May election dates. These dates will be added to the logo as the elections draw near.
- After the elections, the final phase will focus on the newly-elected European Parliament, its election of the next European Commission President and the inauguration of the new Commission.

<http://www.europarl.europa.eu/news/en/news-room/content/20130906IPR18827/html/European-Parliament-launches-information-campaign-towards-2014-elections>

13 September: Commission launches new innovation indicator

On 13 September, DG Research, Innovation and Science launched a new innovation indicator. The "Indicator of Innovation Output" measures the extent to which ideas from innovative sectors are able to reach the market, thus providing better jobs and making Europe more competitive.

The indicator was developed at the request of EU leaders to benchmark national innovation policies and shows that significant differences remain between EU countries.

The novelty of the indicator is that it focuses on innovation output. It complements the Commission's Innovation Union Scoreboard (IUS) and Summary Innovation Index (SII). These assess the innovation performance of Member States and the EU more widely, against a set of 24 innovation indicators including inputs, throughputs and outputs.

http://europa.eu/rapid/press-release_IP-13-831_en.htm

16 September: WHO Europe will pursue a mental health action plan



The WHO Regional Committee for Europe - the decision making body for the World Health Organization's European Region - held a meeting during 16-19 September in Izmir, Turkey.

The meeting was attended by more than 300 delegates from 51 Member States in the WHO European Region, international partners and nongovernmental organisations. Jean Georges, Executive Director of Alzheimer Europe, was present as part of the Alzheimer's Disease International (ADI) delegation.

The main foci of the meeting were the WHO's programmes on vaccination and prevention of communicable diseases. However, there were also discussions about non-communicable diseases and the European Mental Health Action Plan.

The Member States agreed on a European mental health action plan for 2014–2020, which will help countries improve their populations' mental well-being and reduce the burden of mental disorders. The plan has seven interlinked objectives and proposes integrated action.

[Sixty-third session of the WHO Regional Committee for Europe](#)

21 September: Tonio Borg salutes dementia patients and their carers



Tonio Borg, EU Commissioner for Health and Consumer Policy, issued the following statement on World Alzheimer's Day:

21 September is World Alzheimer's Day.

On this occasion, I wish to pay tribute to dementia patients and their caregivers, whose taxing journey deserves all our praise and support.

Every 4 seconds, a new case of dementia is diagnosed somewhere around the world. In Europe alone, dementia affects six million people. And yet, dementia and its countless sufferings are still vastly unknown. There is a tendency to associate dementia with recurrent memory loss only. However, there is much more to it.

Over time, people with dementia end up suffering deterioration of all their cognitive functions: memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. This makes dementia one of the major factors of disability and dependency in older people, overwhelming their lives as well as that of their caregivers to the point of social exclusion.

As the population ages, we expect dementia to affect 12 million people by 2040. It is no wonder then that dementia and its main cause, Alzheimer's disease, rank at the top of our public health agendas.

To help EU Member States address dementia, in 2011 the Commission launched a joint action - ALCOVE - to improve knowledge on dementia, and to foster exchanges on how to preserve health, quality of life, autonomy and dignity of people living with dementia and their carers. Earlier this year, ALCOVE produced a set of recommendations to health professionals and decision-makers in this regard.

There is cause for hope. Medical progress and the understanding of the brain are now well underway. However, much remains to be done at grass-root level. Raising awareness about dementia is necessary to give patients and their caregivers the support they need in their everyday struggles.

This is the purpose of national dementia action plans. While eight Member States have already adopted their plans, nine more countries are working on theirs or have committed to do so. I can only encourage the remaining Member States to follow suit.

I am confident that Dementia will remain one of our top health priorities for the decades to come and that, together, we will rise to its challenges.

http://ec.europa.eu/commission_2010-2014/borg/personally_speaking/index_en.htm

26 September: Parliament committee approves Horizon 2020 and COSME programmes

On 26 September, the Parliament's Industry and Research Committee approved the Horizon 2020 research and innovation programme and also the COSME programme for SMEs. Both programmes aim to attract new participants, strengthen support for small firms and better control EU spending.

The committee resolution states that a portion (EUR 817 million) of the Horizon 2020 budget will be used to widen the group of researchers participating in the programme, by attracting new applicants or promoting networking of research institutions. Public-private partnerships will also be opened up to new members and an additional EUR 462 million will fund measures to strengthen the role of science in society.

At least 11% of the Horizon 2020 budget should go to small and medium sized enterprises (SMEs) and special measures will ensure that calls for tenders are SME-friendly.

COSME (Competitiveness of Enterprises and small and medium-sized enterprises) is another programme approved by the Committee and is entirely dedicated to SMEs. Bureaucracy will be reduced and 60% of its budget will be earmarked for risk-capital or loan guarantees.

The committee members also stepped up controls on EU funding for public-private-partnerships (PPPs) and made sure that all EU-funded scientific publications are accessible to the public. They also agreed to provide the European Institute of Technology (EIT) its own budget of EUR 2.7 billion.

The final votes in the Parliament's plenary session and the Council of Ministers will take place once the EU's long-term budget has been approved. The budgets for the new programmes are expected to be EUR 77 billion for Horizon 2020 and EUR 2 billion for COSME for 2014-2020.

Six MEPs were involved in the committee negotiations, including two members of the European Alzheimer's Alliance (EAA):

Maria Da Graça Carvalho (Portugal), EAA member

Jürgen Creutzmann (Germany)

Christian Ehler (Germany)

Philippe Lamberts (Belgium)

Teresa Riera Madurell (Spain)

Marisa Matias (Portugal), EAA member

<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2F%2FEP%2F%2FNONSGML%2BIM-PRESS%2B20130617IPR12353%2B0%2BDOC%2BPDF%2B0%2F%2FENhttp://www.europarl.europa.eu/news/en/news-room/content/20130617IPR12353/html/EU-programmes-for-research-and-small-firms-in-2014-2020-approved>

26 September: Final FP7 grant provides EUR 660 million for research

On 26 September, the European Research Council awarded over EUR 660 million to 284 senior research leaders. They will carry out their research in 18 different countries across the European Research Area. With up to EUR 3.5 million per grant, the funding will enable them to pursue their most ground-breaking ideas together with their teams.

One particular project, led by Prof Sara Linse from Lund University (Sweden) seeks to understand the molecular mechanisms behind Alzheimer's disease. Prof Linse's MAMBA project has received funding of EUR 2.6 million and will conduct a very precise survey of all the molecular mechanisms through every step of the disease.

This was the last grant under the EU's Seventh Research Framework Programme (FP7). The next call will fall under Horizon 2020, the new Framework Programme.

http://erc.europa.eu/sites/default/files/press_release/files/press_release_adg2013_results.pdf

26 September: EMA working parties elect new Chairpersons

On 26 September, the Patients' and Consumers' Working Party (PCWP) and the Healthcare Professionals' Working Party (HCPWP) of the European Medicines Agency (EMA) elected new co-Chairpersons.

David Haerry of the European AIDS Treatment Group (EATG) is the new co-chair of the PCWP. He has been a member of the PCWP since 2006 and has 15 years of experience as an advocate for HIV patients' rights. He replaces Lise Murphy of the European Organisation for Rare Diseases (EURORDIS), who was co-Chair of the PCWP since 2010.

Gonzalo Calvo, Chair of the European Association for Clinical Pharmacology and Therapeutics (EACPT), is the new co-chair of the HCPWP. He is a consultant in clinical pharmacology in Barcelona and has extensive experience in medicines regulation, including nearly ten years as a member of the Agency's Committee for Medicinal Products for Human Use (CHMP). This is the first time that the HCPWP has elected a co-Chair, following its formal establishment last June.

David Haerry and Gonzalo Calvo will co-Chair these working parties for the next three years, together with Isabelle Moulon, Head of Patients and Healthcare Professionals at the EMA.

The main role of the PCWP and the HCPWP is to provide recommendations to the EMA and its scientific committees on all matters of interest to either patients or healthcare professionals in relation to medicinal products, as well as to monitor interactions between the Agency and patients, consumers and healthcare professionals.

Alzheimer Europe was accepted as a member of the PCWP on 26 July 2013 and will participate in the group's work until 2016.

www.ema.europa.eu/ema/index.jsp?curl=pages/contacts/CHMP/people_listing_000017.jsp&mid=WC0b01ac0580028d32

www.ema.europa.eu/ema/index.jsp?curl=pages/contacts/CHMP/people_listing_000032.jsp&mid=WC0b01ac0580028dd3

27 September: Competitiveness Council proposes nine new PPPs

On 27 September, the Competitiveness Council held a debate on the state of the Innovation Union strategy and on steps towards the completion of a common European Research Area.

The Council members took note of a presentation on a new generation of public and private partnerships (PPPs) that will implement major elements of the Innovation Union and other relevant EU strategies to stimulate the creation of growth and jobs. These PPPs will carry out large-scale and long-term innovation activities under Horizon 2020, the EU's next research framework programme.

The Council members proposed to set up five PPPs as Joint Technology Initiatives in the fields of bio-based industries, aeronautics, electronics, fuel cells and hydrogen and innovative medicines. They also proposed four new PPPs for research programmes jointly undertaken by member states with EU participation, in the areas of active and assisted living, clinical trials in African countries, metrology and research-performing SMEs.

http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/en/intm/138840.pdf

Members' News

1 September: Slovenia's Spominčica relaunches newsletter

The Slovenian Alzheimer Association has re-launched its newsletter after a two year hiatus. The first new issue of "Spominčica" - named after the association - had an initial print run of 18,000 copies with the aim of covering the entire country. It introduces the key players and activities of the association, including contact details for regional offices all around the country.

There are also articles that describe the symptoms of dementia and the involvement of Slovenian GPs with patients and their families. The first issue also features a comparison of temporary vs permanent care and a column that provides advice on living with dementia every day.

Spominčica is available for download on the association's website.

www.ljudmila.org/~zzppd/clanki/SPOMINCICANasaZena1.9.13.pdf

1 September: Alzheimer Nederland launches Music Memories campaign

Everybody has unforgettable music memories. Music coupled with moments of happiness, sadness and other important events in our lives. To raise awareness that Alzheimer's disease can erase even these most treasured memories, Alzheimer Nederland started a campaign to save those memories. Everybody can share

their music memory on the website of a national radio station and during some major public events. On Saturday 19 and 26 October, the campaign comes to an end on national television. The two fundraising programs will be devoted entirely to special stories, entertainment, celebrities, music and - of course - memories.

1 September: German alliance campaigns for patient and carer rights



The "Alliance for Good Care", which includes the German Alzheimer's society, ran an e-card campaign on behalf of patients and carers during Germany's recent federal elections.

The campaign urged citizens to send an e-card to the heads of all the political parties in the German Parliament. This card outlined the goals and demands of the alliance, including personalised services for patients and better benefits and recognition for carers. Senders could also add personal testimonials and other comments.

The alliance is composed of 30+ member associations and supporters, including associations representing the interests of people requiring care and family caregivers, welfare and social organisations, trade unions and professional associations. Together, they claim to represent 13.6 million individual members, including hundreds of thousands of people living in care, family caregivers and professional caregivers.

The ultimate aim of the alliance is to improve health care through solidarity-based financing. More details about the e-card campaign can be seen on the alliance's website.

www.buendnis-fuer-gute-pflege.de/die-kampagne/e-card/

5 September: Alzheimer Nederland hosts the Alzheimer's Society

On 5-6 September, the strategic leadership team of the UK Alzheimer Society paid a two day visit to the Netherlands. During their stay they visited an "Odensa house", which is an informal walk-in centre for people with dementia, their carers, friends and family where they can receive information about dementia and meet their peers. The houses are open five days a week and are run by volunteers.

The Alzheimer Society visitors also attended one of the 220 monthly Alzheimer Café meetings for patients and carers. On the second day, they visited the premises of Alzheimer Nederland for meetings to plan future cooperation and a general exchange of knowledge.



9 September: Cyprus Alzheimer Association holds musical memory evening

On 9 September, the Cyprus Alzheimer Association organised a musical event entitled "Memories" in the gardens of the Presidential Palace in Nicosia. The event

was held under the auspices of Ms Andri Anastasiades, First Lady of the Cypriot Republic.



In her welcoming speech, she praised the achievements of all volunteers in the association. Cypriot President Nikos Anastasiadis, elected in February 2013, was also present at the event. Antigoni Diakou, head of the Cyprus Alzheimer Association, invited the President to support the association in the fight against Alzheimer's disease by promoting the Cyprus National Dementia Plan.

Musical entertainment was provided by a skilled trio that played a set of old songs that are still beloved by all. This was symbolic of the long-term memories that people with dementia often retain and also to illustrate the important role that music can play to improve their quality of life.



10 September: Alzheimer's Society disputes claims of dementia screening



A recent article that appeared in the British Medical Journal caused some controversy in the UK. The article was entitled "Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis".

The Alzheimer's Society strongly disputed the claims made in the article. Chief Executive Jeremy Hughes said: "It's astounding to hear talk of an 'unwanted war' on dementia when in fact we need nothing less than an all-out fightback. We should be backing doctors up and down the country who are helping ensure people with dementia are diagnosed."

In a press release, the charity pointed out that population screening does not exist in the UK and there are no plans to introduce it. The charity supports the current case finding approach where clinicians ask those who are at a higher risk of developing dementia if they are worried about their memory and then refer them for appropriate tests if they are concerned.

Mr Hughes added: "There is surely no other condition where we could tolerate, let alone encourage people being kept in the dark, without treatments or support and unable to make decisions about their life."

www.bmj.com/content/347/bmj.f5125
www.alzheimers.org.uk/site/scripts/press_article.php?pressReleaseID=1017

12 September: Spain's CEFAA holds press conference for World Alzheimer's Day

CEFAA, the Spanish federation for Alzheimer's disease and other dementias, held a press conference entitled

"Alzheimer - A Matter of State" with government officials on 12 September, ahead of World Alzheimer's Day.

The main aims of the conference were to raise awareness of the status of people with Alzheimer's disease in Spain and to put forward a four-pillar programme to deal with the challenges of dementia in the future.



The conference speakers were Mr Koldo Aulestia, President of CEAFA, Ms Maria Angeles Aguado, an Executive from the Agency for Elderly People and Social Services and Mr José María Paz, Deputy Prosecutor

for the Protection and Defence of the Rights of Older Persons.

Mr Aulestia pointed out that dementia affects 3.5 and 4.8 million people in Spain - including people living with the affliction and their families - and that this number will likely double by 2030. He also explained the role of CEAFA and outlined why the country needs a sustainable and comprehensive national dementia plan.



CEAFA's four-pillar programme consists of the following main axes: support for families, legal protection, health and training for health professionals including caregivers. The programme

has been developed over several years, together with people with dementia and their families, health professionals and other dementia experts. Mr Aulestia said that CEAFA remains ready and willing to actively participate in any form of working group that will have a dementia strategy as its ultimate goal.

Mr Paz acknowledged that people with dementia often face legal challenges, particularly with regard to advance directives. He said that these could only be overcome if Spain were to introduce legislation that specifically addresses the needs of people with dementia. Unfortunately, support for such legislation is currently scarce due to lack of human and financial resources.

Ms Maria Angeles Aguado praised CEAFA for its many years of work in helping people with dementia and noted the excellent relationship between the association and local and national government agencies. She looks forward to continuing this cooperation as the partners pursue their goal of developing a national dementia strategy in Spain.

19 September: German Alzheimer's Association and DZNE join forces

The German Alzheimer's Association (DAIzG) and DZNE (the German Center for Neurodegenerative Diseases) have joined forces to develop joint information services for people with dementia and their families all over Germany.



DAIzG offers support and assistance for people with dementia and their families, while DZNE investigates the

causes of diseases of the nervous system and develops strategies for prevention, treatment and care. The partners have been working together on a local level since

2012 and this successful cooperation has led to the current national agreement.

Heike von Lützu-Hohlbein, First Chairperson of DAIZG, said: "This cooperation will enable us to combine our experience deriving from self-help activities with the scientific expertise of the DZNE.

"This expertise will provide the opportunity to network consultation services and make new insights from research more accessible to affected individuals. Ultimately we aim to improve the information and care available to people with dementia."

www.deutsche-alzheimer.de
www.dzne.de

20 September: Royal reception for dementia fundraising in Norway



Since 1974, an annual telethon has been hosted by the Norwegian National Broadcaster (NRK) to benefit a cause promoted by a chosen organisation. On 20 October 2013, 100,000 volunteers will visit every household in Norway to collect money for the Norwegian Health Association and their work to improve the lives of people with dementia.

His Majesty King Harald of Norway is the patron of this year's national fundraising event. On 20 September, the King received a delegation from the association. The delegation included Stig-Atle Aavik (see picture), Norway's representative to the European Working Group of People with Dementia, family carer Ann Iren Garmo Larsen and Wenche Frogn Sellæg, Chair of Norway's Dementia Board.

The King was very interested to hear the viewpoints and experiences of his guests and his support will clearly be of great benefit to the telethon - particularly in raising public awareness of dementia through the national media.



21 September: Belgium's LINAL holds Alzheimer Café Day celebration

The Belgian Ligue Nationale Alzheimer Liga (LINAL) held a special Alzheimer Café Day in the centre of Brussels to commemorate World Alzheimer's Day.



The all-day event was very well attended and has been a LINAL staple for many years. The Alzheimer Café Day is a day to share experiences, to bring back memories and to acknowledge the success of the Alzheimer Café meetings, which continue to increase in popularity and growth.

This year, LINAL introduced art therapy as a new event under the motto "Creativity and autonomy". Two

workshops, led by an art therapist, showed how people with dementia can express their creativity and increase their quality of life. There was also an exhibition of art produced by people with dementia. These works will be printed on cards and sent all around the world as part of a global campaign.



21 September: Alzheimer Portugal holds seven Memory Walks on WAD



Alzheimer Portugal held Memory Walks in seven cities to celebrate World Alzheimer's Day, under the motto "Remember Yourself".

This is the third year that the association organises Memory Walks and they have grown in popularity each year. The walks took place in Beja, Funchal, Ilha Terceira, Matosinhos, Oeiras, Pombal and Vila do Bispo.

In each location, staff from Alzheimer Portugal were on hand to inform participants that timely diagnoses and specialised services for people with dementia are still scarce realities in the country. The association also called attention to the importance of reducing the risk of developing Alzheimer's disease or another form of dementia.



21 September: Federazione Alzheimer Italia holds conference and award ceremonies on WAD



On 21 September, Federazione Alzheimer Italia (FAI) held a conference

entitled "Alzheimer's disease: information about care, research and support" at the Palazzo Marino, seat of the municipality of Milan. The conference commemorated World Alzheimer's Day and also the 20th anniversary of FAI.

Pierfrancesco Majorino, Councilor of Social Affairs and Culture of Health welcomed the participants. Gabriella Salvini Porro, President of FAI and Francesco Brancati, President of the National Association of Scientific Medical Media followed him. They delivered the journalism award for best coverage of Alzheimer's disease to the four winners of the 2013 edition.

Ms Salvini Porro, along with colleagues from the Italian Society for the study of dementias and the University of Milan, also presented awards to six young graduates in medicine and clinical psychology for their outstanding theses relating to Alzheimer's disease.

This was followed by a screening of the video "Living with dementia, the Alzheimer Café" and a presentation on the basic concepts of the Cafés and related guidelines.

The conference closed with a presentation by Marc Wortmann, Executive Director of ADI (Alzheimer's Disease International), who gave highlights of the newly released World Alzheimer Report 2013. Mr Wortmann pointed out that as the world population ages, the traditional system of "informal" care by family, friends, and community will not be sustainable. The new report predicts that the number of dependent older people will rise from 101 million in 2010 to 277 million in 2050, an almost threefold increase.

The conference attracted wide media coverage and was attended by family members of people with dementia, health professionals and members of the public who wished to better understand the challenges of Alzheimer's disease.



21 September: Cyprus opens first dementia day care centre



On 21 September, the Cyprus Alzheimer Association opened the country's first Day Care Centre for people with Alzheimer's disease in Limassol. The new facility was officially inaugurated by Mr Andreas Christou, mayor of Limassol while his Eminence Bishop of Limassol Mr Athanasios blessed the building.

The Day Care Centre will offer services such as non-pharmaceutical interventions, group activities and support groups for caregivers and family members of people with dementia.

21 September: Alzheimer Hellas fills September with WAD events



The Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) filled the month of September with events that were open to the public and free of charge to commemorate World Alzheimer's Day.

The month started with an Awareness Week from 2-8 September in Neapolis, where the association manned a stand that provided information about dementia to the public. This was followed by a photo exhibition entitled "Memento" that took place between 11-20 September at

a famous archaeological site. Three photographers displayed collections from a trip to India that had clear references to the function of memory "that comes from experience, facts and any human activity".

Alzheimer Hellas also operated a stand in central Thessaloniki during 16-21 September, where staff provided information and raised awareness about dementia and Alzheimer's disease. They also gave a demonstration of cognitive training with the use of tablet computers and distributed a short test to older members of the public.

On World Alzheimer's Day, a chess tournament for players of all ages took place in a local college. The tournament was organised in collaboration with local chess clubs to demonstrate that chess and other mind games can reduce the risk of dementia. The final activity was a Memory Walk on 23 September. This took place in central Thessaloniki and was followed by a presentation on the latest data about dementia.

Throughout the month, local and national radio and TV stations aired special spots about the World Alzheimer's Day events and staff from Alzheimer Hellas participated in numerous press interviews.



21 September: Slovenian Memory Walk raises awareness of dementia

Slovenia's Spominčica organised a very popular Memory Walk to commemorate World Alzheimer's Day.



A large number of people joined on the walking tours in various Slovenian cities. In the capital, the walk was held under the patronage of the Mayor of Ljubljana. He joined the walkers for the entire tour and also sponsored a reception for them at the town hall. Along the way, members of the association provided information about dementia and also distributed the new issue of the Spominčica newsletter, which was recently re-launched.

The Memory Walk was preceded by an Alzheimer Café meeting, which took place on 20 September. This meeting featured a presentation by Dr. Ales Kogoj, President of Spominčica, who was also pleased to welcome several special guests. These included Professor Nino Mimica, head of Croatia's Alzheimer's Disease Societies and Guillermo Nagore, the Spanish journalist who in 2012 walked from Santiago de Compostela to Jerusalem in order to raise awareness for Alzheimer's disease.

Dr. Kogoj and all the other members of the association are very pleased with the large turnout to the Memory Walk in support of people with dementia and their families.



21 September: Alzheimer Uniti Italy organises full week of activities for World Alzheimer Day



The week started on 18 September with a visit by people with Alzheimer's disease, their families and all the staff of the Association to the Wednesday audience of Pope Francesco, who gave an address including a welcome to our very group!

Friday 20 September was the occasion of our 15th Annual Alzheimer Convention at the Campidoglio in Rome entitled "Dementia within a welcoming community". This year the new mayor of Rome, Ignazio Marino (a medical doctor), opened the day by saying that he gives his support to efforts to help people suffering from dementia. The presentations were on the subjects of new scientific research, dementia medications, technology, nutrition, problems of limited resources and palliative care.

On Saturday 21 September, we had our stand in the beautiful piazza San Lorenzo in Lucina, where we gave out information to the public, with the usual accompanying entertainment by the Carabinieri Band.

To complete the busy week, we opened our 5th Alzheimer Café on Monday 23 September in the heart of Rome.



23 September: Dutch documentary on dementia airs on national TV

On 23 and 24 September, a new documentary entitled DementieEnDan ("Dementia, and then...") aired on national Dutch television. This beautiful and moving work is about living with dementia, including all the barriers but also the possibilities.

The film was produced by Ireen Ditschuyzen and follows five people with dementia and their partners. We see the

uncertainty after a brain scan that shows deterioration, but also the triumph after running a half marathon. We see a pianist in ecstasy behind her piano and then her anxiety as she is admitted to a nursing home.

The broadcast was part of a week-long, national "DementieEnDan" campaign that raised awareness about Alzheimer's disease. Alzheimer Nederland was a partner in this campaign.

www.dementieendan.nl

Policy watch

21 September: French Ministers announce update on new neurodegenerative disease plan



In a joint announcement, three French Ministers expressed their support for people with dementia and their carers on World Alzheimer's Day. Marisol Touraine (Social Affairs and Health Minister), Geneviève Fioraso (Minister for Higher Education and Research) and Michèle Delaunay (Minister for the Elderly and Autonomy) also provided an update on the progress of the new "Neurodegenerative Plan". This will be the continuation of France's pioneering Plan Alzheimer.

Following the evaluation of the 3rd Plan Alzheimer (2008-2012) by Professors Joël Ankri and Christine Van Broeckhoven, four thematic working groups are being formed to identify the measures and actions of the new plan. The themes are:

- 1) Improve diagnosis and early detection of the disease
- 2) Respond to patients' needs at each stage of the disease and in the entire country
- 3) Increase awareness and conform to the highest standards of ethics, quality and welfare
- 4) Increase the quantity and quality of research.

The working groups will co-Chaired by the three Ministers and various other stakeholders, including patient organisations, will also be involved. France Alzheimer has already contributed 15 recommendations that the organisation would like to see in the new plan.

The new Neurodegenerative plan is expected to be finalised in the first quarter of 2014.

<http://www.social-sante.gouv.fr/actualite-presse,42/communiqués,2322/la-journee-mondiale-de-la-maladie,16249.html>

Science Watch

28 August: Scientists develop "miniature brains" from stem cells

A team of Austrian scientists has grown a number of "miniature brains" in a laboratory. These cerebral organoids are roughly comparable to the brain development of a nine-week old human foetus but are incapable of thought.

The researchers from the Institute of Molecular Biotechnology of the Austrian Academy of Sciences (IMBA) used either embryonic stem cells or adult skin cells

to produce the neuroectoderm - the part of an embryo that develops into the brain and spinal cord.

This was placed in tiny drops of gel that provided a scaffold for the tissue to grow and then into a bath supplying nutrients and oxygen. As the cells grew, they developed into separate regions of the brain. The organoids reached a maximum size of approximately four millimetres in two months and have survived for one year.

Dr. Jürgen Knoblich, Deputy Director and Senior Scientist at IMBA, said: "What our organoids are good for is to model development of the brain and to study anything that causes a defect in development. Ultimately we would like to move towards more common disorders like schizophrenia or autism. They typically manifest themselves only in adults, but it has been shown that the underlying defects occur during the development of the brain."

Dr. Paul Matthews, Professor of Clinical Neurosciences at Imperial College, London, commented: "I think it's just mindboggling. The idea that we can take a cell from a skin and turn it into, even though it's only the size of a pea, is starting to look like a brain and starting to show some of the behaviours of a tiny brain, I think is just extraordinary. Now it's not thinking, it's not communicating between the areas in the way our brains do, but it gives us a real start and this is going to be the kind of tool that helps us understand many of the major developmental brain disorders." Dr. Matthews was not involved in the study.

www.nature.com/nature/journal/v501/n7467/full/nature12517.html
www.youtube.com/watch?v=ir0HETfH978

1 September: Dr. Giovanni Frisoni, new Professor of Clinical Neuroscience HUG



On 1 September, Dr. Giovanni Frisoni took up the chair of full Professor of Clinical Neuroscience at Geneva University Hospitals (HUG) in Switzerland, where he will lead the local Memory Clinic.

He will continue to work as Deputy Scientific Director of IRCCS Fatebenefratelli on a part-time basis for at least the coming 2 years.

Dr. Frisoni has been a keynote speaker at several Alzheimer Europe Conferences and is a frequent contributor to our newsletter and Dementia in Europe magazine. Alzheimer Europe wishes him all the best in his new position.

2 September: Protein blocker restores memories in mouse models

Scientists at Yale School of Medicine have shown that blocking the activity of the mGluR5 protein with an existing drug can restore memory in mouse models.

This protein is one link of a chain of various proteins that build up in the brain and eventually interfere with cognitive function. Researchers believe that blocking mGluR5 may break the entire chain and thus prevent further buildup.

The drug in question is similar to one being developed to treat Fragile X syndrome. The study was led by Dr.

Stephen Strittmatter, Professor of Neurology and Neurobiology at Yale. He said: "What is very exciting is that of all the links in this molecular chain, this is the protein that may be most easily targeted by drugs. This gives us strong hope that we can find a drug that will work to lessen the burden of Alzheimer's."

[www.cell.com/neuron/abstract/S0896-6273\(13\)00552-7](http://www.cell.com/neuron/abstract/S0896-6273(13)00552-7)

2 September: HSPG receptors cause transmission of faulty tau proteins

Scientists at the Washington University School of Medicine (WU) in St. Louis (Missouri) have found that HSPG receptors are responsible for allowing misfolded tau proteins to move between cells. When these receptors were disabled, the tau proteins could no longer spread and form into tangles.

HSPGs, or heparan sulfate proteoglycans, are carbohydrate molecules that bind themselves to proteins and regulate activities such as blood coagulation and tumour metastasis.

In this case, the researchers showed that HSPGs are essential for binding, internalising and spreading clumps of tau. When the HSPGs were genetically disabled or chemically modified, clumps of tau could not enter cells, thus inhibiting the spread of misfolded tau. This was also the case for corrupted forms of alpha-synuclein, a protein linked to Parkinson's disease.

Dr. Marc Diamond, senior author and Professor of Neurology at WU, said: "Many of the enzymes that create HSPGs or otherwise help them function are good targets for drug treatments. We ultimately should be able to hit these enzymes with drugs and potentially disrupt several neurodegenerative conditions.

"We're now sorting through about 15 genes to determine which are the most essential for HSPGs' interaction with tau. That will tell us which proteins to target with new drug treatments."

www.pnas.org/content/110/33/E3138.abstract?sid=3e9bfd41-58f9-4a88-b4cf-3204031a7948

10 September: Incontinence is more likely in people with dementia

A new cohort study indicates that incontinence is more prevalent in people with dementia. The study also showed that people with dementia and incontinence were more likely to receive incontinence medications and indwelling catheters.

The study was made by scientists at Kingston University and St George's University of London, who analysed 250,000 primary care records. They found that people with dementia experience three times the rate of diagnosis for urinary incontinence and more than four times the rate of fecal incontinence than those without dementia.

Robert Grant, lead author and Senior Lecturer in Health and Social Care Statistics in both universities, said: "Incontinence is a common problem for people living with dementia in the community. They need good quality services, including advice and support for carers managing incontinence. With an ageing population, providers and

planners of dementia services should anticipate high levels of need.

"Some aspects of clinical management of urinary incontinence are different for patients with dementia compared with those without. Further study is required to understand the clinical reasoning of health care practitioners providing care for this population, particularly in the use of indwelling catheters, given the known risks."

www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001505

11 September: New clinical trial of liraglutide for Alzheimer's disease

Imperial College in London has announced a new clinical trial of liraglutide, an existing drug in use for treating diabetes.

Researchers at Lancaster University (UK) recently showed that liraglutide reduces the buildup of plaque in Alzheimer mouse models in an advanced stage of the disease. The treated mice also performed better on object recognition tests. A previous study had shown improvements in mice with early stages.

The trial, which will receive funding from the UK Alzheimer's Society, will recruit up to 200 participants and will be led by Dr. Paul Edison, a Clinical Senior Lecturer in Neuroscience at Imperial College.

Dr. Doug Brown, director of research and development at Alzheimer's Society, said: "Our focus on re-purposing existing drugs as dementia treatments is an incredibly exciting way of bringing new treatments closer. This exciting study suggests that one of these drugs can reverse the biological causes of Alzheimer's even in the late stages and demonstrates we're on the right track. We're now funding a major new trial to bring it closer to a position where it can be improving the lives of people with dementia."

Liraglutide is a glucagon-like peptide-1 agonist (GLP-1 agonist) developed by Novo Nordisk for the treatment of type 2 diabetes. It has been marketed in Europe as Victoza since 2009.

www.sciencedirect.com/science/article/pii/S0028390813003626



www.alzheimer-europe.org/Donation

16 September: Beta-amyloid fibrils are distinct for each person

A team of scientists have isolated distinct molecular structures of beta-amyloid fibrils in the brains of various people with Alzheimer's disease at different stages of the disease. These may assist in the development of diagnostic imaging and also more patient-specific treatments.

The researchers from University Hospital Zürich and the Stanford University School of Medicine were funded by the American NIH. They extracted beta-amyloid fibril fragments from the brain tissue of two patients with

different clinical histories and degrees of brain damage. They used these fragments to grow a large quantity of fibrils in a dish. The results were that a single fibril structure prevailed in the brain tissue of each patient, but the molecular structures were different between the two patients. These results support three conclusions:

- Fibrils in the brain may spread from a single site.
- Structural variations in the fibrils may correlate with variations in AD.
- Structure-specific amyloid imaging agents may be an important future goal.

Dr. Robert Tycko, senior study author and NIH researcher, said: "This work represents the first detailed characterization of the molecular structures of beta-amyloid fibrils that develop in the brains of patients with Alzheimer's disease.

"This detailed structural model may be used to guide the development of chemical compounds that bind to these fibrils with high specificity for purposes of diagnostic imaging, as well as compounds that inhibit fibril formation for purposes of prevention or therapy."

[www.cell.com/abstract/S0092-8674\(13\)01029-5](http://www.cell.com/abstract/S0092-8674(13)01029-5)

18 September: NIH approves new funding for AD clinical trials

On 18 September, the American National Institutes of Health (NIH) announced new funding of USD 45 million (EUR 33.3m) for Alzheimer's disease research.

The bulk of the funds will support therapeutic prevention trials in cognitively healthy populations at high risk of developing AD. Smaller awards will fund translational research to identify new therapeutic targets by creating network models of Alzheimer's disease.

The largest award of USD 33.2 million (EUR 24.5m) will partially fund a clinical trial that will be conducted by the Banner Alzheimer's Institute in Phoenix, Arizona. This trial will test whether an anti-amyloid therapy can slow cognitive decline in 650 cognitively healthy people between 60 and 75 years old. All participants will have two copies of the ApoE4 gene variant, which puts them at higher risk of developing Alzheimer's disease.

This trial will be led by Dr. Eric Reiman, Professor of Psychiatry at the University of Arizona and Dr. Pierre Tariot, Geriatric Psychiatrist and Director of the Banner Institute. They are in the process of selecting the pharmaceutical partner and the drug for the trial, which will start in early 2015. Banner is a non-profit health organisation that cooperates closely with the University.

The Dominantly Inherited Alzheimer Network (DIAN) will also receive funding. This involves a trial of gantenerumab and solanezumab in people who carry Alzheimer's disease mutations and will also test other drugs in related biomarker studies.

The four year trial is already recruiting participants and is led by Dr. Randall Bateman, Professor of Neurology at Washington University in St. Louis, Missouri. DIAN is an international research partnership of 13 institutions in Australia, Germany, the UK and the US that is investigating dominantly inherited Alzheimer's disease.

Solanezumab will also be tested in the Anti-Amyloid in Asymptomatic Alzheimer's Disease (A4) trial, where the drug will be administered to cognitively healthy people with biomarker evidence of Alzheimer's disease.

For more details on these and other research projects that are receiving funding from the NIH, please consult the Alzheimer Research Forum website.

www.alzforum.org/new/detail.asp?id=3597

19 September: New scan technique shows tau in living humans

A Japanese research team has developed a class of tau ligands called PBBs that are very effective in detecting tau tangles in PET scans of brains of living people.

Ligands are molecules that attach themselves to other molecules for a particular task. In this case, the new complex molecules become visible in PET scans. They are based on PBBs, or phenyl/pyridinyl-butadienyl-benzothiazoles/benzothiazoliums.

The scientists from the National Institute of Radiological Sciences (NIRS) in Chiba specifically cited the ligand [11C]PBB3 as a key player in creating a 3D picture of tau in the brain.

Dr. Makoto Higuchi, a researcher at NIRS, said: "Positron emission tomography images of tau accumulation provide robust information on brain regions developing or at risk for tau-induced neuronal death."

www.sciencedirect.com/science/article/pii/S089662731300799X

27 September: Two ADAM10 gene mutations increase A β load in mice

Researchers from Massachusetts General Hospital have identified two mutations in the ADAM10 gene that increase the production and accumulation of beta amyloid in the brains of late-onset Alzheimer mouse models. The mutations also inhibited growth of new neurons in the hippocampus.

The research team was led by Dr. Richard Tanzi, Professor of Neurology at Massachusetts General. According to the scientists, this is the second gene with a confirmed role in late-onset Alzheimer's disease and the fifth gene overall linked to the disease.

Dr. Tanzi said: "What we found regarding the many effects of these two rare mutations in ADAM10 strongly suggests that diminished activity of this enzyme can cause early-onset Alzheimer's disease, and these findings support ADAM10 as a promising therapeutic target for both treatment and prevention."

[www.cell.com/neuron/abstract/S0896-6273\(13\)00794-0](http://www.cell.com/neuron/abstract/S0896-6273(13)00794-0)

Dementia in Society

19 September: Terry Pratchett chastens UK government's dementia policy



Novelist Sir Terry Pratchett has accused the Government of "pussy footing" around on dementia treatment and withholding vital research funds.

Writing in a blog entry on the UK

Alzheimer's Research website, the famous author also said that the government was providing dementia research with "barely enough money to buy a middling Premier League striker".

Terry Pratchett, aged 65, was diagnosed with a variant of Alzheimer's disease called posterior cortical atrophy in 2007 and became a patron of Alzheimer's Research UK in 2008. He has become an ardent campaigner for higher awareness and more research for dementia.

In his blog entry, he said that care services were forced to "paper over the cracks" of a lack of funds and that science needs to deliver on its promises.

"If we're serious about this thing, and want to match the fanfare with the funding, then more money needs to be found down the back of David Cameron's sofa."

www.dementiablog.org/terry-pratchett-on-dementia/

New Publications & Resources

1 September: New MSc course in counselling and dementia care



The Association for Dementia Studies and the Psychology Department at the

University of Worcester (UK) have developed an MSc Counselling course. This is designed to give people the knowledge that underpins therapeutic counselling and dementia care.

The course is open to those who have particular interest in counselling, for further development with a view to professional training in counselling or clinical psychology.

It is also pertinent for those working in Health and Social Care, including those with an interest in dementia care, wishing to extend their knowledge and research base in psychological approaches to care and psychological function.

For more information, please contact Dr Peter Forster at pforster@worc.ac.uk

www.worcester.ac.uk/courses/counselling-msc.html

1 September: EC seeks entries for 2013 EU Health Prize for Journalists

The European Commission is calling for submissions for its 2013 "EU Health Prize for Journalists". This is the fifth edition of the prize, which is awarded to stimulate high-quality journalism that raises awareness of issues related to healthcare and patients' rights.

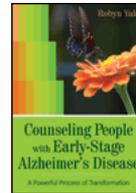
This year, the theme is "Europe for Patients". Journalists are encouraged to submit their articles published in print or online media in any EU Member State, including Croatia, until the deadline of 30 September 2013.

http://ec.europa.eu/health-eu/journalist_prize/

18 September: New counselling book aims at early dementia

A new book on counselling has been released by author Robyn Yale. "Counseling People with Early Stage Alzheimer's: A Powerful Process of Transformation"

introduces a new model for professionals who are helping people navigate this difficult chapter of their lives.



According to the author, most people with early dementia do not have access to individualised interventions for education and support. This book shows how this counselling model can empower the person to move towards acceptance of the illness while learning to manage and adapt to it. Given the opportunity to express feelings and concerns, people can gain valuable insights and the courage to acknowledge their impairments while also focusing on their abilities. The book also includes personal accounts of sessions between people with early dementia and their counsellors.

"Counseling People with Early Stage Alzheimer's: A Powerful Process of Transformation" is Ms Yale's second book. Her earlier work discussed the development of support groups for people with early-stage Alzheimer's disease. Both are available for sale at the Health Professions Press website.

www.healthpropress.com/store/yale-70071

19 September: ADI releases World Alzheimer Report 2013



Alzheimer's Disease International (ADI) has released its annual World Alzheimer Report 2013 entitled "Journey of Caring: An analysis of long-term care for dementia".

The report reveals that, as the world population ages, the traditional system of "informal" care by family, friends, and community will require much greater support. Globally, 13% of people aged 60 or over require long-term care. Between 2010 and 2050, the total number of older people with care needs will nearly treble from 101 to 277 million.

Long-term care is mainly about care for people with dementia; around half of all older people who need personal care have dementia, and 80% of older people in nursing homes are living with dementia. The worldwide cost of dementia care is currently over USD 600 billion (EUR 444b), or around 1% of global GDP.

The 2013 report makes the following recommendations:

- Governments around the world should make dementia a priority by implementing national plans, and by initiating urgent national debates on future arrangements for long-term care.
- Systems should be in place to monitor the quality of dementia care in all settings – whether in care homes or in the community.
- Autonomy and choice should be promoted at all stages of the dementia journey, prioritising the voices of people with dementia and their caregivers.
- Health and social care systems should be better integrated and coordinated to meet people's needs.
- Front-line caregivers must be adequately trained and systems will need to be in place to ensure paid and unpaid carers receive appropriate financial reward in

order to sustain the informal care system and improve recruitment and retention of paid carers.

- Care in care homes is a preferred option for a significant minority – quality of life at home can be as good, and costs are comparable if the unpaid work of family caregivers is properly valued.
- The quality of care in care homes should be monitored through the quality of life and satisfaction of their residents, in addition to routine inspections, as care homes will remain an important component of long-term care.

The report was researched and authored by Prof Martin Prince, Dr Matthew Prina and Dr Maëlynn Guerchet on behalf of the Global Observatory for Ageing and Dementia Care, which is hosted at the Health Service and Population Research Department, King's College London. The report was funded by a grant from Bupa.

www.alz.co.uk/research/WorldAlzheimerReport2013.pdf

21 September: Australian film shows the importance of social interaction for people with dementia

A new short film named "Love, Loss and Laughter: Seeing Dementia Differently" has been released in Australia. The film was produced by Corinne Maunder and is evidence of her devotion to her grandmother, who has been living with dementia for 15 years.

The 16-minute film shares the story of an eponymous photo exhibition that is currently on tour in Australia. The exhibition includes some 100 photographs of people living with dementia. The images offer a unique, compassionate and positive portrayal of people living with dementia - illustrating that they continue to have needs around social interaction and engagement in much the same way as everybody else.

<http://www.fightdementia.org.au/film-festival-finalist-captures-the-emotions-of-dementia.aspx>

26 September: The Parliament Magazine issues special dementia feature

The Parliament magazine has published a special supplement on dementia in its September issue. The 16-page feature contains a series of interviews with notable EU figures, MEPs and various experts in dementia, including the following:

- Tonio Borg, European Commissioner for Health and Consumer Policy, states that the fight against

dementia must be high on national and EU health agendas.

- Máire Geoghegan-Quinn, European Commissioner for Research, Innovation and Science, explains that investments in research, innovation and awareness are all needed to overcome the societal challenges of dementia.
- Marina Yannakoudakis, MEP (UK) and Vice Chairperson of the European Alzheimer's Alliance (EAA) argues that EU funding for research must be directed into treatments for Europe's great health challenges.
- Angelika Werthmann, MEP (Austria) and also an EAA member, points out that policymakers have a duty to work with dementia patients, carers and relatives to develop innovative and practical solutions.
- Jean Georges, Executive Director of Alzheimer Europe, praises the considerable progress of recent years but also stresses the continuing need for European collaboration on dementia.

The special supplement can be seen on The Parliament Magazine's website.

www.theparliament.com/digimag/dementiasupplement



Contact Alzheimer Europe:
 Alzheimer Europe, 145 route de Thionville, L-2611, Luxembourg
info@alzheimer-europe.org, www.alzheimer-europe.org
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 Executive Director: Jean Georges; EU Public Affairs Officer: Annette Dumas; Administrative Assistant: Kate Ellis; Editor – Dementia in Europe Magazine: Julie Fraser; Information Officer: Dianne Gove; Conference and Event Coordinator: Gwladys Guillory; Communications Officer: Alex Teligadas; Administrative Assistant: Grazia Tomasini.

AE Calendar 2013

Date	Meeting	AE Representative
10-12 October	23rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", AE Board meeting and Annual General Meeting (St Julian's, Malta)	AE Board members and AE Staff
13 October	Mediterranean Alzheimer Alliance Meeting (St Julian's, Malta)	Alex
15 October	Carers Interest Group meeting in the European Parliament (Brussels, Belgium)	Annette
17 October	Meeting organised by Sirpa Pietikäinen (MEP, Finland) with national constituents (Brussels, Belgium)	Annette

Future Conferences

Date	Meeting	Place
5-9 October 2013	26 th ECNP (European College of Neuropsychopharmacology), www.ecnp-congress.eu	Barcelona, Spain
10-12 October 2013	23rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", www.alzheimer-europe.org/EN/Conferences	St. Julian's, Malta

17-19 October 2013	CAG2013: Aging...from Cells to Society, http://cag2013.ca/prospectus	Halifax, Canada
17-20 October 2013	8 th International Congress on Vascular Dementia – ICVD 2013, www.kenes.com/icvd	Athens, Greece
24-25 October 2013	Colloque Cesco 2013: Ensemble dans l'action: les outils en soutien aux personnes atteintes de la maladie d'Alzheimer, www.iugm.qc.ca/index.php/fr/prof/formationcontinue/colloque/289-cesco.html	Montréal, Canada
25-27 October 2013	6th International Conference on Alzheimer's Disease and Associated Disorders in the Middle East, www.alzheimermiddleeastconference.org	Istanbul, Turkey
14-16 November 2013	6th annual conference Clinical Trials for Alzheimer's disease CtAD 2013, www.ctad-alzheimer.com	San Diego, USA
8-9 December 2013	2 nd Middle East and North Africa Conference of Alzheimer's Disease International, www.adidubai2013.org	Dubai, UAE
11-14 December 2013	The 16 th Asia Pacific regional Conference of Alzheimer's disease international, www.aprc2013-hongkong-macau.com	Hong Kong & Macau, China
20-22 March 2014	58 th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), www.dgkn-kongress.de	Berlin, Germany
20-23 March 2014	30 th International Congress of Clinical Neurophysiology of the IFCN (ICCN), www.iccn2014.de	Berlin, Germany
26-29 March 2014	13th Int. Geneva/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Geneva, Switzerland
8-11 May 2014	8th World Congress on Controversies in Neurology (CONY), http://www.comtecmed.com/cony/2014/	Berlin, Germany
26-27 June 2014	International Dementia Conference, Risky Business 2 – this time it's personal! http://www.dementiaconference.com/call-for-papers	Sidney, Australia
5-9 July 2014	9 th FENS Forum of Neuroscience, http://forum.fens.org/2014	Milan, Italy
20-22 October 2014	24th Alzheimer Europe Conference "Dignity and autonomy in dementia", http://www.alzheimer-europe.org/Conferences	Glasgow, United Kingdom
23-25 October 2014	9 th International Conference on Frontotemporal Dementias, www.ubccpd.ca	Vancouver, Canada

23rd Alzheimer Europe Conference
 Living well in a dementia-friendly society
 St. Julian's, Malta, 10-12 October 2013
 Mark the dates!

www.alzheimer-europe.org/conferences








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