



NEWSLETTER

October 2013

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Editorial

Thank you to all the sponsors, presenters and delegates that came to St. Julian's and made our 23rd Conference a huge success!



This was the best-attended AE conference of the past several years - and probably the warmest as well. We are especially grateful to the Maltese government and EU officials who gave us exceptional support and provided ample evidence of Malta's commitment to combat dementia on national and European levels.

This newsletter provides an overview of the conference. Extensive coverage will follow in the next issue of the Dementia in Europe magazine. Meanwhile, many presentations, pictures and videos have already been posted on the AE website.

AE also held a successful Annual General Meeting in Malta, where delegates approved the accession of AMPA Monaco and FAAS Iceland as full members of Alzheimer Europe. We extend a warm welcome to our new members and look forward to working with them.

Among our other members, Portugal and Switzerland recently celebrated 25 year anniversaries and both associations also report good progress towards their respective national dementia plans. France's new plan for neurodegenerative diseases is also progressing and may include some of the 15 recommendations made by France Alzheimer. In addition, CEFAA recently made a new proposal for a dementia plan to the Spanish government. Finally, we report on the latest activities of the Mediterranean Alzheimer's

Alliance, which now includes nine AE members.

In Brussels, we were pleased to welcome Ms Susy De Martini, MEP (Italy) to the European Alzheimer's Alliance. In addition, the EU enacted a new directive on patients' rights that defines the rights of EU citizens to choose where they receive medical treatment and to be reimbursed no matter where they live.

On the scientific front, the European Medicines Agency is updating its treatment guidelines for both Alzheimer's disease and amyotrophic lateral sclerosis. The EMA also issued a new symbol to clearly identify medicines that are subject to additional monitoring. In addition, the JPND announced two imminent calls that will fund research for neurodegenerative diseases. Prof Philippe Amouyel, Chair of the JPND Board, also made the news as lead author of a study that identified 11 new genes linked to Alzheimer's disease.

In this issue, we also report on a number of interesting new resources. WHO Europe published its European Mental Health Plan and the EU produced a new public health brochure. Janssen and Deloitte released a joint report on European health R&D and there is also an Australian guide to managing BPSD. In addition, Fondation Médéric Alzheimer has published an English-language version of their very popular report on the benefits of outdoor spaces and gardens for people with dementia.

Finally, we would like to thank all the contributors to our European Dementia Monitor project. The initial results will be presented in the European Parliament at our next lunch debate on 3 December.

Jean Georges
Executive Director

Alzheimer Europe

4 October: Ethics working group meets in Brussels

On 4 October, the ethics working group held its second meeting to discuss the first draft of the report on the ethical issues linked to the way that dementia is perceived and portrayed.

The participants (listed below) were from a wide range of backgrounds linked to ethics and dementia. They debated the ethical implications surrounding various topics such as explanatory models of dementia, strategic communication and the use of metaphor, to name but a few, and reworked the structure and content of the future report.

- Dr Debby Gerritsen
- Ms Bénédicte Gombault
- Dr Dianne Gove
- Dr Fabrice Gzil
- Ms Jana Kasparkova
- Prof. Jan Oyebo
- Dr Christine Swane
- Associate Prof. Baldwin Van Gorp
- Ms Aino Valtanen
- Dr Daphne Wallace (UK)

9 October: EWGPWD holds preparatory meeting for the Alzheimer Europe Conference

The European Working Group of People with Dementia met on 9 September 2013 in Malta to prepare their participation in Alzheimer Europe's Annual Conference.

The group, chaired by Helga Rohra, prepared their presentations for the symposium "Nothing about us without us", where conference delegates could hear their key messages based on their personal experience of dementia and ask questions. The members of the group wanted to help reduce the fear associated with dementia, focus on remaining capacities and show that people with dementia have a role to play in society. The group also helped Nina Baláčková prepare for her speech in one of the plenary sessions.

All the members agreed that it was important to be easily recognisable as a member of EWGPWD. For this reason, they had arranged to wear special green access badges. They also agreed on how to organise their stand and on who would be present to greet and inform participants. Everyone had a role to play, including the distribution of copies of the newly created information sheet about the group.



10 October: INTERDEM holds meeting in Malta

The INTERDEM group met on 10 October in Malta prior to Alzheimer Europe's annual conference. New members made short presentations about their research interests and work and were welcomed to the group. This was followed by presentations of members' updated publications.

In the afternoon, INTERDEM held its business meeting which focused on on-going projects, collaboration with other groups and the creation of a website taskforce, as well as of an INTERDEM PhD exchange programme - see link below. The meeting ended with workshops on positive outcomes and technology.

www.interdem.org/index.php/home/interdem-news/171-phd-exchange-programme-interdem

10 October: AE holds Board meeting in Malta

On 10 October, the Alzheimer Europe Board convened in St. Julian's, Malta. All the Board officers and four of six Board members were present, along with guests Gerry Martin, CEO of the Alzheimer Society of Ireland and Marc Wortmann, Executive Director of ADI.

Amongst other activities, the Board members adopted AE's 2012 Annual Report and agreed to submit the 2014 work plan and budget for approval to the Annual General Meeting. They also discussed the further development of joint AE/ADI activities in Europe and approved requests for AE to move to new offices and expand its staff.

The next AE Board meeting will take place on 2 December in Brussels, Belgium.



10 October: AE holds Annual General Meeting

Alzheimer Europe held its 2013 Annual General Meeting on 10 October in St. Julian's, Malta. The meeting was attended by representatives from 26 full member associations and one provisional member association, as well as various guests including Marc Wortmann, Executive Director of ADI.

The delegates reviewed and adopted AE's 2012 Annual and Financial reports and voted in favour of AMPA Monaco and FAAS Iceland being accepted as full members of Alzheimer Europe. The association now has a total membership of 36, with 32 full members and four provisional members.

Following a review of 2013 activities, the delegates adopted the "St. Julian's Appeal" - a document aimed at the leaders participating in the G8 dementia summit in December 2013 - and voted in favour of the European Dementia Pledge as a campaign tool for the 2014 European elections. There was also a discussion about Alzheimer Europe's ongoing Dementia Monitor project, which will benchmark national dementia policies and

allow comparisons and rankings among countries. The initial results of the Dementia Monitor will be presented in the European Parliament in December 2013.

Finally, delegates reviewed and approved the 2014 Work Plan and the 2014 Budget. Amongst other activities, Alzheimer Europe will continue to collaborate with European dementia initiatives and will relaunch the European Alzheimer's Alliance after the elections. AE's participation in EU research projects will be expanded and an Expert Advisory Panel will be launched to monitor scientific developments in dementia. The association will also overhaul its communications strategy and the 24th Alzheimer Europe Conference will take place in Glasgow, UK on 20-22 October 2014 under the theme "Dignity and autonomy in dementia."

10 October: Monaco and Iceland associations join Alzheimer Europe



Alzheimer Europe is very pleased to welcome AMPA Monaco and FAAS Iceland as full member associations. The applications of both associations were unanimously approved at AE's 2013 Annual General Meeting.

This brings Alzheimer Europe's total membership to 36, including 32 full members and four provisional members. AE has worked together with both associations in the past and we now look forward to closer ties and direct participation in all of our activities.



More information about dementia activities in Iceland and Monaco can be found on the associations' websites.

www.alzheimer.is
www.ampa-monaco.com

10 October 2013: Alzheimer Europe calls on G8 to step up international research efforts on dementia

At its Annual General Meeting in St. Julian's, Malta on 10 October 2013, Alzheimer Europe and its member organisations adopted the following appeal:

St. Julian's Appeal to G8 Dementia Summit

Alzheimer Europe and the undersigned national member organisations:

- Welcome the UK Prime Minister's initiative to convene a G8 Dementia Summit on 11 December in London,
- Fully support the Summit's objective of developing greater international collaboration and public private partnerships for research into the causes, treatment and prevention of Alzheimer's disease and other forms of dementia,
- Call upon the G8 countries to:
 1. Include and consult Alzheimer associations and people with dementia in the decision making process and definition of a global research agenda,
 2. Adopt a holistic approach to research to include psycho-social, care, socio-economic and health systems research,

3. Substantially increase the funding dedicated to all areas of dementia research,
4. Promote dementia as a priority in other international bodies including the G20, the Organisation for Economic Co-operation and Development (OECD), the World Health Organisation (WHO) and the United Nations.

10-12 October: Alzheimer Europe holds 23rd Conference in Malta

Alzheimer Europe held its 23rd Annual Conference in St. Julian's, Malta during 10-12 October 2013 with the motto "Living well in a dementia-friendly society". The conference featured over 110 speakers in plenary and parallel sessions, special symposia and workshops as well as poster presentations.

The conference was held under the Distinguished Patronage of His Excellency Dr George Abela, President of Malta. President Abela officially opened the conference on 10 October by welcoming over 520 delegates to the island and congratulated the Organising and Programme committees for their efforts. He also wished all the participants a very successful conference as they explored the impact of perceptions and the image of dementia on the lives of people with dementia and their carers.

The delegates were also welcomed by Minister of Health Dr Godfrey Farrugia, a representative of Ms Marie-Louise Coleiro Preca, Minister for the Family and Social Solidarity, Parliamentary Secretary for the Rights of Persons with Disabilities and Active Ageing Dr Franco Mercieca and Joseph Cuschieri, Maltese Member of the European Parliament. All of these policymakers restated and affirmed the commitment of the Maltese government to the development of national dementia strategy.

The opening ceremony concluded with a keynote lecture by Mr Martin Seychell, another fellow Maltese and Deputy Director General of the European Commission's DG Health and Consumers. Mr Seychell described the EU's contribution to addressing the challenge of dementia, such as supporting Member States in dealing with the present challenges and preparing them for the future challenges that will undoubtedly come.

The first plenary session on 11 October was chaired by Iva Holmerová (Czech Republic) and focused on integrated care. Angiolina Foster (Scotland) spoke about the commitment of the Scottish Government to post-diagnostic support and Chris Gastmans (Belgium) discussed dignity-enhancing care for persons with dementia and its application to advance directives. They were followed by Gráinne McGettrick (Ireland), who outlined Ireland's progress in improving dementia palliative care and Jacqueline Parkes (UK) who presented aspects of improving access, care pathways and social care for people with young onset dementia.

Charles Scerri (Malta) chaired the second plenary session that featured presentations on prevention. Martin Orrell (UK) explored the role of case management for preventing institutionalisation and hospitalisation and Finland's Tiia Ngandu gave an overview of our current understanding of the prevention of dementia. Armelle Leparre-Desplanques (France) spoke about how the ALCOVE project toolbox can help to prevent behavioural problems and avoid the use

of anti-psychotics and, finally, Myrra Vernooij-Dassen (Netherlands) presented solutions to prevent carer burn-out by empowerment.

In between the two plenaries, the European Working Group of People with Dementia (EWGPWD) held a highly popular symposium entitled "Nothing about us without us". This was chaired by Helga Rohra (Germany) and featured presentations by Stig Atle Aavik, Jean-Pierre Frognet, Raoul Grönqvist, Agnes Houston and Dermot Slevin. They presented various aspects of how they live with dementia, with a common theme of focusing on their remaining capacities to stay active in society for as long as they possibly can.

On 12 October, the third plenary was chaired by Maurice O'Connell (Ireland) and dealt with innovation and dementia. Nina Baláčková (Czech Republic) spoke about the activities of the EWGPWD, which is giving a voice to people with dementia. She was followed by Elisabetta Vaudano (Italy), who showed the high priority of Alzheimer's disease within the work of IMI - the Innovative Medicines Initiative. David Mamo (Malta) discussed the behavioural and psychological symptoms of dementia (BPSD) and Franka Meiland from the Netherlands gave an update of assistive technologies that are supporting people with dementia and their carers.

The fourth and final plenary session was chaired by Malta's Stephen Abela and focused on a dementia friendly society. Joost van Hoof (Netherlands) presented the latest in ageing-in-place or the living arrangements for people with dementia in the community. Carmelo Aquilina (Malta/Australia) showed evidence of the persistence of the self in dementia and Anthea Innes (UK) described several personal journeys to dementia friendly societies.

The conference also included 20 parallel sessions, three special symposia and poster sessions that featured over 50 exhibits. These dealt with specific aspects of dementia, including post-diagnostic support, perceptions and image of dementia, psychosocial care, epidemiology and telecare. Delegates learned about country-specific dementia projects and the latest developments in legal and ethical issues. One particularly well-attended session concentrated on the importance of involving people with dementia. This was emphasised in three presentations from three different continents, showing a welcome positive trend to reduce stigma and increase the quality of life of people with dementia all over the world.

The conference ended with an invitation by Alzheimer Scotland's Jim Pearson to the 24th Alzheimer Europe Conference in October 2014. This was followed by closing remarks and a farewell from Heike von Lützu-Hohlbein and Stephen Abela, respectively the Chairpersons of Alzheimer Europe and the Malta Dementia Society.

Alzheimer Europe and the Malta Dementia Society are very grateful to the presenters, delegates and event staff that helped make the conference a success. The efforts and determination of people with dementia and their carers are particularly appreciated. Their collective contribution has triggered a shift in public perceptions over the past years, leading to a growing commitment by national and European policy makers to give dementia the attention it so rightly deserves.

The 23rd Alzheimer Europe Conference received funding from the European Union in the framework of the Public Health programme.

18 October: AE remains eligible for EMA activities

On 18 October, Alzheimer Europe received a positive outcome from a periodic EMA re-evaluation of eligibility. The letter states that AE "continues to comply with the definition of patients'/consumers' organisations and fulfils all the necessary criteria. Therefore, it continues to be eligible to be involved in the Agency's activities."

Alzheimer Europe is a member of the EMA's PCWP - the Working Party with Patients' and Consumers' Organisations - for the period 2013-2016. The PCWP provides recommendations to the European Medicines Agency and its human scientific committees on all matters of interest to patients in relation to medicinal products.

The working party is composed of representatives from patients' and consumers' organisations that fulfil the eligibility criteria, as well as the Agency's human scientific committees and the Agency secretariat.

www.ema.europa.eu

28 October: Incontinence working group holds second meeting

On 28 October, the incontinence working group in Brussels held its second meeting in Brussels. This is a joint project which is organised and conducted by Alzheimer Europe in collaboration with SCA Global Hygiene.

The meeting was chaired by Dianne Gove, Information Officer for Alzheimer Europe and attended by Nicole Huige, Kai Leichsenring, Vikky Morris, Helga Rohra, Breda Savage and Anthony Scerri.

The group continued to work on the development of guidelines to improve continence care for people with dementia living at home. The guidelines will be circulated to a wider group of experts with relevant experience and to people with dementia and carers before a preliminary set of guidelines is presented at the 5th Global Forum on Incontinence to be held in Madrid in April 2014. The final set of guidelines and the accompanying report will be launched at the 24th Alzheimer Europe Conference in October 2014.

31 October: 2013 AE Conference presentations are online!

We are pleased to report that most of the presentations from the 23rd Alzheimer Europe Conference are now available on our website. The remaining presentations, as well as more photos, will follow very soon.

www.alzheimer-europe.org/Conferences/Previous-conferences/2013-St-Julian-s-Malta/Detailed-programme-abstracts-and-presentations



Impressions from the 23rd Alzheimer Europe Conference



Maltese President George Abela opens the conference



The opening ceremony in the impressive Grandmaster Suite



Štefanija Lukič-Zlobec (Slovenia), Anne Arndal (Denmark) and Nino Mimica (Croatia) collect their badges



A view from the welcome reception on a very warm evening



Angiolina Foster (Scotland) speaking at a plenary session



Members of the EWGPWD greet visitors to their stand



Dr Gary Geipel (USA) at Lilly's symposium on clinical trials



Heike von Lützu-Hohlbein (Alzheimer Europe) and Stephen Abela (Malta Dementia Society) close the conference



Jim Pearson (Scotland): "See you next year in Glasgow!"

European Alzheimer's Alliance

27 June: MEP Cristian Busoi leaves the European Parliament

Mr Cristian Busoi, MEP (Romania) and member of the European Alzheimer's Alliance, left the European Parliament in June 2013.

He was a member of the EAA since March 2012. We would like to thank Mr Busoi for his contribution - particularly his attendance and support of the 2013 Romanian National Alzheimer Conference - and wish him all the best for the future.

3 October: MEP Susy De Martini joins the Alliance



The European Alzheimer's Alliance is pleased to welcome Susy De Martini, MEP (Italy). She belongs to the European Conservatives and Reformists Group (ECR).

Ms De Martini sits on the Committee on Foreign Affairs and on the Delegation for relations with the United States. She is also a substitute for the Committee on Budgets.

Ms De Martini joined the Alliance on 3 October.

Alzheimer Europe Networking

On 1 October, Annette participated in the European Patients' Forum launch of its EU campaign Manifesto (Brussels, Belgium).

On 2 October, Jean attended a European Parliament lunch debate on European Joint Programme Initiatives (Brussels, Belgium).

On 9 October, the European Working Group of People with Dementia met to prepare its participation in the AE Conference (St Julian's, Malta).

On 10-12 October, AE Board members and AE Staff attended the 23rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", AE Board meeting and Annual General Meeting (St Julian's, Malta).

On 11 October, members of the AE Board and AE member organisations attended an information meeting organised by Nutricia (St. Julian's, Malta).

On 13 October, Alex attended the Mediterranean Alzheimer Alliance Meeting (St Julian's, Malta).

On 15 October, Annette attended the Carers Interest Group meeting in the European Parliament (Brussels, Belgium).

On 17 October, Annette attended the meeting organised by Sirpa Pietikäinen (MEP, Finland) with national constituents (Brussels, Belgium).

On 28 October, Dianne attended the second meeting of Alzheimer Europe's working group on good incontinence care for people with dementia living at home (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), Jäättänen 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:** De Martini Susy (ECR), 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), Sârbu Daciana Octavia (S&D), Tanasescu Claudiu Ciprian (S&D). **Slovakia:** Mikolášik Miroslav (EPP), Zaborská Anna (EPP). **Slovenia:** Kleva Kekuš Mojca (S&D), Peterle Alojz (EPP). **Spain:** Badia i Cutchet Maria (S&D), Estarás 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

21 October: JPND will launch two calls in December 2013

The EU Joint Programme – Neurodegenerative Disease Research (JPND) expects to launch two Joint Transnational Calls later this year aimed at supporting transnational collaborations in the field of neurodegenerative disease research.

The 2-step calls are anticipated to launch in early December 2013, with a likely first stage (pre-proposal submission) deadline of February 2014. Further detail will be provided on the call launch date. However, the indicative titles of each call are provided below:

“A call for European research projects for Cross-Disease Analysis of Pathways related to Neurodegenerative Diseases”

The aim of the call is to establish a limited number of ambitious, innovative, multi-national and multi-disciplinary collaborative research projects that:

- combine experimental approaches from fundamental, pre-clinical and/or clinical with computational approaches;
- perform network analyses in different neurodegenerative and other chronic diseases to elucidate the underlying mechanisms common and differing in the investigated diseases;
- will add value to existing research by analysing diseases across traditional clinical boundaries, thereby gaining deeper understanding of the pathophysiological mechanisms of the diseases.

“A call for European research projects for Pilot Studies on Preventive Strategies related to Neurodegenerative Diseases”

The aim of the call is to establish pilot initiatives to develop preventive strategies. Proposals should entail multidisciplinary studies which may focus on new paradigms for multimodal preventive interventions including culture specific aspects, on harmonisation initiatives, or on proof-of-concept, and feasibility studies. Proposals may include research-based evaluation of interventions and validation of outcome measures.

JPND will pilot the use of a new online partnering tool for these calls. The tool will enable call applicants to showcase their research group's expertise, search for appropriate partners, pitch call-related ideas and draft their pre- and full-proposals online. It will be made available through the JPND website and will be announced in a JPND News alert in November 2013.

www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals

22 October: Commission presents its work programme for 2014

On 22 October, the European Commission adopted its 2014 work programme.

The work programme will focus on the finalisation of the banking union, the single market and the digital agenda. It will also ensure that the new measures under the Multiannual Financial Framework for 2014-2020 swiftly become operational – in particular to combat youth unemployment.

http://ec.europa.eu/atwork/pdf/cwp_2014_en.pdf
http://ec.europa.eu/atwork/pdf/ip_13_13_978_en.pdf

22 October: Commission presents new toolbox for the effective use of Structural Funds for health investments

On 22 October, the European Commission presented a new toolbox for the effective use of Structural Funds for health investments in 2014-2020.

This toolbox has been developed by the working party on public health at senior level, chaired by Hungary.

The main function of the toolbox is to make an immediate start to help improve the quality and effectiveness of planning, decision-making and implementation of Structural Funds investment programmes and projects in health through a range of suggested methodologies and guidelines.

The toolbox includes a focus on critical success factors, the Funds framework and mechanisms, strategic and financial planning or implementation.

<https://webgate.ec.europa.eu/eipaha/news/index/show/id/473>
<http://www.gyemszi.hu/site/index.php?mid=357&lang=en>

Members' News

1 September: Jersey Alzheimer's Association appoints new Manager



Mark Blamey, BSc was appointed as Manager of the Jersey Alzheimer's Association on 1 September.

He has personal experience of caring for people living with dementia and has also completed in depth training with Alison Holmes who is a qualified dementia trainer in the UK. Mark is able to add value and advice on the issues surrounding dementia and to assist in the direction of dementia services in Jersey. He is cognisant with the types, symptoms, progression and treatment of the condition and what happens to the brain, memory and skills when someone gets dementia.

He has studied Wellbeing and being Person-Centred throughout all stages of dementia (Kitwood) including Wellbeing for carers, family and professionals. This includes examining conflicts, barriers and opportunities, looking particularly at different forms of communication and behaviour as a form of communication.



Mark will help to raise awareness of dementia in our community and promote the services and activities provided by the Jersey Alzheimer's Association. He is interested in creating dementia-friendly environments both in the home and in professional establishments. One of his aims is to make Jersey a dementia-friendly Island.

Mark may be contacted, in confidence, for advice and information at markblameyjaa@gmail.com

21 September: AMPA Monaco holds World Alzheimer's Day celebrations



Monaco's AMPA association commemorated World Alzheimer's Day with a Memory Walk, a modern ballet performance and a flash mob. These seemingly disparate activities were very successful in raising awareness of dementia among people of all backgrounds and ages.

The 4th Monaco Memory Walk took participants on an hour-long tour of the city and ended with a performance by a choir of singers with dementia. The ballet evening was the world premiere of a new work about the

experience of a man who develops dementia. This was produced by a Cuban dance group in cooperation with AMPA. The flash mob consisted of some 700 people - including 500 teenagers - who assembled in a public square and briefly assumed the shape of a seahorse or hippocampus, which is AMPA's symbol (see picture).



AMPA also held a public conference that featured presentations on the association's activities and also on dementia risk factors, dealing with memory impairments and assistive technologies.

www.monacochannel.mc/Chaines/Monaco-Info-Les-Reportages/Videos/Journee-Mondiale-de-lutte-contre-la-maladie-d-Alzheimer

21 September: Alzheimer Scotland holds Memory Walk on World Alzheimer's Day



Alzheimer Scotland held a very successful Memory Walk on 21 September to commemorate World Alzheimer's Day. In all, 295 people took part in the walking challenge, many participating in honour of family members who have been affected by dementia.

Popular attractions on the day of the Memory Walk included a display of vintage cars from Ecosse Classic Wedding Cars, vintage hair and beauty make-overs by Boombarbers and Glamcandy, face painting, arts and crafts, a bouncy castle and a home baking stall.

Money raised by the event will be funding projects supporting people with dementia and their families in communities across Scotland, such as Alzheimer Scotland's Dementia Advisors and Dementia Nurses, the Alzheimer Scotland Dementia Research Centre and their freephone Dementia Helpline.



21 September: France Alzheimer lists priorities for the next "neurodegenerative diseases plan"



On 21 September, France Alzheimer presented 15 recommendations for the next "neurodegenerative diseases plan" that President Hollande has pledged to launch during his mandate. This new plan will pay specific attention to Alzheimer's disease. The recommendations include the following items:

- Launch of an information campaign to raise awareness of the disease and encourage early diagnosis.

- Develop a process for rapid post-diagnosis consultations
- Develop and disseminate a single tool to evaluate the needs of the person.
- Maintain funding for training programmes for family carers.
- Increase the staff/patient ratio in both generalist units and units that deal with people at an advanced stage of the disease.
- Decrease the out-of-pocket costs incurred by carers.
- Develop cognitive-behavioural units.
- Improve support for people with dementia below 60 years old.
- Develop end of life training programmes.

The original French-language document can be seen on the association's website.

www.francealzheimer.org/15-propositions-pour-am%C3%A9liorer-parcours-soin/776

21 September: Alzheimer Society of Ireland runs brain health campaign



The Alzheimer Society of Ireland ran a two-week brain health campaign called "Forget Me Not" to coincide with World Alzheimer's Day.

The campaign ran across radio and online, aiming to raise public awareness about how people could reduce their risk of developing Alzheimer's disease and other forms of dementia in later life by looking after their brain, body and heart. An information leaflet was developed to accompany the campaign which outlines tips and advice for how you can keep your brain, body and heart as healthy and active as possible. The leaflet is available on the society's website.

www.alzheimer.ie



1 October: Alzheimer Portugal awards active ageing prize

alzheimer



In an award ceremony on 1 October, Alzheimer Portugal (AP) awarded its Dr. Maria Raquel Ribeiro Active Ageing Prize to Mrs Tereza da Conceição Fradique, aged 96. Mrs Fradique, an active Alzheimer

Portugal volunteer, won this Prize in the category "Family and Community" for her volunteer activity and to recognise her remarkable positive attitude and determination in life.

This prize was originally created to pay tribute to Maria Raquel Ribeiro, a very important figure in the Portuguese Social Security administration and aims to make known and highlight examples of life that help to convey a positive image of elderly people.



www.alzheimer-europe.org/Donation

4 October: Swiss Alzheimer Association celebrates 25th anniversary



On 4 October, the Swiss Alzheimer Association hosted 600 guests at a Silver Jubilee conference to celebrate its 25th anniversary.

The conference featured VIP guest Maya Graf, Chairperson of the Swiss Parliament, who congratulated the Association for "breaking the taboo" around Alzheimer's disease and other forms of dementia.

Switzerland is due to launch its first national dementia strategy at the end of November 2013. The conference included a political round table discussion on how the lives of Swiss people with dementia will be in ten to 15 years. The common theme that emerged was that the new national strategy will have a substantial positive impact on the quality of life of people with dementia and their families and carers.

There was also a presentation by Heike von Lützu-Hohlbein, Chairperson of Alzheimer Europe, who outlined the various strategies and actions on dementia that are being developed on a European level.

The participation of the group "Carpe Diem" was without doubt the highlight of the conference. The group consists of seven people with early-onset Alzheimer's disease who are very active in presenting various aspects of their experiences of living with Alzheimer's disease. According to Birgitta Martensson, Executive Director of the Swiss Alzheimer Association, their statements on how they live with dementia will certainly be remembered.



13 October: Mediterranean Alzheimer's Alliance meets in Malta

The 3rd Mediterranean Alzheimer's Alliance (MAA) workshop took place on the fringe of the Alzheimer Europe Conference on 13 October in Malta. This Alliance was launched by Monaco's Association Monégasque pour la recherche sur la maladie d'Alzheimer (AMPA) in April 2012 in Marrakech, Morocco. It unites associations, scientists and professionals working together to fight Alzheimer's disease and other related disorders in the Mediterranean region. The MAA has three main objectives: to create a network of Mediterranean experts on Alzheimer's disease and other related disorders in order to share common concerns, to identify needs and develop specific solutions and to encourage future collaboration between Alzheimer associations, clinicians

and researchers across the Mediterranean. The overarching aim of the MAA is to help those working in the field of Alzheimer's disease and other related disorders in the Mediterranean to develop initiatives and to share and exchange their knowledge and best practices.

This meeting was an opportunity to welcome three new associations (Alzheimer Uniti Onlus Italia, Alzheimer Slovenia, Alzheimer Croatia) and three new scientific experts (Médéric Alzheimer Foundation, University of Toulouse, French School of Public Health), making a total of 16 MAA members. The member countries are Croatia, France, Greece, Italy, Lebanon, Malta, Monaco, Morocco, Portugal, Slovenia, Spain and Tunisia. During this workshop, the members discussed the report to be published by MAA next year, which will present the Alzheimer situation in each country and their specific needs.

The next stage will be a 4th workshop in Lisbon in 2014. This will be an opportunity for the MAA to elaborate recommendations so that the Mediterranean region can present its common characteristics and to make sure that Alzheimer's disease and other related disorders become a priority in every country. It will also be possible for other Mediterranean Alzheimer actors to join the Alliance.



17 October: CEAFA launches a chocolate campaign for dementia



Spain's CEAFA Alzheimer association has teamed with an online chocolate retailer in a campaign to raise dementia awareness and provide funding for the association.

Clubdelchocolate.com offers a package called "Chocolate for memory" that contains a variety of black chocolate products and donates EUR two from each sale to CEAFA.

www.clubdelchocolate.com/p.520.0.0.1.1-chocolate-para-la-memoria.html

18 October: Alzheimer Portugal celebrates 25th anniversary

On 18 October, Alzheimer Portugal organised a conference to celebrate its 25th anniversary. The popular event commemorated the main achievements of the association in research, specialised care and support and legal rights since it was founded by Professor Carlos Garcia. However, the main focus of the conference was the progress of the Portuguese National Dementia Plan, in

a session chaired by Alzheimer Portugal's Maria do Rosário Zincke dos Reis.

This session began with António Leuschner, President of the National Council for Mental Health and also a member of Alzheimer Portugal's Scientific Committee. He gave an overview of the various existing dementia plans in Europe and the progress that has been achieved in Portugal. Mr Leuschner was followed by Beatriz Santiago, Chairperson of the "Group of Studies of Brain Aging and Dementias", who made a presentation on the importance of including research in a National Plan.

Marisa Matias, a Portuguese Member of the European Parliament (MEP), was also present at the conference and continued to show her support for the fight against dementia. She gave a presentation on dementia activities at the European level, including a short film that was made for the 2012 European Year of Active Ageing. The film documents the visit of various MEPs, including Ms Matias, to Alzheimer Portugal's Day Care Centre in Lisbon and their discussions with residents about their experiences of living with dementia.

The last speaker was Álvaro de Carvalho, Coordinator of the National Mental Health Programme. He outlined the conclusions of a May 2013 meeting that was hosted by the Ministry of Health and provided considerable impetus to the development of the National Dementia Plan. During that meeting, a group of some 40 dementia experts persuaded the government that existing dementia prevalence figures are sufficiently accurate to allow the next phase of the plan to proceed right away.

He also announced that the agreement between the Health Ministry and Alzheimer Portugal is ready to be signed. This key document designates Alzheimer Portugal as the national reference for specific care and services for people with dementia and the dissemination of good practices, mainly through training family and professional carers. This gives Alzheimer Portugal a mandate to train doctors, nurses, psychologists and other professionals from the National Health System. The agreement also recognises Alzheimer Portugal as a partner in the creation and implementation of the Dementia National Plan.



28 October: Alzheimer Nederland awards fellowship grants



Each year, Alzheimer Nederland awards a number of individual fellowship grants to promising young Dutch researchers, in order to promote international exchange of knowledge and techniques.

This year, seven grants with a total value of EUR 120,000 were awarded for the following research topics: messenger proteins, astrocytes, cerebral amyloid angiopathy (CAA), micro-infarctions, biomarkers, micro-bleeds and amyloid antibodies via gene therapy.

More information can be found on the Alzheimer Nederland website or via email to Mr Dinant Bekkenkamp: d.bekkenkamp@alzheimer-nederland.nl

www.alzheimer-nederland.nl/actueel/onderzoek/2013/oktober/subsidies-2013-7-internationale-onderzoeken.aspx

Policy Watch

25 October: Entry into force of the Directive on Patients' Rights in Cross-border Healthcare

On 25 October, the Directive on Cross-Border Healthcare entered into force in the EU. It defines the rights of EU citizens to choose where they receive medical treatment across the EU and to be reimbursed for it no matter where they live.

The new Directive introduces three major changes focusing on patients' rights:

- citizens have the right to choose and be reimbursed for treatment, in both public and private health care, anywhere in the EU,
- prior authorisations for cross-border healthcare will become the exception rather than the rule,
- citizens have the right to make informed decisions about treatment options. They will be able to receive any relevant information from national contact points, as established under the new Directive, and information from health care and treatment providers directly.

The Directive calls for mutual assistance and cooperation between Member States, in particular on the interoperability of e-Health tools and the use of health technology assessment. It also facilitates the recognition of prescriptions for medical products in every Member State.

The Directive will provide for the development of European reference networks, to encourage the pooling of knowledge and maximise the cost effective use of resources in highly specialised healthcare, such as the diagnosis and treatment of rare diseases.

http://ec.europa.eu/health/newsletter/117/focus_newsletter_en.htm
http://europa.eu/rapid/press-release_MEMO-13-932_en.htm
[http://eur-](http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF)

[lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF](http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF)

30 October: CEAFA and Sanitas present a policy proposal to the Spanish Parliament



On 30 October, Spain's CEAFA and the Sanitas Foundation presented a proposal for a national dementia policy to the Committee on Health and Social Services of the Spanish House of Representatives.

Both organisations share the goal of Alzheimer's disease and other forms of dementia becoming a public health priority at the national and international levels.

Mr Koldo Aulestia, President of CEAFA, said: "Alzheimer's is more than just a disease; the figures show that it has become a real social and health problem that affects all strata of society, extending its effects not only on individuals but also on family caregivers."

His sentiment were echoed by Mr David Pérez de Ciriza, Director of Sustainability and Institutional Relations of Sanitas, who added: "The focus of state policy and the creation of a National Dementia Plan ensures that health and social systems are adequately structured and equipped to ensure high quality care that allows people live well with dementia today and in the future."

Science Watch

1 August: EMA releases draft guideline for ALS medicines



The European Medicines Agency (EMA) has released a draft guideline on medicines for the treatment of amyotrophic lateral sclerosis (ALS) released for a six-month public consultation.

The document focuses on the design of studies for medicines that have an impact on the course of the disease (disease-modifying treatments) as well as medicines that treat the symptoms of ALS. Guidance is provided on the choice of meaningful outcome parameters used in studies and the clinical relevance of functional tests of disability, including motor- and respiratory-function tests and their relationship to survival.

Comments should be made using the submission form and sent no later than 31 January 2014 to cnswpsecretariat@ema.europa.eu

More information is available on the EMA website.

www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2013/07/news_detail_001867.jsp&mid=WC0b01ac058004d5c1

19 September: EMA approves a new generic memantine drug

On 19 September, the EMA approved a generic drug named Memantine Accord. It has been authorised in 5 mg, 10 mg, 15 mg and 20 mg tablets intended for treatment of patients with moderate to severe Alzheimer's disease. Memantine Accord will be marketed by Accord Healthcare Limited.

www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicine_s/002766/smops/Positive/human_smop_000586.jsp&mid=WC0b01ac058001d127

1 October: 11 new genes are linked to AD

Researchers at the Pasteur Institute in Lille, France have published the results of a genetics study that identifies 11 new genes associated with late-onset Alzheimer's disease.

The researchers were led by Dr. Philippe Amouyel, Professor of Epidemiology and Public Health at the University Hospital of Lille. They conducted a genetic analysis of more than 74,000 people, in search of DNA regions that were common in people with Alzheimer's disease.

Dr. Amouyel said: "This helps us understand the pathophysiology of the disease. If we are able to develop preventative treatments for Alzheimer's disease, they would need to be used very early on. This could help us

identify people who are more prone to the disease by estimating their individual risk."

www.nature.com/ng/journal/vaop/ncurrent/full/ng.2802.html

1 October: New symbol identifies medicines that need additional monitoring

 The European Commission has introduced a new way of identifying medicines that are being monitored particularly closely. These medicines have a black inverted triangle displayed in their package leaflet, together with a short sentence that reads "This medicinal product is subject to additional monitoring."

This does not mean that the medicine is unsafe. All medicinal products on the EU market have undergone rigorous tests to demonstrate their quality, safety and efficacy and to prove that their benefits outweigh their risks. However, it is important to continue to monitor their use once on the market and look out for adverse reactions that are not listed in the product information.

The black symbol is intended to identify the medicines which are subject to more intensive post marketing monitoring (additional monitoring), so that new emerging information can be immediately shared with the regulatory authorities, medical communities, marketing authorisation holders and patients.

For new biological medicinal products and those containing new active substances, the black symbol will normally be removed after five years, once the use of the product is established.

More information, including a video and a factsheet, can be found on the EMA website.

www.ema.europa.eu/ema/index.jsp?curl=/pages/special_topics/general/general_content_000586.jsp

17 October: Glymphatic system may be key to flushing brain toxins

A new study has shown that the space between brain cells in mice may increase during sleep, allowing the brain to flush out toxins that build up during waking hours. The researchers were led by Dr. Maiken Nedergaard, Professor of Neurosurgery at the University of Rochester Medical Center (URMC) in New York.

They determined that, during sleep, a plumbing system called the glymphatic system may open, letting cerebrospinal fluid (CSF) flow rapidly through the brain. The team injected dye into the CSF of mice and monitored its flow through their brains while monitoring electrical brain activity. The dye flowed rapidly when the mice were unconscious but slowed remarkably when the same mice were awake.

Dr. Nedergaard said: "We were surprised by how little flow there was into the brain when the mice were awake. It suggested that the space between brain cells changed greatly between conscious and unconscious states."

The scientists then tested whether this was controlled by the glymphatic system by injecting mice with beta amyloid and measuring how long it lasted when they were asleep or awake. The toxic protein disappeared faster

when the mice were asleep, suggesting that sleep normally clears toxic molecules from the brain.

This means that the cells regulating the glymphatic system may be new targets for treating a range of neurodegenerative disorders.

www.sciencemag.org/content/342/6156/373



www.alzheimer-europe.org/Donation

25 October: FDA approves second brain imaging drug

The US Food and Drug Administration today approved flutemetamol F18 injection, a radioactive diagnostic drug for use with positron emission tomography (PET) imaging of the brain in adults being evaluated for Alzheimer's disease and other forms of dementia.

The drug works by attaching itself to beta amyloid and producing a PET image of the brain that is used to evaluate the presence of beta amyloid. A negative scan means that there is little or no beta amyloid accumulation in the brain, while a positive scan means that there is probably a moderate or greater amount of amyloid in the brain.

Flutemetamol F18 injection is marketed as Vizamyl by GE Healthcare. Last year, the FDA approved florbetapir F18 injection, a similar drug that is marketed as Amyvid by Lilly.

www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm372261.htm

31 October: EMA seeks opinions for new dementia treatment guidelines

On 31 October, the European Medicines Agency (EMA) released a concept paper on the need to revise the guideline on medicines for the treatment of Alzheimer's disease and other dementias for public consultation.

Recent progress in understanding Alzheimer's disease suggests that the structural and biological changes associated with the disease start to occur as early as ten to 20 years prior to the emergence of the clinical symptoms. As a consequence, early and even pre-symptomatic patients are now being included in clinical development programmes and it is expected that some medicines may be more effective at that stage than they would be later in the illness.

New research diagnostic criteria are being used in clinical trials for different stages of the disease. In addition, a number of biomarkers to help identify and select patients at the pre-dementia stage of the disease have been developed by medicines developers; several have received a qualification opinion from the Agency's Committee for Medicinal Products for Human Use (CHMP) for use in the development of medicines.

The concept paper describes how these new developments have had an impact on recent and future clinical-trial protocols and discusses the elements to

consider as part of the revision of the current guideline. These include the:

- impact of new diagnostic criteria for Alzheimer's disease, including early and even asymptomatic disease stages on clinical-trial design;
- choice of parameters to measure trial outcomes and the need for distinct assessment tools for the different disease stages in Alzheimer's (different signs and symptoms, differences in change over time, severity);
- assessment of efficacy and safety in different age groups;
- potential use of biomarkers and their temporal relationship with the different phases of Alzheimer's disease at different stages of medicine development (mechanism of action, use as diagnostic test, enrichment of study populations, stratification of subgroups, safety and efficacy markers, etc.);
- design of long-term efficacy and safety studies;
- usefulness of combination therapy and corresponding study designs.

The comments submitted on the concept paper will be considered in the development of the revised guideline. Comments should be sent to cnswpsecretariat@ema.europa.eu by 31 January 2014 using the template provided.

www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2013/10/news_detail_001938.jsp&mid=WC0b01ac058004d5c1

Dementia in Society

31 October: President Obama proclaims National Alzheimer's Disease Awareness Month



The US president has proclaimed November 2013 as "National Alzheimer's Disease Awareness Month". The full text of the proclamation is shown below.

Alzheimer's disease is an irreversible and progressive brain disease that slowly erodes precious memories, thinking skills, and the ability to perform simple tasks. It affects millions of Americans, including senior citizens as well as younger Americans with early-onset Alzheimer's disease. This month, we stand with everyone confronting the painful reality of an Alzheimer's diagnosis; lend our support to the families who care for them; and renew our commitment to delaying, preventing, and ultimately curing this disease.

In research labs across our country and around the world, scientists are working to unlock the answers to Alzheimer's disease. My Administration proudly supports this promising research. Earlier this year, I proposed the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, which aims to revolutionize our understanding of the human brain. By mapping the brain, we hope to better comprehend the causes of disorders like Alzheimer's disease and enhance our work on improving treatment. In September, the National Institutes of Health announced support for

innovative new studies to help find effective interventions for this devastating degenerative brain disease. And my Administration also remains committed to implementing the first-ever National Plan to Address Alzheimer's Disease, which lays out a roadmap to preventing and effectively treating Alzheimer's disease by 2025.

Working together with scientists, patient advocates, and those living with this disease, we can give a sense of hope to millions of families, patients, and caregivers. For resources and information on living with or caring for someone with Alzheimer's disease, please visit www.Alzheimers.gov

As we offer our support to Americans with Alzheimer's disease, we also recognize those who care and provide for them, sharing their loved ones' emotional, physical, and financial strains. This month, we honor their compassion, remember those we have lost, and press toward the next great scientific breakthrough.

NOW, THEREFORE, I, BARACK OBAMA, President of the United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States, do hereby proclaim November 2013 as National Alzheimer's Disease Awareness Month. I call upon the people of the United States to learn more about Alzheimer's disease and support the individuals living with this disease and their caregivers.

IN WITNESS WHEREOF, I have hereunto set my hand this thirty-first day of October, in the year of our Lord two thousand thirteen, and of the Independence of the United States of America the two hundred and thirty-eighth.

www.whitehouse.gov/the-press-office/2013/10/31/presidential-proclamation-national-alzheimers-disease-awareness-month-20

New Publications & Resources

16 September: WHO Europe publishes a Mental Health Action Plan



In September 2013, the WHO Regional Committee for Europe agreed on a European Mental Health Action Plan for 2014–2020. This will help countries improve their populations' mental well-being and reduce the burden of mental disorders.

Mental disorders are one of the top public health challenges in the WHO European Region, as measured by prevalence, burden of disease and disability, affecting more than a third of the population every year. In all countries, most mental disorders are much more prevalent among those who are most deprived.

The European Mental Health Action Plan focuses on seven interlinked objectives and proposes effective and integrated actions to strengthen mental health and well-being in the European Region. Investing in mental health is essential for the sustainability of health and social policies in the European Region.

This document contains a draft European Mental Health Action Plan that corresponds to the four priority areas of the new European policy framework for health and well-being, Health 2020, and will contribute directly to its implementation.

The Action Plan was developed in close consultation with Member States, guided by the Standing Committee of the WHO Regional Committee for Europe. It is available for download on the WHO Europe website.

www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/publications/2013/the-european-mental-health-action-plan

1 October: Commission publishes "Improving health for all citizens" booklet

On 1 October 2013, the European Commission presented its new publication "Improving health for all EU citizens". This publication is a part of a series that explains what the EU does in different policy areas, why the EU is involved and what the results are.

The publication explains why we need a public health policy, how the EU goes about it and what the EU does. It also gives a list of useful links.

http://ec.europa.eu/health/health_policies/docs/improving_health_for_all_eu_citizens_en.pdf

1 October: New US website for people with dementia

The US Alzheimer's Association has launched a website called "I Have Alzheimer's Disease" that contains a wealth of information and advice for people living with dementia.

The website includes special sections for dealing with a dementia diagnosis, planning for the future and overcoming stigma, with a notable section on early onset dementia.


alzheimer's association

www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp

13 October: Janssen and Deloitte publish new health report

A new report entitled "Investing in European health R&D" shows that European research and development (R&D) investments in health have stagnated since 2010 and this is the first time after decades of annual increases. The report was commissioned by Janssen Pharmaceutica and the research was conducted by Deloitte Health Economics group.

According to the report, this decline is due to the current economic situation, reinforced by the uncertainty about future market conditions, and increasingly limited reward mechanisms for innovative technologies, amongst others. The findings are worrying in the light of Europe's increasing disease burden and aging population, as well as the millions of people whose health cannot be improved without new health care approaches.

Healthcare costs in Europe are expected to increase to 12-15% of GDP by 2030. The report concludes that increased health R&D investment is even more important to address in the context of growing healthcare expenditure.

For example, new technologies improve the quality of healthcare provision, leading to improved outcomes and increased life expectancy. New technologies also lead to efficiency gains, as their cost tends to decrease over time for both medicines and medical devices. Improved health leads to better productivity among the working

population and may even increase the maximum working age. Health R&D investments also have the potential to provide high economic yields, both in terms of return on investment and deploying a highly educated workforce with technical skills.

The report can be downloaded from Janssen's website.

www.janssen-emea.com/reports/health/investment-study

21 October: New guide to outdoor living spaces for people with dementia



Fondation Médéric Alzheimer (FMA) has published an English-language version of their very popular report on outdoor spaces.

"Gardens: Outdoor living spaces for the well-being of people with Alzheimer's disease and their entourage" analyses the operational features of twenty-one gardens in care homes and day care centres that are supported by FMA. The results are mainly based on site surveys - including observation, interviews with professionals, residents and families - but also on seminars and reports from field teams.

Results were gathered over several years and show a growing interest in outdoor spaces and their development. There is a huge diversity of practices and examples of creating and maintaining outside spaces that are attractive and lively. It is quite clear that such spaces provide resources and benefits to people with cognitive impairments.

Gardens are often perceived as privileged places, as they are meeting points between the care home and the outside world. They provide a space for pleasant and memorable activities, which help to improve the living environment and quality of life of the residents. In addition, many care home residents are keen gardeners, actively participating in its operation and upkeep. Residents are also routinely consulted on design, landscaping and other future plans for outdoor spaces. In this sense, a garden becomes a living space that residents, care professionals, family members and visitors can all call their own.

The report is available free of charge on the foundation's website.

www.fondation-mederic-alzheimer.org/content/download/16665/73747/file/Report%20GARDENS%20FONDATION%20MEDERIC%20ALZHEIMER%20September%202013.pdf

28 October: New resource for people with dementia in Ireland



The Alzheimer Society of Ireland has launched a new booklet entitled "I have dementia...How do I plan for the future?"

The aim of this new resource is to help people with early stage dementia and their families to plan for their future. It provides accessible information and signposting around financial, legal, health and care planning. Helen Rochford Brennan, a member of the Irish Working Group of People with Dementia, kindly gave her time and support to this project.

The booklet is part-funded by the Irish Hospice Foundation and can be downloaded on the society's website.

[www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimers_PlanForFuture-Brochure_web1-\(1\).pdf](http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimers_PlanForFuture-Brochure_web1-(1).pdf)

29 October: New report on managing BPSD - behavioural and psychological symptoms of dementia

Australia's Dementia Collaborative Research Centres (DCRC) have published a report entitled "Managing Behavioural and Psychological Symptoms of Dementia".

This is a guide to good practice for managing behavioural and psychological symptoms of dementia (BPSD). It aims to provide guidance for clinicians in their role of assisting residential aged care facility staff, community care staff and family members caring for persons living with dementia who present BPSD symptoms.

The report includes a comprehensive evidence and practice-based overview of BPSD management principles, as well as practical strategies and interventions for assisting care staff and family carers to manage behaviours in dementia. The empirical evidence contained in this guide, in combination with clinical expertise, may assist in achieving improved outcomes for those with dementia.

The report can be downloaded on the DCRC website.

http://dementiaresearch.com.au/images/dcrc/output-files/328-2012_dbmas_bpsd_guidelines_guide.pdf

Job opportunities

29 October: AE is hiring Communications, Project and Finance Officers

Alzheimer Europe is accepting applications for the following positions:

Communications Officer (m/f) (Full time)

- As the Communication Officer, you will:
- Edit the association's newsletter
- Maintain and update the association's website (www.alzheimer-europe.org)
- Develop the organisation's social media presence.

You should have the following experience and qualities:

- Completed university education and/or significant experience in a similar position (education or background in communication or journalism will be considered as an advantage)
- A perfect knowledge of English (additional languages would be considered a plus)
- Excellent writing skills
- Experience of social media
- Good computer knowledge (Internet applications, Word)
- A keen sense of responsibility and initiative,
- Willingness to work in a small team.

Project Officer (m/f) (Full time)

As the Project Officer, you will:

- Collaborate with the organisation's national member associations in the development of national reports on dementia policies
- Develop and update databases on clinical trials and diagnostic and treatment guidelines in Europe
- Support the development of project applications towards EU programmes
- Help in the dissemination of EU funded research projects.

You should have the following experience and qualities:

- Completed university education and/or significant experience in a similar position (education or background in communication or project management will be considered as an advantage)
- A perfect knowledge of English (additional languages would be considered a plus)
- Excellent writing skills
- Good computer knowledge (Internet applications, Word)
- A keen sense of responsibility and initiative
- Willingness to work in a small team.

Finance Officer (m/f) (Part time)

As the Finance Officer, you will:

- Deal with daily book keeping, invoicing and financial monitoring of the organisation
- Prepare monthly financial reports
- Prepare annual financial reports for audit purposes
- Develop annual budgets
- Prepare budgets and monitor accounts of EU projects
- Support fundraising activities.

You should have the following experience and qualities:

- Completed university education and/or significant experience in a similar position (education or background in accounting, financial management or fundraising will be considered as an advantage)
- A perfect knowledge of English and French (additional languages would be considered a plus)
- Excellent accounting skills
- Good knowledge of accounting software and other computer programmes (Internet applications, Excel)
- A keen sense of responsibility and initiative
- Willingness to work in a small team.

Please apply by sending your CV, together with a cover letter, by **22 November 2013**, to: Alzheimer Europe, 145, route de Thionville, L-2611 Luxembourg or via e-mail to info@alzheimer-europe.org



www.alzheimer-europe.org/Donation

Contact Alzheimer Europe:

Alzheimer Europe, 145 route de Thionville, L-2611, Luxembourg info@alzheimer-europe.org, www.alzheimer-europe.org

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Alzheimer Europe Staff

Executive Director: Jean Georges; EU Public Affairs Advisor: 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
5 November	AGE Platform launch of its EU campaign Manifesto, (Brussels, Belgium)	Annette
14 November	Conference “It is Time to Care” (Rome, Italy)	Jean
22 November	GSK Health Advisory Board (London, United Kingdom)	Jean
25 November	EIP AHA conference of partners (Brussels, Belgium)	Annette
27 November	Scientific Advice Meeting at European Medicines Agency (London, United Kingdom)	Jean
2-3 December	AE Board meeting, EP Lunch debate and corporate meeting (Brussels, Belgium)	AE Board and staff
10-11 December	EMA working party for CHMP WPCP meeting (London, UK)	Jean & Alex
11 December	NILVAD project meeting (London, UK)	Alex
12-13 December	EMIF project - 2 nd AD General Assembly (Amsterdam, the Netherlands)	Alex

Future Conferences

Date	Meeting	Place
14-16 November 2013	6th annual conference Clinical Trials for Alzheimer’s disease CtAD 2013, www.ctad-alzheimer.com	San Diego, USA
22 November 2013	Open Info Day - Horizon 2020 "Health, demographic change and wellbeing", http://ec.europa.eu/research/health/horizon-2020-health-open-info-days_en.html	Brussels, Belgium
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), www.comtecmed.com/cony/2014/	Berlin, Germany
31 May-3 June 2014	EFNS-ENS Joint Congress of European Neurology, www.JointCongressofEuropeanNeurology.org	Istanbul, Turkey
26-27 June 2014	International Dementia Conference, "Risky Business 2 – this time it's personal!", http://www.dementiaconference.com/call-for-papers	Sydney, 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”, www.alzheimer-europe.org/Conferences	Glasgow, United Kingdom
23-25 October 2014	9 th International Conference on Frontotemporal Dementias, www.ubccpd.ca	Vancouver, Canada

24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014

Mark the dates!

www.alzheimer-europe.org/conferences



The Alzheimer Europe newsletter arises from the 2013 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.