



NEWSLETTER

January 2013

Highlights in this issue

2 January: AE welcomes Kate Ellis	2
14 January: EMA approves two generic dementia drugs	9
24 January: Commission seeks expert advisors	4
30 January: Commission hiring post-docs researchers	11
31 January: MEP Marina Yannakoudakis becomes EAA Vice-Chair	3



Table of contents

Editorial	1
Alzheimer Europe.....	2
AE Projects	2
European Alzheimer's Alliance	3
AE Networking 2013.....	3
EU Developments.....	4
Members' News	5
Science Watch	8
Dementia in Society	10
New Publications & Resources.....	10
Job opportunities	11
AE Calendar 2013	11
Future Conferences.....	12

Editorial

Alzheimer

Europe started the new year by welcoming a new colleague: Kate Ellis joined us on 2 January as a replacement for Gwladys, who is now on maternity leave. In addition, we bid farewell to Jan Frederik Meijer, one of the founding members of the European Working Group of People with Dementia.



The European Alzheimer's Alliance also saw a departure, as Frieda Brepoels resigned from the European Parliament. She was an ardent EAA activist and we thank her for her efforts. We're also very pleased to welcome Marina Yannakoudakis as the new Vice-Chairperson of the alliance.

In a few weeks we'll be holding the first lunch debate of the year at the European Parliament. The debate will focus on clinical trials and we'll also circulate the latest issue of Dementia in Europe magazine. This will be followed by a Public Affairs meeting where we'll outline our research plans for 2013. We hope to see many delegates from our member associations in Brussels - especially as they'll play a major role in our research.

Our members were also productive in January. The Dutch association provided funding for dementia-related research and Jersey launched a new specialised nursing service. Slovenia continues to attract crowds to its Alzheimer Café sessions. Portugal opened a new care home designed for people with dementia and the association's new Board members took office. Spain's CEAFA also elected a new Board and Federazione Alzheimer Italia began their annual awareness campaign. The UK Alzheimer's Society

unveiled a dementia mapping tool and also released new home care resources.

Back in Brussels, the Commission is recruiting post-doc researchers - including specialists in the life and health sciences - as well as experts from all fields for the Horizon 2020 programme. The Commission also launched a new health initiative targeting chronic diseases and multimorbidity. Meanwhile, Ireland took over the EU Council Presidency and will try to conclude the discussions around research funding in Horizon 2020.

In scientific news, the EMA approved two generic drugs for dementia and a Dutch group - including Alzheimer Nederland - is researching ways to ease the impact of lumbar punctures. The NILVAD project, in which AE is a partner, has appointed a new Scientific Medical Advisor and has also secured additional funding. The DECIDE project is drawing to an end, with a final workshop and conference planned in February.

January also saw the release of a report from Mental Health Europe, urging governments to replace existing guardianship policies with supported decision-making.

Finally, our website has been updated with the latest news about the 23rd Annual Conference in Malta. The abstracts are already coming in and we look forward to reading many more by the 30 April deadline. For those who are unfamiliar with our conferences, we suggest a visit to the AE website: it now features videos from our 2012 conference in Vienna.

Jean Georges
Executive Director

Alzheimer Europe

2 January: Kate Ellis joins Alzheimer Europe



Alzheimer Europe is pleased to welcome Kate Ellis, who joined the team on 2 January. Kate will replace Gwladys during her maternity and parental leave and will stay with us until July 2014. You can reach her every afternoon at:

Katherine.ellis@alzheimer-europe.org

14 January: Jan Frederik Meijer resigns from EWGPWD

Jan Frederik Meijer, Vice Chairperson of the European Working Group of People with Dementia, has resigned from the Group following a second opinion that contradicted his initial dementia diagnosis.

Mr Meijer's second opinion concluded that he is not suffering from any form of dementia. It was issued at VU University Medical Center (VUmc) in Amsterdam, an institution that specialises in dementia at younger ages. Jan Frederik was initially diagnosed four years ago at the age of 58.

Alzheimer Europe was very pleased to hear that Jan Frederik is not living with dementia. This highlights once again the importance of obtaining an early and accurate diagnosis, for all age groups. It is particularly critical in younger people like Jan Frederik, where dementia is less prevalent but often more difficult to diagnose.

The EWGPWD was very glad to have Jan Frederik in the group, even for such a short time. The remaining members, along with everyone at Alzheimer Europe, thank him for his contributions and wish him all the best for the future.

15 January: AE announces abstract deadline for 2013 Conference

The deadline for submitting abstracts for the 2013 Alzheimer Europe Conference is **30 April 2013**. For more information and updates, please visit the AE website.

www.alzheimer-europe.org/Conferences/St.-Julian-s-Malta-2013

15 January: Videos from Vienna are online

The videos and photos from the 22nd Alzheimer Europe Conference are now available on the AE website. There are videos of all the plenary sessions and many of the parallel sessions, including the German-language sessions and those involving people with dementia.

www.alzheimer-europe.org/Conferences/Previous-conferences/2012-Vienna/Conference-Photos-and-Videos



AE Projects

2 January: NILVAD welcomes new Scientific Medical Advisor



The NILVAD partners are delighted to welcome Dr. Sean Kennelly to the project as Scientific Medical Advisor to Dr. Brian Lawlor, Project Coordinator.

Dr. Kennelly, a Consultant Geriatrician at Dublin's Tallaght Hospital, has been informally associated with the project since it began. He will provide his expertise and input during the clinical trial phase. Dr. Lawlor said: "Going forward, I hope that Sean will also be able to contribute to the some of the scientific developments that will arise from our work."

9 January: NILVAD partner secures funding for sub-study



Dr. Olga Meulenbroek, NILVAD partner from Radboud University Nijmegen Medical Centre in the Netherlands, has recently received funding for the proposed sub-study on cerebral blood flow (CBF). She made successful applications to both ADDF (Alzheimer's Disease Drug Foundation) and Alzheimer Nederland.

ADDF, founded in 2004, is a public charity that supports the advancement of drugs to prevent, treat, and cure Alzheimer's disease, related dementias, and cognitive aging. Alzheimer Nederland has provided help and information to people with dementia and their communities for more than 25 years.

The CBF sub-study will monitor the effects of Nilvadipine on cerebral autoregulation, blood pressure, cerebral blood flow and cerebral damage of the participants in Nijmegen throughout the clinical trial, using sophisticated blood monitoring and measurement techniques that include Arterial Spin Labelling (ASL) MRI, transcranial doppler and near infra-red spectroscopy.

www.nilvad.eu

21 January: DECIDE will hold training sessions and user forum



The DECIDE project team will hold a training session for new users and a forum for existing users on

21-22 February.

DECIDE is an FP7-funded project aimed at implementing an e-infrastructure and e-service for the automatic extraction of disease markers for Alzheimer's disease from RMI and PET/SPECT images and EEG traces.

DECIDE is already available to trained users through a simple web interface. The service is primarily aimed at researchers and clinicians. It is intended for research purposes and also as a support to early diagnosis of the disease.

On 22 February, the [DECIDE User Forum](#) will bring together early adopters and newly trained users, in order

to discuss the exploitation of DECIDE applications in real patient cases. By discussing case histories, users can gain a better understanding of the service, while the project can collect valuable feedback to further improve the tools it offers and fit them to the real needs of clinical and research users.

Participants may attend the User Forum training in Rome, Italy, or access the session remotely. In either event, they are invited to register at:

<http://agenda.ct.infn.it/confRegistrationFormDisplay.py/display?confId=883>

For more information, please see:

http://agenda.ct.infn.it/event/decide_UF

The DECIDE Applications Training on 21 February is intended for those who have not yet been trained, or wish to learn more about the other applications. Three application tracks are available:

- GridSPM (PECT/SPECT diagnostic applications)
- GridMRIseg and GridGDI (RMI diagnostic application)
- GridEEG (EEG research application).

Participants for the training - which can also be followed remotely - can register at:

http://agenda.ct.infn.it/event/DECIDE_training_Rome

Participation is free of charge for both events. A limited budget is available to cover travel expenses of participants, in case their organisation cannot support their attendance. However, no reimbursement will be granted without the prior assent of the project managers.

For more details, participants are kindly requested to contact info@eu-decide.eu

European Alzheimer's Alliance

31 January: Marina Yannakoudakis replaces Frieda Brepoels as EAA Vice-Chair



On 31 January 2013, Frieda Brepoels, MEP (Belgium) and Vice-Chairperson of the European Alzheimer's Alliance (EAA), resigned from the European Parliament.

This decision follows her victory in the local elections of October 2012 in Belgium last October: Frieda became Mayor of her hometown Bilzen on 1 January 2013.

Alzheimer Europe warmly thanks Frieda for her unfailing support to dementia during her two mandates in the European Parliament and wishes her all the best for the future.

Marina Yannakoudakis (UK, ECR), a long-standing and supportive member of the Alliance, has accepted to take over as Vice-Chair of the Alliance.

She said: "I am delighted to take over as European Alzheimer's Alliance Vice-Chair. We need more awareness of Alzheimer's as well as ensuring quality care for those affected and adequately funded research into the causes of the disease. I hope that as Vice-Chair of the European Alzheimer's Alliance that I can help to begin to achieve these goals."

For more information on Marina's activities, please see www.marinayannakoudakis.com

The European Alzheimer's Alliance was set up in the European Parliament in 2007. This is a non-exclusive, multinational and cross-party group that currently brings together 65 MEPs committed to support Alzheimer Europe and its members to make dementia a public health priority in Europe. Over the years, the coordinated work of the European Alzheimer's Alliance, Alzheimer Europe and its members has significantly raised awareness about dementia in Europe and helped to prioritise dementia on the EU agenda.

Photos: Frieda Brepoels (left), Marina Yannakoudakis.



www.alzheimer-europe.org/EN/Policy-in-Practice2/European-Alzheimer-s-Alliance

Alzheimer Europe Networking 2013

On 9 January (Brussels, Belgium) Dianne attended a meeting of the proposed FP7 project PACE.

On 10 January 2013 (Brussels, Belgium) Annette attended the Sanofi EU Patients Workshop dedicated to Clinical Trials.

On 10-11 January (Malta) Gwladys had a meeting in Malta for the 23rd Alzheimer Europe conference.

On 17 January (Luxembourg, Luxembourg) Jean met Marc Wortmann from ADI.

On 21 January (Brussels, Belgium) Dianne attended the ALCOVE meeting on advance directives and competence assessment organised by the King Baudouin Foundation.

On 25 January (Prague, Czech Republic) Dianne attended the INTERDEM meeting.

On 28 January 2013 (Brussels, Belgium) Annette attended the Europabio/Pfizer meeting in the European Parliament on "The future of clinical trials".

On 29-30 January (Brussels, Belgium) Dianne attended the EFGCP seminar "Virtual future: the ethical dimensions of emerging technologies in clinical trials and research".

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at 65, representing 22 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:** Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnock 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), Weisgerber Anja (EPP). **Greece:** Chountis Nikolaos (GUE-NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP). **Ireland:** Aylward Liam (ALDE), Childers Nessa (S&D), Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP). **Italy:** Mauro Mario (EPP), Panzeri Pier Antonio (S&D), Toia Patrizia (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **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). **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badiá i Cutchet Maria (S&D). **United Kingdom:** Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (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

8 December: EU announces Joint Action on chronic diseases

On 8 December 2012, the European Commission announced the launch of a Joint Action called "Addressing chronic diseases and promoting healthy ageing across the lifecycle". This will address the burden of chronic diseases - with a special focus on multimorbidity - with a budget of EUR five million.

An additional budget of EUR one million will be made available for project grants in support of the Joint Action. The grants will focus on the promotion of healthy lifestyles among the 65+ age group through the prevention of specific risks, e.g. unhealthy lifestyles and social isolation.

http://ec.europa.eu/eahc/documents/health/calls/2013/HP_work_plan_for_2013.pdf

http://ec.europa.eu/health/major_chronic_diseases/reflection_process/index_en.htm

1 January: Ireland takes over the EU Council Presidency



On 1 January, Ireland took over the Presidency of the Council of the European Union from Cyprus for the next six months.

The Presidency programme "For stability, jobs and growth" was officially launched on 9 January and will continue the EU drive for recovery. It aims to secure stability in the aftermath of the economic crisis, particularly investment in sustainable jobs and growth.

In the field of justice and home affairs, the Presidency will seek to strengthen the rights of the citizens within the scope to the European Year of Citizens. In research, the Presidency will seek to reach an agreement on Horizon 2020 - the next EU programme for research and innovation. In health policy, the Presidency will promote the legislative proposals to improve public health and support research and innovation. This will cover cross-border health threats, Health for Growth (the next EU Public Health programme), tobacco and pharmaceutical and medical devices.

<http://eu2013.ie/>

10 January: Launch of 2013 European Year of Citizens

On 10 January 2013, the European Year of Citizens 2013 was officially launched in Dublin, Ireland, by European Commission President José Manuel Barroso, Irish Prime Minister Enda Kenny and Deputy PM Eamon Gilmore.

The launch was immediately followed by the first Citizens' Dialogue of the European Year with European Commission Vice-President Viviane Reding and Irish Minister of State for European Affairs, Lucinda Creighton. This Dialogue gave the audience the opportunity to discuss the EU's future, their rights, the kind of Europe they want to live in, and their expectations for the European Union. Their opinions will feed into future Commission proposals on strengthening rights in the Union.

The European Year will raise awareness of EU citizens' rights and will trigger public debate on the development of EU citizenship in particular and of Europe in general, with a view to the EP elections of 2014.

To support its members and other stakeholders to spread key messages at local and regional level, the Committee of the Regions has developed an online toolkit with background information and communication material.

A range of events, conferences and seminars will be organised across the EU at Union, national, regional or local level. Ms Reding and other EU Commissioners will join forces with national and local politicians to hold debates with citizens all across Europe - to listen to them and answer their questions.

<http://europa.eu/citizens-2013>

<http://europa.eu/citizens-2013/en/news/european-year-citizens-2013-officially-launched>

www.cor.europa.eu/ey2013

<http://ec.europa.eu/european-debate>



www.alzheimer-europe.org/Donation

24 January: Commission seeks expert advisors for Horizon 2020

The European Commission has launched a call asking experts from all fields to participate in shaping the agenda of Horizon 2020, the EU funding programme that will follow FP7.

Advisory groups will provide advice for the preparation of the Horizon 2020 calls for project proposals. Groups will be set up on topics of major concern - including coping with the challenges of ageing - and they will remain active until 2020.

The expert advisory groups will start their work during spring 2013 and the first Horizon 2020 calls are expected to go out by the end of the year.

Interested individuals can register until 6 March 2013. More information is available on the Horizon 2020 website.

http://ec.europa.eu/research/horizon2020/index_en.cfm?pg=h2020-experts

28 January: Future and Emerging Technology winners

On 28 January, the European Commission announced the "Human Brain Project" and "Graphene" as the winners of the multi-billion euro Future and Emerging Technologies (FET) competition.

These projects will receive one billion euros to deliver ten years of world-beating science at the crossroads of science and technology. Each initiative involves researchers from at least 15 EU Member States and nearly 200 research institutes.

The Human Brain Project will create the world's largest experimental facility that will develop a highly detailed model of the human brain, study how the brain works and develop personalised treatments for neurological and related diseases. The project involves scientists from 87 institutions and is led by Prof Henry Markram of the École Polytechnique Fédérale de Lausanne.

The project intends to advance knowledge in neuroscience and neuro-informatics, as the brain simulation will collect and integrate experimental data, identifying and filling gaps in our knowledge. In medicine, the project's results will facilitate better diagnosis, combined with disease and drug simulation. In computing, new techniques of interactive supercomputing will impact a range of industries, while devices and systems, modelled after the brain, will overcome fundamental limits on the energy-efficiency, reliability and programmability of current technologies, clearing the road for systems with brain-like intelligence.



www.humanbrainproject.eu

http://europa.eu/rapid/press-release_MEMO-13-36_en.htm

<http://ec.europa.eu/digital-agenda/en/news/graphene-and-human-brain-project-win-largest-research-excellence-award-history>

Members' News

28 December 2012: Correction to "Scottish Dementia Working Group celebrates 10th birthday"



The photo caption in this article from last month's newsletter was incorrect. The gentleman is Edward McLaughlin, not David Batchelor. He is pictured with Nicola Sturgeon and Agnes Houston (right). Alzheimer Europe regrets the error.

2 January: Jersey launches Admiral Nurse Service

Jersey Alzheimer's Association Dementia Matters



On 2 January, the Jersey Alzheimer's Association was very pleased to welcome Carol Courtney, an Admiral Nurse who will operate the first such service outside the UK.

Admiral Nurses are specialist mental health nurses who work exclusively with families affected by dementia to offer specialist psychological support, information and advice on all aspects of caring. They may be involved at different points over time, from pre-diagnosis to beyond bereavement. The Admiral Nurse Service is fully funded by the Jersey Alzheimer's Association.



Carol Courtney, RMN, PG DIP (Health Sciences Research) Diploma in Counselling (Gestalt), PG Cert Systemic Practice, Behavioural Family Therapy (Trainer), has over 23 years' experience of working in both adult and older adult mental health. She has been an Admiral Nurse for 10 years in the UK. Prior to this, she worked in clinical dementia research at Birmingham University for six years. Carol also heads a special interest working group for Dementia UK on family therapy and Admiral Nursing; she is working towards a PhD on using and adapting family therapy models for families dealing with dementia.

6 January: Alzheimer Portugal celebrates anniversary and opens first dementia care home



On 6 January, Alzheimer Portugal celebrated the 10th anniversary of its first Day Care Centre in Lisbon - the first centre conceived specifically for people with dementia in Portugal. On the same day, the association inaugurated the first care home of the association that is specifically designed for people with dementia.

The Home and Day Centre "Casa do Alecrim" is a new construction, specially designed to cater to the needs of people with dementia. The design favours autonomy, security and respect and features indoor and outdoor dining areas.

The home is staffed by six people who can host up to 30 clients in home care, 15 in day care and 50 in home support service. Every new resident is encouraged to contribute to an individual Intervention Plan. This plan

accommodates the habits, tastes and customs of the resident and will be reviewed on a regular basis. The home, located in Cascais, also offers a range of therapeutic activities for both residents and day clients.

Maria do Rosario dos Reis Zincke, President of the National Directorate of Alzheimer Portugal, said:



"With this equipment, the result of hard work and enormous generosity of various individuals and entities, both public and private, Alzheimer Portugal takes another significant step in improving the quality of life for people with dementia and their family caregivers. The Casa do Alecrim was designed, and will be, a privileged centre of care and the dissemination of good practices."

January 6 was also the day the new Board took office, following the elections of 17 November. The new Chairman is João Carneiro da Silva. He is a civil engineer, former carer and a very enthusiastic member of Alzheimer Portugal from the very beginnings of the association in 1998.

The election results showed that the new Board has strong support from the associates. Alzheimer Portugal is very proud of its achievements and remains optimistic on the abilities of the Board to face the huge demanding challenges of these difficult times.

6 January: UK dementia map shows regional variations of diagnosis



The UK Alzheimer's Society has produced an interactive map that highlights the number of people who have a diagnosis of dementia in different Primary Care Trusts (PCT) in the UK. PCTs are units of the NHS that commission health care on a local level. The map shows wide variations in how many people are receiving diagnoses of dementia.

The results are based on a survey of Memory Clinics, with two thirds of all PCTs responding. The aim of the survey was to investigate the quality of assessment received by people with dementia.

Results show a 3% increase in the number of people in the UK that have been diagnosed with dementia. This raises the number of people who now have a formal diagnosis to 46%. However, there are thought to be another 428,000 people (54%) who are living with the condition but are not diagnosed.

Jeremy Hughes, Chief Executive at Alzheimer's Society said: "It's disgraceful that more than half of all people with dementia are not receiving a diagnosis, and disappointing to see such a disparity in diagnosis rates in different regions of the UK. This goes against best clinical practice and is preventing people with dementia from accessing the support, benefits and the medical treatments that can help them live well with the condition."

The results of the survey also showed that only 11% of all memory services in the UK are accredited. The average waiting time for an appointment is 32.5 working days, more than the 4-6 weeks recommended by the Memory Service National Accreditation Programme. Some memory clinics reported waiting times of up to 9 months.

alzheimers.org.uk/dementiamap

14 January: Alzheimer Scotland comments on the launch of Souvenaid



On 14 January, Alzheimer Scotland issued a press release in response to the launch of the Souvenaid food supplement, which was introduced to the UK market on the same day. Souvenaid is aimed at people in the early stages of Alzheimer's disease and can be obtained without prescription.

The Scottish association urges Nutricia (Souvenaid's maker) to take steps to make the product available via prescription through the NHS, so that it may be reimbursed in the same way as other food supplements.

See also the article on page 9 of this newsletter about the launch of Souvenaid. The full text of the press release can be found on Alzheimer Scotland's website.

www.alzscot.org

15 January: Alzheimer Nederland awards EUR 1.8 million for dementia research

Alzheimer Nederland has announced awards of EUR 1.8 million for nine dementia research projects and three fellowships.



The research projects will investigate potential causes of dementia, including stress, blood-brain barrier leakage, brain functioning (fMRI), newly identified proteins in the hippocampus and a novel gene mutation that causes Amyotrophic Lateral Sclerosis (ALS) and Fronto-temporal dementia (FTD).

Researchers will also aim to reduce the effects of dementia symptoms, namely symptoms of paratonia in Alzheimer's disease and relieving symptoms of vascular dementia with medicines that stimulate deficit neurotransmitters and also reduce factors leading to comorbidity.

Another project will study the effects of the drug nilvadipine on blood pressure and cerebral autoregulation, blood flow and damage.

Finally, three research fellows will receive funding to introduce new knowledge from abroad to Dutch research groups.

20 January: FAI launches annual campaign in Italy



On 20 January, Federazione Alzheimer Italia (FAI) started its annual campaign to raise awareness and funds for "Pronto Alzheimer" - the first telephone hotline for families of people with Alzheimer's disease in Italy. The campaign will run until 10 February, supported by a TV spot called "The memory

room" that will appear on national and local television networks.

The hotline provides callers with information, support, psychological help and advice relating to the legal, social security, psychological and social aspects of living with dementia. In addition, callers are directed towards the most appropriate local services available.

Pronto Alzheimer was created 20 years ago to give practical help to people with dementia, their families and caregivers. Since then, it has responded to over 130,000 requests for help.

In 2012, the service recorded 5,127 contacts from all over Italy in a dedicated database. 3,176 of these contacts were from patients' family members, with many making multiple contacts. The main topics of interest were:

- information about the disease and patient management, research, diagnostic centres and local services, legal and fiscal problems (2,939 calls)
- requests for explanatory documentation and books (506)
- psychological support (172)
- appointments to receive legal, psychological and social support (152).

Today, Pronto Alzheimer represents 30% of all FAI activities and has become the national reference point both for the families and the professionals who deal with Alzheimer's disease.



www.youtube.com/user/AlzheimerItalia

21 January: Alzheimer Hellas organises New Year's Celebration event



On 21 January, Alzheimer Hellas celebrated the New Year by holding an event to cut the "Vasilopita", or Saint Basil's pie. This is a very common custom in Greek homes: the pie contains a special coin and tradition holds that whoever finds it will be lucky for the whole year.

The successful social event was held in Thessaloniki and attracted more than 300 people, including people with dementia, their families and caregivers and Alzheimer Hellas staff. They had the opportunity to socialise in a friendly environment and the programme also included live music and dancing.

Alzheimer Hellas has more such events planned for 2013, in the continuous effort to improve the quality of life for people with dementia.

23 January: Spominčica holds Alzheimer Cafés in Slovenia



Slovenia's Spominčica association began the year with two Alzheimer Café events. The first one took place in Ljubljana and featured an interactive memory exercise and a cultural programme with poetry readings and a song recital. The second Café took place on 31 January in the town of Domžale. Both events were very well attended.

Štefanija Lukič-Zlobec, Vice President of the association, happily reports that she may soon need bigger venues, as the Café events keep gaining in popularity. There are already four sessions planned for February.



26 January: Spain's CEFAA elects new Board



On 26 January, the Confederación Española de Asociaciones de Familiares de personas con Alzheimer y otras Demencias (CEFAA) elected a new Board. The new Board members are:

- President: Mr Koldo Aulestia (pictured)
- Vice President: Mr Juan Carlos Rodríguez
- Secretary: Mr Josep Gasulla
- Treasurer: Mrs Rosa M^a Cantabrana.



The new Board members, elected by majority vote of the CEFAA associations, will work toward improving the lives and social benefits of people with Alzheimer's disease. In particular, they will continue to campaign for a national Alzheimer's strategy and increase CEFAA's visibility and influence within the Spanish government.



www.alzheimer-europe.org/Donation

28 January: Alzheimer Nederland aims to reduce the impact of lumbar punctures

Alzheimer Nederland, along with three other Dutch health care associations, is participating in a large research project to reduce the impact of lumbar punctures. These invasive procedures are commonly used in diagnosing Alzheimer's disease.

The associations will support Dutch technology institute "TNO" in its investigation of using non-invasive light

technology to measure proteins in the spinal fluid. The project team (pictured) signed the agreement on 28 January.



www.alzheimer-nederland.nl/actueel/onderzoek/2013/januari/vervangingsruggenprik.aspx

Science Watch

2 January: Alzheimer's gene variants are found in infants

A recent study shows that brain changes found in adults with gene variants linked to Alzheimer's disease can also be seen in MRI brain scans done on new born babies.

Researchers from the University of North Carolina (UNC) School of Medicine gave MRI scans to 272 babies shortly after birth. Each infant's DNA was screened for common variations in genes associated with disorders like Alzheimer's disease, schizophrenia and bipolar disorder. When these brain changes were compared to those from adults with the same afflictions, the researchers found many similarities.

Dr. Rebecca Knickmeyer, study author and Assistant Professor of Psychiatry at UNC, said: "These results suggest that prenatal brain development may be a very important influence on psychiatric risk later in life. This could stimulate an exciting new line of research focused on preventing onset of illness through very early intervention in at-risk individuals."

<http://cercor.oxfordjournals.org/content/early/2013/01/02/cercor.bhs401.1.abstract?sid=b7395aa3-8956-42bb-a10b-41a2782f108c>

2 January: Memantine is ineffective in FTD trial

A clinical trial of Memantine to treat frontotemporal lobar degeneration (FTD) has not shown any benefits.

The trial, sponsored by the University of California (San Francisco) and Forest Laboratories, involved 81 participants who received memantine or placebo over 26 weeks. The treatment had no effect on either NPI or CGIC measurements.

[www.thelancet.com/journals/laneur/article/PIIS1474-4422\(12\)70320-4/fulltext#article_upsell](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(12)70320-4/fulltext#article_upsell)

2 January: TFP5 reverses memory loss in mouse models

A new study shows that injections of the TFP5 molecule reversed dementia symptoms and improved memory in Alzheimer mouse models. The research team was led by Dr. Harish C. Pant, Senior Investigator at the National Institute of Neurological Disorders in Bethesda, Maryland.

Researchers gave injections of TFP5 to a group of mice and saline injections to the controls. The TFP5 mice

showed a significant restoration of memory loss and did not experience any weight loss, neurological stress or signs of toxicity. TFP5 works by partially blocking the activity of Cdk5, a chemical that is abnormally hyperactive in Alzheimer's disease.

Dr. Pant said: "We hope that clinical trial studies in AD patients should yield an extended and a better quality of life as observed in mice upon TFP5 treatment. Therefore, we suggest that TFP5 should be an effective therapeutic compound."

www.fasebj.org/gca?gca=fasebj%3B27%2F1%2F174&allch=&submit=Go

8 January: Beta blockers may protect against dementia

A new study suggests a link between the use of beta blockers and fewer signs of dementia. The study was led by Dr. Lon White, Professor of Geriatric Medicine at the University of Hawaii.

Researchers examined the brains of 774 elderly men after death. 610 of these men had high blood pressure or were being treated for high blood pressure. Among the 350 who had been treated, 15% had received beta blockers alone, 18% had been given beta blockers plus another high blood pressure medication and the rest had received other drugs.

The study found that all the treatments were better at protecting the brain than no treatment. More importantly, the men who had taken only beta blockers had significantly fewer brain abnormalities than the rest. Those who had taken beta blockers and another drug also showed less abnormalities. In addition, all men who had taken any beta blockers had significantly less brain shrinkage than the others.

Dr. White said: "These results are exciting, especially since beta blockers are a common treatment for high blood pressure."

The results of this study will be presented at the American Academy of Neurology's annual meeting in March 2013.

www.abstracts2view.com/aan/view.php?nu=AAN13L_S44.005&terms=

11 January: Bilingual people maintain cognitive function in old age

Researchers from the University of Kentucky (UK) College of Medicine in Lexington have shown that bilingual people maintain more cognitive control abilities as they age. The study team, led by Dr. Brian Gold, Associate Professor of Anatomy and Neurobiology at UK, performed two tests on 110 monolingual and bilingual subjects.

The first was an attention-switching task that required quick sorting of colours and shapes: the bilingual subjects were significantly better than the monolinguals. The subjects then repeated the task while undergoing MRI scans. Results showed that the brains of the monolingual people were working harder to complete the task, while the bilingual brains were much more efficient, similar to those of young adults.

For Dr. Gold, these results suggest that lifelong bilingualism offsets age-related declines in the neural efficiency for cognitive control processes.

www.jneurosci.org/content/33/2/387.abstract?sid=bf4daf5-8e74-45ce-a8f3-a8b52f6cb31d

14 January: Souvenaid food supplement launches in UK

A new food supplement called Souvenaid has been launched in the UK. It is designed to support synapse formation and function in early Alzheimer's disease.

Souvenaid is marketed in the form of a milkshake and contains a combination of nutritional precursors (docosahexaenoic acid, eicosapentaenoic acid, uridine monophosphate and choline) and cofactors (phospholipids, folic acid, vitamins B, C and E and selenium).

A clinical trial has shown that the supplement showed some benefit for memory in people with mild Alzheimer's disease who were not taking any other medicine.

Souvenaid is produced by Nutricia, the medical food division of Danone Research.

www.ncbi.nlm.nih.gov/pubmed/22766770



www.alzheimer-europe.org/Donation

14 January: EMA approves Memantine Merz and Maruxa generics

The European Medicines Agency (EMA) has approved the drugs Memantine Merz and Baruxa for the treatment of moderate to severe Alzheimer's disease. Both drugs are generic versions of Merz's Axura and Lundbeck's Ebixa.

Memantine works by blocking special types of receptor called NMDA receptors, to which the neurotransmitter glutamate normally attaches. Neurotransmitters are chemicals in the nervous system that allow nerve cells to communicate with one another.

Changes in the way glutamate transmits signals within the brain have been linked to the memory loss seen in Alzheimer's disease.

In addition, overstimulation of the NMDA receptors can result in cell damage or death. By blocking NMDA receptors, memantine improves the transmission of signals in the brain and reduces the symptoms of Alzheimer's disease.

http://www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicines/002711/human_med_001599.jsp&mid=WC0b01ac058001d124
http://www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicines/002658/smops/Positive/human_smop_000472.jsp&mid=WC0b01ac058001d127

16 January: MPL molecule clears plaque in mouse models

A team of researchers from Quebec's Université Laval and GlaxoSmithKline (GSK) has discovered that the MPL molecule can stimulate the brain's natural defence mechanisms in people with Alzheimer's disease. MPL (monophosphoryl lipid A) has been used by GSK as a vaccine component for many years.

The scientists were led by Dr. Serge Rivest, Professor at Université Laval's Faculty of Medicine. They gave weekly injections of MPL to Alzheimer mouse models over a twelve-week period. This caused an 80% decline of senile plaque and significant improvements in learning and cognitive function.

Dr. Rivest sees two potential uses for MPL. It could be administered by intramuscular injection to slow the progression of the illness, or incorporated into a vaccine against amyloid beta. He said: "The vaccine could be given to people who already have the disease to stimulate their natural immunity. It could also be administered as a preventive measure to people with risk factors for Alzheimer's disease."

www.pnas.org/content/early/2013/01/15/1215165110.abstract?sid=8dab73c9-f54d-4d70-8c8a-1beccb081ff1

22 January: Hearing loss is a factor in cognitive decline

A study from Johns Hopkins University shows that older adults with hearing impairments are more likely to suffer early memory and thinking problems than those without hearing loss.

The study, led by Dr. Frank Lin, lead author and Assistant Professor at Johns Hopkins, concluded that cognitive problems developed 30-40% faster when hearing declined to 25 decibels, the threshold of mild hearing loss.

The researchers followed 1,984 adults ages 75-84 from 2001 to 2007, all of whom had normal brain function and hearing when the study began. The participants underwent various cognitive tests and hearing tests at regular intervals. The people who developed hearing impairments took 7.7 years to show mental decline, compared to 10.9 years for those with healthy hearing.

Dr. Lin said: "Our findings show how important it is for physicians to discuss hearing with their patients and be proactive in addressing hearing declines. Hearing loss doesn't directly contribute to dementia, but leads to cognitive load on the brain."

<http://archinte.jamanetwork.com/article.aspx?articleid=1558452#qundefind>

25 January: CRF hormone protects the brain from memory loss

A study from the University of Nottingham (UN) shows that a stress hormone called CRF produced during moderate exercise protects the brain from memory loss.

Dr. Marie-Christine Pardon, Senior Fellow at UN's School of Biomedical Sciences, led a team to establish the role of the stress hormone CRF (corticotrophin-releasing factor) in the onset of Alzheimer's disease.

CRF acts as a neurotransmitter, i.e. it sends signals from one neuron to another. It's important in memory formation and retention; people with Alzheimer's disease are known to have insufficient levels of it.

The researchers blocked CRF in Alzheimer mice and found that the mice had reduced anxiety, but increased reaction when confronted by a stressful situation - in this case being placed in a new environment. This was due to the abnormal functioning of the brain receptor CRFR1, which

is normally activated by CRF. This explains why people susceptible to stress are more at risk of developing Alzheimer's.

The scientists also found that interrupting the hormone from binding on to the CRFR1 receptor blocked the improvement of memory normally promoted by exercise. However, a regular exercise routine restored the normal function of the CRF system.

These results are in line with the idea regular exercise is a means of improving one's ability to deal with everyday stress in addition to keeping sharp mental abilities.

Dr. Pardon said: "This is the first time researchers have been able to identify a brain process directly responsible for the beneficial effects of exercise in slowing down the progression of the early memory decline characteristics of Alzheimer's disease.

"Overall, this research provides further evidence a healthy lifestyle involving exercise slows down the risk of Alzheimer's disease and opens avenues for the new interventions targeting the altered CRFR1 function associated with the early stages of the disease."

www.j-alz.com/issues/34/vol34-3.html

Dementia in Society

7 January: Austrian study targets drivers with dementia

A recent study shows that most drivers with dementia give up driving at the behest of their caregivers – not because of accidents or revoked licenses.

The study was led by Dr. Stephan Seiler, Researcher at the Department of Neurology of Graz Medical University (Austria), who sought to find which factors were considered when dementia patients stopped driving.

The results come from a survey of 240 people with dementia who were former or current car drivers. They show that around 40% of people with mild to moderate dementia are still driving. Among people who had stopped driving, 136 (98%) said they stopped because of unacceptable risk, as judged by their caregivers. Car accidents and revocation of the driving license were cited by only 9 people.

The decision by caregivers to have people stop driving may have been made based on symptoms: in this study, people with more severe symptoms were more likely to have stopped driving. Also, people whose caregiver had a higher level of burden were more likely to have stopped driving.

The authors conclude that caregivers' risk judgments - and not accidents or license issues - were the reason most people with dementia stopped driving.

www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0052710

9 January: Problem-focused coping helps to slow dementia

A new study from Utah State University (USU) shows that the decline of brain function in Alzheimer's disease can be slowed by changing the environment of the diagnosed person.

Caregivers who regularly used "positive" coping strategies - including problem-focused coping, seeking greater social support, counting blessings - were able to slow cognitive decline. Conversely, "negative" strategies (e.g. avoidance or wishful thinking) resulted in a faster decline of cognitive and functional measures.

Dr. JoAnn Tschanz, Assistant Professor of Neuropsychologist at USU, is the lead author of the Cache County Dementia Progression Study. The study, which also involved researchers from Johns Hopkins University, assessed 226 people with dementia and their caregivers semi-annually for up to six years.

Dr. Tschanz said: "Except for psychiatric symptoms, few studies have examined how caregiver characteristics affect the rate of dementia progression, and our findings indicate significant associations between caregiver coping strategies and the rate of cognitive and functional decline in dementia. Greater use of problem-focused coping may be mutually beneficial for both patients and caregivers."

www.ajgp-online.org/article/PIIS1064748112000097/abstract

New Publications & Resources

10 January: MHE presents results of guardianship survey



On 10 January, Mental Health Europe (MHE) released the results of a 2012 survey to determine the status of guardianship and related decision-making policies in 27 EU countries.

The results show that 25 member states implement plenary substitute decision-making, which is contrary to the United Nations Convention for the Rights of Persons with Disabilities (UN CRPD). This type of guardianship effectively denies people with mental health problems input in such basic decisions like choosing a place to live, refusing medical treatment or signing contracts, on the sole basis of their disability.

MHE believes that governments should develop legislation that abolishes existing guardianship regimes and policies and replaces them with supported decision-making. This would respect a person's autonomy, preferences and wishes. Governments should also review any law that would allow for the deprivation of liberty on the basis of disability and should abolish involuntary confinement linked to mental health problems.

Links to the full press release and the survey report are shown below.

www.mhe-sme.org/news-and-events/mhe-press-releases/stripped_of_dignity.html
http://issuu.com/silvanamhe/docs/mapping_exclusion

29 January: UK Alzheimer's Society offers new resources



The UK Alzheimer's Society has released a new training DVD for homecare workers.

The DVD features people with dementia, their family members and those who care for them. The training package is presented in four modules that cover the experience of dementia,

communication and behaviour, person-centred approaches and wellbeing and relationships. It also includes facilitator notes, learner notes and exercises. The DVD is available via email to dementiatraining@alzheimers.org.uk

The Society also launched a new tool called the “Handy Guide to Selecting a Care Home”. This is designed as an independent aid for people when choosing care homes. It suggests some issues to think about and questions that may be useful to ask staff when visiting potential care homes.



www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1597

25 January: JPND publishes first newsletter



The EU Joint Programme - Neurodegenerative Disease Research (JPND) has launched its first newsletter. The newsletter will be

produced every six months and provides a synopsis of JPND news stories for the international neurodegenerative disease research community. Content will include updates on JPND activities, featured research from JPND-funded projects as well as interviews with JPND Scientific Advisory Board and stakeholder representatives.

JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases.

The newsletter is available on the JPND website.

http://neurodegenerationresearch.eu/fileadmin/Newsletter/JPND_Newsletter_-_January_2013_edition_01.pdf

Job opportunities

30 January: The Commission is hiring post-doctorate researchers

The Joint Research Centre (JRC) of the European Commission has launched a selection procedure for fixed term positions to set up a database of over 3,000 successful candidates with a research background. They will be placed on a reserve list and called for interview according to the needs of the services.

The selection is aimed at researchers in the following areas:

- Natural sciences
- Quantitative sciences
- Human and social sciences
- Agricultural, environmental and earth sciences
- Health sciences

Most of the posts available will be for the JRC Institutes in Germany, Belgium, Italy, Spain and the Netherlands. Some positions will also be offered in Brussels for other Commission Directorates-General.

More information can be found on the EPSO website, which will also handle registrations until 1 March 2013.

http://europa.eu/epso/apply/jobs/cast/2013/cast_jrc/index_en.htm
<http://ec.europa.eu/dgs/jrc/index.cfm?id=7000&lang=en>

Contact Alzheimer Europe at:

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

Alzheimer Europe Board

Chairperson: Heike von Lützu-Hohlbein (Germany); Vice-Chairperson: Iva Holmerová (Czech Republic); Honorary Secretary: Charles Scerri (Malta); Honorary Treasurer: Maria do Rósario Zincke dos Reis (Portugal); Members: Patrick Maugard (France), Maurice O’Connell (Ireland), Sirpa Pietikäinen (Finland), Helga Rohra (Germany), Alicja Sadowska (Poland), Henry Simmons (UK - Scotland).

Alzheimer Europe Staff

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
12 February	Meeting with Nutricia (Luxembourg, Luxembourg)	Jean
18-19 February	EFNA’s workshop on the ‘European Month of the Brain’ (Brussels, Belgium)	Annette
25-27 February	Board meeting, Company round table and Dementia Monitor meeting, Lunch debate on “Clinical trials on AD” and EU Public Affairs meeting (Brussels, Belgium)	AE Board, members and staff
28 February	Presentation at the Romanian Alzheimer Society annual conference (Bucharest, Romania)	Annette
28 February-1 March	Launch of European Medical Information Framework Programme (Brussels, Belgium)	Jean
28 March	ALCOVE Final Symposium (Paris, France)	Heike, members and staff
12 April	EWGPWD meeting (Brussels, Belgium)	Helga, AE staff

Future Conferences

Date	Meeting	Place
19-20 February 2013	Workshop for "European Month of the Brain", European Federation of Neurological Associations (EFNA), http://efna.net/emobworkshop/	Brussels, Belgium
27 February-2 March 2013	National Alzheimer Conference, www.alzcongres.ro	Bucharest, Romania
6-10 March 2013	11th International Conference on Alzheimer's and Parkinson's Diseases, www.kenes.com/adpd	Florence, Italy
21-22 March 2013	SDCRN's 3rd Annual Dementia Research Conference: "Nations and Generations", http://www.sdcnrn.org.uk/resources/conference-2013	Stirling, Scotland
21-23 March 2013	57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Leipzig, Germany
28 March 2013	ALCOVE Final Symposium, www.alcove-project.eu/index.php?option=com_content&view=article&id=46&Itemid=184	Paris, France
11-14 April 2013	The 7th World Congress on Controversies in Neurology (CONy), www.comtecmed.com/cony/2013/	Istanbul, Turkey
18-20 April 2013	28th International Conference of Alzheimer's Disease International: Dementia: Action for global change, www.adi2013.org	Taipei, Taiwan
18-21 April 2013	9th International Congress on Mental Dysfunction & Other Non-Motor Features in Parkinson's Disease and Related Disorders – MDPD 2013, www.kenes.com/mdpd2013	Seoul, Korea
4-12 May 2013	Neural Stem Cells in Development and for Brain Repair, www.nsas.it/neural-stem-cells-for-development-and-repair	Cortona, Italy
23-24 May 2013	3 rd International Conference on Neurodegenerative Disorders: Immunotherapy and Biomarkers, http://eventus.trippus.se/immunotherapy_uppsala2013	Uppsala, Sweden
5-6 June 2013	Pioneers in healthcare info@researchmedia.eu	Brussels, Belgium
8-11 June 2013	23 rd ENS 2013 meeting, www.congrex.com	Barcelona, Spain
23-27 June 2013	The 20th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
21-26 September 2013	XXI World Congress of Neurology, www.oegnt.at	Vienna, Austria
5-9 October 2013	26 th ECNP (European College of Neuropsychopharmacology), www.ecnp-congress.eu	Barcelona, Spain
10-12 October 2013	23 rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", www.alzheimer-europe.org/EN/Conferences	St. Julian's, Malta
17-20 October 2013	8 th International Congress on Vascular Dementia – ICVD 2013, www.kenes.com/icvd	Athens, Greece
11-14 December 2013	The 16 th Asia Pacific regional Conference of Alzheimer's disease international, www.aprc2013-hongkong-macau.com	Hong Kong & Macau
20-23 March 2014	58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Berlin, Germany
21-24 March 2014	30 th International Congress of Clinical Neurophysiology (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
5-9 July 2014	9 th FENS Forum of Neuroscience, http://forum.fens.org/2014	Milan, Italy

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



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.