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Editorial

In June, Alzheimer Europe organised a Board meeting, a Lunch Debate at the European Parliament and a Public Affairs meeting. These took place in Brussels and we are very pleased that all three were well attended.

The Lunch Debate was hosted by Irish MEP Liam Aylward and focused on how Alzheimer’s disease will be addressed in the new European health programmes: there will be a significant shift after the end of the FP7 programme.

In all, 12 MEPs attended or were represented at the Lunch Debate. Nine of them are also members of the European Alzheimer’s Alliance (EAA); we are glad to see the ongoing commitment of the Alliance to the cause of dementia.

Ms Marina Yannakoudakis, MEP (UK) and active EAA member, also attended a recent meeting of the Dementia Action Alliance.

The Public Affairs meeting was a very useful forum for comparing existing national dementia strategies and defining best practices for forthcoming plans. We are grateful to our members for their significant input, which will be included in Alzheimer Europe’s 2012 Dementia in Europe Yearbook.

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Our member organisations were also busy at home: Finland named a new Executive Director while our colleagues in Romania attended a conference on patients’ rights, appeared on TV and held their first Alzheimer Café. The Irish association is finalising a report that will help shape the new national dementia strategy. Jersey welcomed a new colleague who will manage the association’s new service for counselling and family support. Belgium’s Ligue Alzheimer has received accreditation to train health professionals. Greece launched a new care programme, held seminars and co-produced a play. Alzheimer Unite led a reading group in Rome and Scotland won an award for Charity of the Year.

On the European front, the Commission launched an initiative to improve patient registries and the European Medicines Agency (EMA) approved the use of a new drug for amyotrophic lateral sclerosis (ALS). The EMA also translated its website on suspected side effects into 23 languages.

The Vienna Conference is just around the corner now: the final Conference programme and all the abstracts will be available on our website by the end of July. We have more than 350 registered attendees and it looks like we’ll top last year’s record of 470. People can still register online until 28 September, so we are expecting a very lively conference.

The latest issue of Dementia in Europe magazine also appeared in June. It notably features interviews with John Dalli, Commissioner for Health and Human Policy and MEP Françoise Grossetête, who also chairs the European Alzheimer’s Alliance.

On behalf of the entire Alzheimer Europe team, I would like to wish all our readers an enjoyable and restful summer holiday. We will also be taking some time off, so the next newsletter will appear in early September.

Jean Georges
Executive Director
Alzheimer Europe

25 June: Alzheimer Europe holds Board Meeting in Brussels

The Alzheimer Europe Board met in Brussels on 25 June. The Board discussed the following items:

- adoption of the 2011 annual report and financial statements
- presentation of 2012 financial forecasts and risk assessment
- presentation of 2013 budget
- adoption of the draft 2013 work plan
- progress of European projects: DECIDE, PharmaCog, NILVAD
- preparation for the 2013 Annual Conference in Vienna
- preparation for the European Parliament lunch debate on 26 June.

The next Board Meeting will take place in Vienna on 4 October 2012.

26 June: Alzheimer Europe holds lunch debate at the European Parliament

On 26 June, Alzheimer Europe held its 13th lunch debate at the European Parliament in Brussels. The event was hosted by Liam Aylward, MEP (Ireland) and was entitled "Alzheimer’s disease in the new European public health and research programmes". There were some 55 people at the event, which featured principal speakers Philippe Cupers and Jürgen Scheftlein, both from the European Commission.

Dr. Cupers (Head of Sector for Neuroscience, DG Research & Innovation) presented "The place of Alzheimer’s disease in Horizon 2020". Currently, research on neurodegenerative diseases - including Alzheimer’s disease - is a priority in the 7th Framework Programme (FP7). Research on Alzheimer’s disease has received funding of approx. EUR 115 million since 2007. This is expected to reach EUR 150 million by the end of the programme in 2014. The IMI and JPND programmes also provide funds for research into neurodegenerative diseases.

After FP7, the main EU funding instrument will be Horizon 2020. This programme will begin in 2014, funded with some EUR 80 billion. Alzheimer’s disease does not have a specific priority within Horizon 2020, as was the case in FP7. Instead, there will be a horizontal approach – the disease will be addressed through all three main pillars of the programme: industrial leadership, excellent science and societal challenges.

The Month of the Brain is planned for May 2013. This will be a showcase for FP7 achievements in brain research and forward thinking on brain research in Europe.

Mr Scheftlein, Policy Officer in charge of the Mental Health Unit at the DG Health & Consumers, presented "The place of Alzheimer’s disease in the Health for Growth programme and the European Innovation Partnership (EIP) for Active and Healthy Ageing (AHA)".

At present, there is significant investment for early diagnosis, training of caregivers and support for people with dementia and their families to maintain a high quality of life. There is an increasing level of national commitment, as Alzheimer’s disease continues to appear on policy agendas in the Member States. Strong NGOs are also very active, supporting all manner of campaigns and activities. All of these have contributed toward an improvement in the lives and rights of people with dementia.

The new EIP programme has gotten off to a good start. Diagnosis is one of the six main objectives and this has already made an impact: the EIP partners have given significant input, leading to 260 commitments for action.

The other new programme is Health for Growth. This will contribute to innovative and sustainable health systems. This includes access to better, safer health care and protection from cross-border threats.

The following Members of the European Parliament attended the debate or were represented by their assistants:

- L. Aylward, Ireland
- M. Harkin, Ireland
- F. Brepoels, Belgium
- P. Liese, Germany
- N. Childers, Ireland
- A. Lulling, Luxembourg
- B. Crowley, Ireland
- S. Pietikäinen, Finland
- N. Griesbeck, France
- A. Werthmann, Austria
- F. Grossetête, France
- M. Yannakoudakis, UK

Other participants included representatives from the European Commission, national policy makers, Alzheimer associations and pharmaceutical companies.

Impressions from Alzheimer Europe’s lunch debate

Liam Aylward, MEP (Ireland) welcomes the speakers at the beginning of the meeting

The speakers: Jürgen Scheftlein and Philippe Cupers take questions after their presentations

Markus Lütström (Finnish Alzheimer Society) with Irish MEPs Nessa Childers and Sean Kelly
26 June: Alzheimer Europe holds Public Affairs meeting in Brussels

Alzheimer Europe held its third Public Affairs meeting on 26-27 June in Brussels. 21 people attended the meeting, including 15 representatives from national Alzheimer Associations.

The meeting was dedicated to a comparison of national dementia strategies and policies in the areas of early diagnosis, treatment and research. The contributions by member organisations will help Alzheimer Europe in the development of national reports which will be included in the organisation’s 2012 Dementia in Europe Yearbook. In addition, the meeting was dedicated to identifying good practices in the three areas covered with the aim of developing recommendations which will also be included in the Yearbook.

The following issues were discussed in detail:

- The role of general practitioners in the detection and diagnosis of Alzheimer’s disease
- Care pathways from primary to secondary care
- Diagnostic protocols
- The reimbursement of treatments
- GP training and support
- Support of dementia research by national governments
- Awareness campaigns and lobbying activities of national Alzheimer associations
- The involvement of national organisations in the development and monitoring of dementia strategies.

Public Affairs meeting attendees:


www.alzheimer-europe.org/Donation
Alzheimer Europe Networking

On 1 June (Brussels, Belgium) Annette had a meeting with A. Garvey to discuss the Transparency Directive.

On 6 June (Trondheim, Norway) Dianne attended the annual IMPACT Consortium Meeting.

On 7 June (Brussels, Belgium) Jean attended a preparatory meeting for the development of a multi-stakeholder initiative on Alzheimer’s disease.

On 7 June (Brussels, Belgium) Annette went to a European Parliament Hearing on “the prevention of age-related diseases in women” and an Experts Roundtable on “active ageing in a lifetime”.

On 12 June (Brussels, Belgium) Annette had dinner with L. Benzece, Health Attaché, EU Permanent Representation Hungary.

On 14-15 June (Brussels, Belgium) Dianne and Rosario attended the first meeting of Alzheimer Europe’s working group on the ethical issues related to the deprivation of freedom.

On 19 June (Brussels, Belgium) Annette attended the AGE Platform thematic seminar on the “impact of the crisis on older people”.

On 19-20 June (Strasbourg, France) Dianne attended the Symposium “Biobanks and biomedical collections - an ethical framework for future research” organised by the Council of Europe Committee on Bioethics.

On 22 June (Luxembourg, Luxembourg), Kristina and Krister Westerlund from Alzheimerforeningen, Sweden paid a visit to the Alzheimer Europe office.

On 21 June (Paris, France) Annette had a Sanofi meeting with patient organisations (EPF, IDF, ESMO) to discuss clinical trials.

On 25-26 June (Brussels, Belgium) AE Board, members and staff attended the Alzheimer Europe Board, the Lunch debate “The place of Alzheimer’s disease in the new European public health and research programmes” and the AE Workshop on national dementia strategies.

On 26 June (Brussels, Belgium), Alzheimer Europe organised a corporate round table with sponsors of the organisation.

On 26-27 June (Brussels, Belgium), Dianne, Jean, Julie, Alex and Annette took part in Alzheimer Europe’s Public Affairs Meeting.

On 27 June (Brussels, Belgium) Heike and Jean attended the meeting with Fondation Médéric Alzheimer.

European Alzheimer’s Alliance

30 May: MEP Yannakoudakis attends Dementia Action Alliance meeting

Marina Yannakoudakis, (MEP, UK) and member of the European Alzheimer’s Alliance attended the last quarterly meeting of England’s Dementia Action Alliance (DAA) held on 30 May in London.

The DAA brings together over 120 organisations from across the not for profit, private and statutory sector to radically improve the lives of people living with dementia.

The Alliance takes a voluntary and organic approach to bringing change, with each member committing to specific actions such as training staff and conducting research, and then holding each other to account on fulfilling them.

Members meet quarterly to exchange good practice and listen to keynote speakers. At this meeting, members listened to Senior Civil Servant David Behan and British celebrity Angela Rippon describe the Prime Minister’s Challenge on Dementia and how members could get involved.

Marina Yannakoudakis received feedback from members and people living with dementia on the strengths of the Challenge and its possible implications for work at a European level.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 66, 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), Bela Marsova (EPP), Frédérique (ALDE), Stano Baro (Greens/EFA), Tarabell Marc (S&D).

**Belgium:** Parvano Antonio (ALDE), Cyprus: Triantaphyllides Kyriacos (GUE/NGL), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP).

**Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D), Italy: Matteo Renzi (S&D), Spain: Carlos (EPP), Carlos (S&D), Matias Aragon (EPP), Toia Patrizia (S&D), Mauro Santilli (S&D), Paulino Christi (S&D), Sánchez Cordero (EPP), Spain: Rafael Anchorena (EPP), Portugal: Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL), Romania: Antonescu Elena Oana (EPP), Busui Cristian (ALDE), Sarbu Daciana (EPP), Slovakia: Mikolajski Miroslav (EPP), Zaborska Anna (EPP), Slovenia: Peterle Aloiz (S&D), Spain: Badia i Cutchet Maria (S&D), United Kingdom: Ashworth Richard (EFP), Hall Fiona (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Lindsay Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derrick (S&D), Watson Graham (ALDE), Willmott Glens (S&D), Yannakoudakis Marina (ECR).

EU Developments

**12 June: Launch of the European Joint Action on Patient Registries**

On 12-13 June 2012, the European Commission and representatives of 11 EU Member States gathered in Brussels to launch the Joint Action (JA) on Patient Registries.

The aim of this JA is to support Member States in developing comparable and coherent patient registries in important fields such as chronic diseases, rare diseases and medical technology. This should rationalise and harmonise the development and governance of patient registries.
registries, thus enabling analyses of secondary data for public health and research purposes.


18 June: EMA’s website on suspected side effects is in 23 languages

On 18 June, shortly after the launch of its website on suspected side-effect reports for medicines authorised in the European Economic Area, the European Medicines Agency (EMA) added reports in the remaining 22 official European Union languages.

The reports on the website come directly from EudraVigilance, the European medicines safety database.


21 June: Council presents conclusions on responding to demographic challenges

On 21 June, the Employment, Social Policy, Health and Consumer Affairs Council meeting adopted conclusions to respond to demographic challenges. Building on the work already undertaken in this area, these Conclusions will contribute to ensuring that policy measures and actions at both national and EU level are consistent and mutually supportive.

For elderly people, the Council inter alia invites the European Commission and the Member States to promote the growth of the “silver economy” in view of its positive impact on the demand for goods and services as well as on the development of new job opportunities and independent living; actively promote improvements in the accessibility of goods and services, innovative assistive technologies, devices and services that are specifically suitable for the elderly and help them to live independent, healthy and physically active lives; enhance independent living by offering adequate training and rehabilitation measures which are conducive to an independent life.

For women, the Council proposes to develop family-friendly policies that promote a balance between work, family responsibilities and private lives for women and men throughout the life cycle, through affordable and accessible quality childcare and care facilities for other dependants.

For persons with disabilities, the Council calls for the continuation of the ratification and application of the UN Convention on the Rights of Persons with Disabilities; take measures to support independent living of persons with disabilities (including transition from institutional to community-based care, including via personal assistance).

On active inclusion and participation, the Council recommends to further improve health and social services, including support for family care, aiming to facilitate the labour market participation of those with care responsibilities; develop policies for more integrated health and social care systems for older persons and persons in vulnerable situations; Open Method of Coordination, collect, analyse and exchange information on new efficient and effective methods to deliver social services through the Open Method of Coordination.


25 June: Cyprus EU Presidency launches website

On 25 June, the Cypriot Presidency of the European Union launched a new website.

The Presidency motto is “Towards a Better Europe”, making Europe more relevant to its citizens and to the world, more effective by contributing to growth, social cohesion and job creation through efficient and integrated policies.

The Presidency’s priorities are:

- A more efficient and sustainable Europe
- A Europe with a better performing and growing economy
- A Europe that is more relevant to its citizens, with solidarity and social cohesion
- A Europe in the world, closer to its neighbours.

The Presidency will deal with issues related to the European Year of Active Ageing and Solidarity between Generations and issues related to health such as the prevention of diseases and the promotion of healthy lifestyle.

The Presidency will also place emphasis on the further participation and involvement of social partners, NGOs and local authorities in the formulation and implementation of the Europe 2020 Strategy.

In the field of health, the Presidency will work on healthy ageing across the lifecycle, serious cross-border threats to health, organ donation and transplantation, pharmacovigilance, clinical trials and the transparency of measures regulating the pricing of medicinal products for human use and their inclusion in the scope of national health insurance systems.

It will also work to protect workers from the risks arising from exposure to electromagnetic fields.

The Cypriot Presidency will continue the negotiation process for the Horizon 2020 from the point reached by the Danish Presidency, aiming to reach agreement among the Member States in the four legislative proposals of Horizon 2020 package.


21 June: Commission launches European Year 2012 Awards for active ageing and solidarity between generations

On 21 June, the European Commission announced the launch of the “European Year 2012 Awards: Honouring the best initiatives that promote active ageing and solidarity between generations”.

The Awards will recognise organisations and individuals that promote active ageing through their activities. They are part of the European Year for Active Ageing and Solidarity between Generations. There are six award categories:

- Workplaces for all Ages: best initiatives by employers, trade unions and non-profit
organisations that promote better working conditions for older employees.

- **Towards Age-Friendly Environments**: outstanding initiatives by regional or local authorities that create an inclusive and accessible local environment which facilitates active ageing and has a positive effect on health and on the quality of life of all generations.

- **Social Entrepreneurs**: most successful initiatives undertaken by social entrepreneurs in promoting active ageing and solidarity between generations.

- **Reporting on Ageing and Relations between Generations**: journalistic work that has made a significant contribution to a better understanding of the challenges presented by an ageing society and how they can be tackled, thus raising the level of the public debate and promoting better policymaking.

- **Life Story Challenge**: story of an older person, including noteworthy contributions that the “active ager” is making in the family, in society or at work.

The competition is open until 1 September 2012 to all citizens of EU Member States, Iceland, Liechtenstein and Norway. The finalists in each category will be invited to an awards ceremony in November.


Members’ News

1 May: Finnish Alzheimer Society appoints new Executive Director

On 1 May, Dr. Eila Okkonen became the new Executive Director of Muistiliitto, the Finnish Alzheimer Society.

Dr. Okkonen brings a wealth of experience to her new position. She was a project manager and piloted the professional master's degree at the University of Applied Sciences in Finland. She also directed an education centre of the Finnish Association of Mental Health. In addition, she has been a Senior Lecturer at Nursing College and also worked as a professional nurse in various Finnish hospitals.

She said: "I am very keen to promote the goals of the Finnish Alzheimer Society. One of my specific areas of interest is a salutogenic orientation to health and mental well-being, where the maintenance of health and the promotion of health resources are highlighted."

Salutogenesis is a therapeutic approach focusing on factors that support human health and well-being, rather than on factors that cause disease. A salutogenic model would mainly concentrate on the relationship between health, stress and coping.

Dr. Okkonen sees a need for education in this area, saying that "we can learn things that everybody should know about" and listed the following priorities:

- How to assess and strengthen our own resources, coping skills and assess risk factors.
- How to improve our skills to cope with problems, crises and other difficulties.
- How to discuss difficult issues gently and openly.

Dr. Okkonen earned her PhD from the University of Helsinki, Faculty of Medicine, based on the thesis “Psychosocial risk factors, coping styles and subjective health of a patient.” She also holds a Master’s degree in Health Care and Teaching from the same university.

http://www.muistiliitto.fi

14 May: Meeting without frontiers for Germans in France

Between 14-21 May, a group of seven couples (a person with dementia and their carer) from the German Alzheimer Association in Munich (AGM) travelled to Provence in France. They were hosted by France Alzheimer Vaucluse (FAV).

This was the result of the long-standing relationship between FAV and AGM who had the idea of the "Meeting without Frontiers" project. The aim was to demonstrate that it was possible for people with dementia and their carers to organise a trip abroad and that the disease was not an obstacle. The trip was an opportunity for the German couples to realise that dementia did not hinder them from discovering new places and enjoying life away from a familiar environment.

The travellers stayed in the town of Isle sur la Sorgue and participated in many activities. These included a reception at the German Consulate in Marseille, a visit of Avignon, and a tour of an oil mill. The group also visited FAV’s offices and a day centre.

This challenging project required careful and well-planned organisation, but it was an eye-opener: all the participants broke the barriers and taboos about the fear of contact. This will open the path for new opportunities and projects and will enable other people with dementia to enjoy this experience.
1 June: Set Care project team provides training tools to caregivers

The Set Care project team - including the Athens Association for Alzheimer Disease and Related Disorders - is due to begin the pilot phase of the project. Set Care is producing a self-study, e-learning tool for family members and carers of people with dementia. Study modules include the following:

- basic healthcare & assistance skills
- psychology and communication
- rights & duties of the care worker
- national service systems
- strategies to deal with elderly people with dementia.

The programme also features multiple choice tests and written exercises, as well as a handbook for trainers with lesson guidelines. The entire course content will be available online and on DVD.

The pilot phase involves distribution of these DVDs to a group of caregivers in Greece and Bulgaria.

The number of elderly people in Greece has increased in the last ten years to reach almost 19% of the population. Among them, some 160,000 people live with dementia and 80% of these people are cared for at home.

1 June: Belgium’s Ligue Alzheimer earns accreditation for training programme

In April 2012, the Belgian Ligue Alzheimer association became an accredited educational institution for its training programme "Réadem". This programme allows professionals to become "Dementia-Referents", i.e. specialists in caring for people with dementia in nursing homes.

The programme is open to health professionals working in nursing homes, including nurses, psychotherapists and dieticians. The objectives are to:

- update the knowledge of mental troubles and disorders of the elderly
- optimise the quality of life of people with dementia in a residential environment
- support all professional nursing home staff
- support the family of people with dementia.

The accreditation of Ligue Alzheimer means that graduates of the Réadem programme are eligible for reimbursement from Belgium’s Sickness and Invalidity Insurance Institution.

1 June: Swiss petition draws 50,000 signatures for Alzheimer’s disease

The Swiss Alzheimer Association is pleased to announce that it has collected over 50,000 signatures for its online petition: the “Alzheimer Priority Manifesto” is a call for support for the growing number of people with Alzheimer’s disease who live at home. The petition urges authorities to provide the necessary resources for these people to remain in their homes for as long as they wish.

The petition for the Alzheimer Priority Manifesto is still accepting signatures - from anywhere in the world - and can be found on the association’s website.

www.alz.ch

4 June: Fundación Alzheimer España signs agreement to develop assistive technologies

On 4 June, Fundación Alzheimer España signed a research agreement with CeDInt (Centro de Domótica Integral) of the Polytechnic University of Madrid for the development of assistive technologies for people with dementia.

Whilst these technologies already play a role in residential care settings, they are not yet widely available in home settings where the majority of people with dementia are cared for despite their undoubted usefulness.

The aim of the agreement therefore is to make these technologies more accessible for carers of people with dementia through the development of simple and practical solutions which are reasonably priced.

The organisations will jointly identify the actual needs of people with dementia and their carers, develop experimentation devices in real life settings and create a counselling service providing individual advice on specific solutions for specific situations.

11 June: Alzheimer Hellas promotes dental care for Greeks with dementia

Alzheimer Hellas continued its series of 2012 workshops with a three day session about dental health care for elderly people with dementia on 11-13 May. The workshop informed some 150 attendees about the special care needed to approach, evaluate and treat people who may be distressed by dental health procedures. There was also a session about preventive care from the home care team of Alzheimer Hellas.

This workshop helped to fill a knowledge gap among dental health professionals and also aimed to improve the quality of life of Greeks with dementia.
14 June: Alzheimer Scotland wins charity award
On 14 June, Alzheimer Scotland won the 2012 Charity of the Year award at the Scottish Council for Voluntary Organisations (SCVO) award ceremony.

The organisation was recognised for making major progress in tackling the difficulties arising from Scotland’s aging population, particularly dramatic increases in the number of Scots living with dementia. There are currently some 80,000 Scots living with dementia and that number is expected to reach 120,000 in the next 20 years.

The past year has seen Alzheimer Scotland part fund the creation of specialist dementia nurses, train Scotland’s first 100 dementia champions and launch a Dementia Research Centre in partnership with the University of Edinburgh. In addition, its effective lobbying work persuaded the Scottish Government to commit to guaranteeing a year of post-diagnostic support to all new dementia patients in Scotland.

Henry Simmons, Chief Executive of Alzheimer Scotland, said, “I would like to say how delighted we are to win this prestigious award. We have only been able to achieve such strong progress thanks to the thousands of people who support us, the dedication and hard work of all our staff and volunteers and to the positive and supportive partnerships with key policy makers at all levels.

“We dedicate this award to all the people with dementia, and their partners, families and carers who we support and who support us. Together we can make sure that no-one goes through dementia on their own.”

15 June: Alzheimer Romania maintains a busy schedule of dementia events
On 15 June, Romanian Alzheimer Society colleagues attended the National Conference for Romanian Patient Rights and presented "The Rights of the Alzheimer Patient". The society also participated in two TV programmes which were broadcast in June: “The importance of early diagnosis in Alzheimer’s disease” and “Campaigns for Alzheimer Patient”.

In addition, the first Romanian Alzheimer Café - also organised by the society - took place on 10 May at the Intercontinental Hotel in Bucharest.

18 June: Alzheimer Uniti Italy leads literary readings for people with dementia
Alzheimer Uniti’s Day Centre has been involved in a literary project, reading passages aloud from the novel “Ragazzi di vita” (“Boys of Life”) by the famous writer and film director Pier Paolo Pasolini. The Day Centre is situated in the part of Rome where Pasolini lived and worked; in fact the whole district has been reading this book through “One district, One book”, where people from this Roman district all read one book together. The Day Centre decided to join this literary project.

Groups of people with mild dementia from the Day Centre met regularly to listen to the book being read aloud. Meanwhile, photographs of the neighbourhood were projected on a screen, showing where events from the novel took place. These readings led to discussion among the participants, thus stimulating autobiographical memory and language. Participants recalled and spoke about the streets and plazas and gardens in their district.

28 June: Greek youth theatre plays for people with dementia
Alzheimer Hellas and the Neapolis youth theatre team jointly organised a theatrical play that was performed on 28 June. The play was the famous “Servant of two masters” by Carlo Goldoni which was interpreted in a new, modern way by the youth team. The play was very successful and was attended by almost 200 people, including people with dementia, caregivers, professionals and members of the association. It was a beautiful inspiring event where all participants enjoyed themselves and proved that art and especially theatre can give a great boost for people with dementia and their families.

30 June: Alzheimer Hellas will host training courses on elderly people and dementia
Alzheimer Hellas and the Panhellenic Institute of Neurodegenerative Diseases (PINDis) will host training courses for health professionals already working or interested in the fields of the Elderly and Dementia. Three courses will be offered:

- Training for trainers of psycho-education for caregivers of people with dementia
- Training of health professionals in the design and development of cognitive training programmes for elderly people
- Training of health professionals in the design and implementation of a physical exercise programme for people with dementia.

These courses will be funded by the “Grundtvig Actions: In-Service Training (IST)” framework, which is part of the European Commission’s Lifelong Learning Program ( LLP). Participants may apply for grants to cover the course fee and living and travelling expenses.

Interested applicants are invited to contact Ms Katerina Aggelidou at tel: +30 2310 30667 ext. 32 or ekpaideusi.alz@gmail.com

http://ec.europa.eu/education/grundtvig/inservice_en.htm
www.alzheimer-hellas.gr
www.pindis.gr
30 June: Jersey launches new Counselling and Family Support Service

The Jersey Alzheimer’s Association is delighted to announce the introduction of its new Counselling and Family Support Service. Sian Wareing-Jones, MA, BSc (Hons), Adv. Dip. Couns., MBACP, a qualified counsellor with experience of working with people with dementia and their families, has been appointed to these roles.

Sian has recently been awarded an MA for her research into Carers’ Experiences of Living with Dementia and is currently undertaking a PhD in dementia care.

Family Support helps to support families or individuals going through a difficult time; this can be with or without the person with dementia being present. Relatives and carers may find it easier to cope with an individual’s behaviour if they understand what is happening and why a person is behaving in a particular way.

These services will be available for anyone with dementia and for individuals or families who have a family member with dementia. This will be provided free of charge by Jersey Alzheimer’s Association.

Jo Cummins, Manager of the Jersey Alzheimer’s Association, said: “We have developed these services because it is of great importance that people with dementia and their families are able to share their thoughts and concerns with someone confidentially, who is trained to listen and who has experience and understanding of the issues of living with dementia.”

30 June: Alzheimer Ireland prepares input for national dementia plan

The Alzheimer Society of Ireland is in the midst of a national consultation that will supply input to the Department of Health for the forthcoming Irish National Dementia Strategy.

During June and July, the society has held a number of focus groups with staff and families living with dementia. This includes a tailored focus group for people living with dementia themselves.

This consultation aims to produce a representative response of both people involved in the organisation and those people living with dementia in Ireland. It is also an opportunity for those involved to influence the future lives of people with dementia and their carers.

The results of the consultations will be submitted to the government at the end of August.
Study results showed that levels of tau in cognitively compared to those with no sign of cognitive decline.

"Overall, the data suggest that changes in plasma total tau levels may provide a new avenue of identifying the onset of mild cognitive impairment and the ensuing Alzheimer's disease."

 Seventy-six Alzheimer's disease.

Science Watch

7 May: EMA approves new riluzole drug for ALS

The European Medicines Agency (EMA) approved the drug Riluzole Zentiva for the treatment of Amyotrophic Lateral Sclerosis (ALS) on 7 June.

Riluzole Zentiva contains the active substance riluzole and acts on the nervous system. The exact way in which it works in ALS is not known. It is thought that the destruction of nerve cells in motor neurone disease may be caused by too much glutamate, a neurotransmitter or chemical messenger. Riluzole stops the release of glutamate and this may help in preventing the nerve cells being damaged.

Riluzole Zentiva is an Aventis product and is the same as Rilutek, another ALS drug authorized in the EU.


4 June: New drug helps lysosomes digest amyloid plaque

A researcher from the University of North Carolina (UNC) has shown that a drug called PADK may slow the development of amyloid beta plaques.

PADK (Z-Phe-Ala-diazomethylketone) helps to speed up the activity of lysosomes, which act as a digestive system to rid brain cells of toxic proteins. As a person ages, lysosomes become less active and allow the build-up of toxins, including amyloid plaque.

Dr. Ben Bahr, Biotechnology Professor at UNC, said: "We are all losing synapses with age, but Alzheimer’s patients are losing them at a much faster rate. If we can speed up lysosomal digestion of Abeta and slow down synaptic pathology, we can restore those memory transmissions."

Dr. Bahr accomplished this in laboratory tests of cultured brain tissue affected by Alzheimer's, as well as in genetically altered mice with the human gene linked to Alzheimer’s disease.

www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0020501

7 June: Tau level in plasma may be a biomarker

An American research team has found significantly lower tau levels in plasma in people with Alzheimer’s disease compared to those with no sign of cognitive decline. Study results showed that levels of tau in cognitively normal seniors were nearly three times greater than those with cognitive impairment.

Dr. Larry Sparks, Senior Scientist at the Banner Sun Health Research Institute in Arizona, said: “As cognitive performance declines so do the circulating levels of tau.

"Identifying patients likely to develop dementia is important in early intervention where support can be provided to delay, or help patients to manage, the cognitive decline associated with dementia."

7 June: Swedish AB vaccine succeeds in creating antibodies

Researchers from Karolinska Institutet in Sweden have successfully completed an initial human trial of a prototype amyloid beta vaccine called CAD106.

A team led by Prof Bengt Winblad tested the vaccine on 46 volunteers aged 50-80 and diagnosed with mild to moderate Alzheimer’s disease. A control group of 12 people received a placebo. After a year, 82% of those who received the drug developed antibodies, a sign that their immune defenses had responded to the toxic protein. The researchers are now planning a larger test.

www.lancet.com/journals/laneur/article/PIIS1474-4422(12)70140-0/fulltext

8 June: New test will identify signs of dementia in people with Parkinson’s disease

Researchers at Australia’s Monash University and the University of Canterbury in New Zealand are developing a test to accurately diagnose people with Parkinson’s Disease who also have cognitive problems indicative of preclinical dementia.

"Identifying patients likely to develop dementia is important in early intervention where support can be provided to delay, or help patients to manage, the cognitive decline associated with dementia."

13 June: ApoE4 gene may cause higher AD incidence in women

Investigators at the Stanford University School of Medicine found that ApoE4, the most common genetic risk factor for Alzheimer’s disease, disrupts brain function in healthy older women but has little impact on healthy older men.

The study showed that women who carry ApoE4 undergo brain changes characteristic of Alzheimer’s disease - and also have elevated levels of tau protein in CSF tests.

ApoE2, E3 and E4 are all part of a family of genes that helps the body transport cholesterol to cells - including neurons - via the blood stream. Cholesterol is essential for the proper functioning of neurons. However, the ApoE4 variant is the least efficient of these transporters: it
"leaks" too much cholesterol in the blood stream, causing a decrease in neuron activity.

All people are born with two copies of E2, E3 or E4 versions of ApoE, in any combination. A person who has one copy of E4 has three times the normal risk for late-onset Alzheimer’s, while a person with two copies faces 20 times greater risk.

This study showed that the heightened risk of E4 may be largely restricted to women: in healthy, older women (but not men) with at least one E4 copy, activity in the precuneus brain region appeared to be uncoordinated with other regions.

According to Dr. Michael Greicius, Assistant Professor of Neurology and Neurological Sciences at Stanford, these findings may help explain why more women than men develop Alzheimer’s disease. www.jneurosci.org/content/32/24/8254.abstract?sid=ebf7df35-7563-405f-bc2c-d1ae7e60f53

14 June: Anykrin G immunisation reduces beta amyloid

Researchers from the University of Zurich have found that a protein called anykrin G, or ankG, triggers the production of antibodies which can reduce the level of beta amyloid in humans.

The scientists found that immunisation in mice significantly reduced the presence of beta amyloid plaques and improved immune cell structure. However, there was no effect on the behaviour of the immunised mice.

Further research is needed to see if ankG can affect symptoms in mice, before it can be considered for human use.

www.nature.com/mp/journal/vaop/ncurrent/full/mp201270a.html

19 June: Researchers identify role of phenylalanine in the formation of amyloid fibrils

Scientists at Tel Aviv University have discovered that phenylalanine, an amino acid, can form amyloid fibrils which are associated with Alzheimer’s disease and also play a part in Parkinson’s disease, diabetes, atherosclerosis and rheumatoid arthritis.

Researcher Ehud Gazit at Tel Aviv University highlighted “This is the first time that it has been demonstrated that an amino acid, rather than a peptide or a protein, can form such a structure.” The researchers hope that their discovery leads to a better understanding of the behaviour of amino acids. In addition, this work could lead to new treatments for the genetic disorder phenylketonuria (PKU), which is caused by high levels of phenylalanine.

25 June: Researchers find evidence for immune suppressive therapy as treatment for dementia

Researchers at Charité Universitätsmedizin in Berlin found evidence that some forms of dementia can be caused by the body’s own immune system and that appropriate immune suppressive therapy can be an effective treatment under those circumstances.

The study, published in the journal Neurology, led the scientists to recommend a new type of therapeutic approach to dementia, as they were able to show that hemodialysis to eliminate antibodies resulted in an improvement of cerebral metabolism in the hippocampus, a part of the brain responsible for memory.

“A completely new approach to diagnosing dementia can possibly result. At the moment we are working on a follow-up study with larger test groups in order to verify our approach even further,” explains Harald Prüß, physician at the Klinik für Neurologie of the Charité. www.neurology.org/content/78/22/1743.abstract?sid=0837258b-10fb-4672-8462-28fc07a20b2b

25 June: Diabetes biomarker also indicates cognitive decline

Results of a new study show a greater risk of cognitive decline among people who develop diabetes later in life. It also links the risk of cognitive decline to the severity of diabetes.

These results emerge from the Health, Aging, and Body Composition (Health ABC) Study, which enrolled 3,069 adults over 70 at two clinics, beginning in 1997. All the patients provided periodic blood samples and took regular cognitive tests over time.

When the study began, hundreds of these patients already had diabetes. A decade later, many more of them had developed diabetes and many also suffered cognitive decline. These two health outcomes were closely linked.

People who had diabetes at the beginning of the study showed a faster cognitive decline than people who developed it during the course of the study - and these people, in turn, tended to be worse off than people who never developed diabetes at all.

The research team was led by Dr. Kristine Yaffe, Professor of Psychiatry at the University of California in San Francisco. The team concentrated on a blood marker known as glycosylated haemoglobin, which measures the severity of diabetes and the ability to control it over time. They found that greater levels of this biomarker were associated with more severe cognitive dysfunction.

The link between diabetes and risk of cognitive decline is not completely understood. Dr. Yaffe said that it may be related to a human protein known as insulin degrading enzyme. This plays an important role in regulating insulin – and also degrades the amyloid beta protein.


28 June: Candidates needed for EUR 1 million Brain Prize

The Grete Lundbeck European Brain Research Foundation is looking for candidates for its EUR one million Brain Prize, which will be awarded for the third time in May 2013.

The Prize recognizes highly original and influential advances in research on the nervous system. If several researchers have contributed significantly to this achievement, more than one individual may receive the Prize.
Nominees can be of any nationality, but the research for which they are nominated must have been conducted in Europe or in collaboration with researchers in Europe. This Prize is intended to raise the visibility of European neuroscience and to be a stimulus to this important field of research. The Grete Lundbeck European Brain Research Foundation is a Danish commercial foundation established in 1954. Its main objective is to maintain and expand the activities of the Lundbeck Group and to provide funding for scientific research of the highest quality.

www.thebrainprize.org/flx/ишь_brain_prize/

Dementia in Society

6 June: Doll therapy pacifies and stimulates care home residents

A Canadian care home has reported a very successful experience with doll therapy. Doll therapy is the use of lifelike dolls, in this case human babies, to help maintain the social skills, behaviour and morale of people with dementia. The Delhi Long Term Care Centre, close to Toronto, brought in two dolls that were shared among six residents for three months.

The dolls were accepted instantly and very happily by the residents, who take turns to look after them. "They're like little mother hens," said Denise Boutin, director of programmes at the centre.

People with dementia sometimes act on instinct instead of reason, which can lead to dangerous behaviour. When dolls are introduced, they can significantly improve the behaviour of the residents. "It can be soothing," said Kathie Savage from the Canadian Alzheimer’s Society. "It gives them something to nurture."

Staff also noticed more eye contact and social interaction between residents and improved communications with visiting family members. The centre is very pleased with the results and is looking into obtaining additional dolls.

www.youtube.com/watch?feature=player_embedded&v=1X1zPVI4fZE

10 June: Staff shortages lead to high drug use in Swiss homes

A recent study shows that more than two thirds of Swiss care home residents with dementia are daily consumers of psychotropic and antidepressant drugs. The survey also showed that many residents take such drugs for long periods of time, sometimes on a permanent basis.

This survey, which was commissioned by the Swiss Alzheimer Society and the Swiss Society for Old Age Psychiatry, collected data from 26,000 people in 400 care homes.

There has been a steady increase of Swiss people with dementia entering care homes: some 65% of current residents have either been diagnosed or show signs of cognitive decline. According to the survey, a resident with dementia requires an additional hour of personal care every day. However, there has been no corresponding increase in qualified people to care for them.

As a result, nursing home carers are faced with both increasing numbers of residents and the need for more care time for each resident. In many cases, this has led to a higher prescription of drugs - especially for those who need the additional care.

It is not clear how this challenging situation can be resolved. Ms Birgitta Martensson, chair of the Swiss Alzheimer Society, said: "The number of people with dementia is continually increasing. We expect this to triple by 2050." The shortage of trained carers is also increasing: according to estimates, Switzerland is currently short by 5,400 trained care personnel every year. By 2020, nursing homes are likely to need some 15,000 carers.

www.swm.ch/content/swm-2011-13254/

30 June: Yitzhak Shamir, 1915-2012

Mr Yitzhak Shamir, former Prime Minister of Israel, passed away on 30 June in Tel Aviv at the age of 96. He had lived in a nursing home since 2004 due to poor health, including Alzheimer's disease. Mr Shamir was Israel's Prime Minister in 1983-84 and again from 1986-92. He is survived by two children and five grandchildren.

New Publications & Resources

12 June: New German booklet and DVD for multigenerational homes

The German Alzheimer Association has released a new booklet called "Together - for each other" that is designed for people who live and work in multigenerational homes.

The booklet encourages people with dementia, family members and carers to participate in the life of the community around them. It provides useful tips, practical examples and checklists and includes a DVD with films of three active multigenerational homes in Germany.

"Together - For Each Other" is available for sale on the association's website.

www.deutsche-alzheimer.de/index/php?id=39&nc_cache=1&detail=64

12 June: Publisher seeks ideas for new dementia comic book

A German publisher has made an open call for ideas for a thematic comic book about dementia. The objective is to increase awareness and knowledge of dementia among people of all ages. People may send in entire stories or just concepts, but illustrations are not required.

Submissions are welcome until 1 August on the publisher’s website.

www.katen.com.de/besonderes/comicprojekt-demenz.html
12 June: Dementia communications guide available in Russian and Turkish

The local government of North Rhine-Westphalia in Germany has translated its brochure entitled "Dementia Communications Guide" into Russian and Turkish. This guide, written by Jennie Powell, provides insights and advice on communicating with people with dementia. The translated brochures are freely available on the government's website.

www.demenz-service-nrw.de/veroeffentlichungen.html

21 June: New guide helps elderly drivers with dementia

The San Antonio Alzheimer's Association (Texas, USA) has launched a new programme called Dementia and Driving. This online tool is designed to help families deal with discussing driving restrictions with elderly family members with dementia.

The programme includes four short video scenarios of families having this type of conversation. Suggested approaches include getting a prescription from a doctor to state they need to stop driving, or pointing out the obvious dangers.

www.alz.org

30 June: European Reminiscence Network launches new website

The European Reminiscence Network recently launched a new website for its project "Remembering Together: Reminiscence Training for people with dementia and their family carers". This project involves partners in ten EU countries. The main emphasis over the two years of the project has been to develop creative reminiscence work involving different participatory art forms with people with dementia and their family carers.

The new website shares the findings of this project across the partnership. It also provides a link to the main website of the European Reminiscence Network, showing other past and current projects.

www.rememberingtogether.eu

Contact Alzheimer Europe at:

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

Alzheimer Europe Board
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# Future Conferences

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<tr>
<th>Date</th>
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<tr>
<td>12-13 July 2012</td>
<td>International Academy on Nutrition and Aging (IANA), <a href="http://www.iagg.info">www.iagg.info</a></td>
<td>Albuquerque, New Mexico</td>
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<tr>
<td>14-19 July 2012</td>
<td>Alzheimer’s Association International Conference 2012 (AAIC 2012), alz.org/AAIC</td>
<td>Vancouver, Canada</td>
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<tr>
<td>5-7 September 2012</td>
<td>7th International conference on creative expression, communication and dementia, <a href="http://www.ceed-society.org">www.ceed-society.org</a></td>
<td>Worcester, UK</td>
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<td>7-10 October 2012</td>
<td>137th Annual meeting of the American Neurological Association, <a href="http://www.aneurna.org">www.aneurna.org</a></td>
<td>Boston, USA</td>
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<td>4-6 October 2012</td>
<td>22nd Alzheimer Europe Conference “Changing perceptions, practice and policy&quot;, <a href="http://www.alzheimer-europe.org/EN/Conferences">www.alzheimer-europe.org/EN/Conferences</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>29-31 October 2012</td>
<td>5th Clinical Trials Conference on Alzheimer Disease (CTAD), <a href="http://www.ctad.fr">www.ctad.fr</a></td>
<td>Monte Carlo, Monaco</td>
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<td>8-11 November 2012</td>
<td>International Conference on Clinical Practice in Alzheimer Disease (CPAD), <a href="http://www.paragon-conventions.com">www.paragon-conventions.com</a></td>
<td>Budapest, Hungary</td>
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<td>5-7 December 2012</td>
<td>Nursing Ethics: intensive course on foundational approaches, contemporary and educational issues in the field of nursing ethics, <a href="http://www.masterbioethics.org">http://www.masterbioethics.org</a></td>
<td>Leuven, Belgium</td>
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<tr>
<td>29-30 January 2013</td>
<td>EFGCP Annual Conference: Virtual future: what are the ethical dimensions of using emerging technologies in clinical trials and research?, <a href="http://www.efgp.eu">www.efgp.eu</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>6-10 March 2013</td>
<td>11th International Conference on Alzheimer’s and Parkinson’s Diseases, <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a></td>
<td>Florence, Italy</td>
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<tr>
<td>21-23 March 2013</td>
<td>57th Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGGN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Leipzig, Germany</td>
</tr>
<tr>
<td>18-20 April 2013</td>
<td>28th International Conference of Alzheimer’s Disease International: Dementia: Action for global change, <a href="mailto:ad2013@mci-group.com">ad2013@mci-group.com</a></td>
<td>Taipei, Taiwan</td>
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22nd Alzheimer Europe Conference
Changing perceptions, practice and policy
Vienna / 4-6 October 2012
Mark the dates!

www.alzheimer-europe.org/conferences

The Alzheimer Europe newsletter arises from the 2012 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.