



NEWSLETTER

September 2012

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Editorial

September has come and gone very quickly in Luxembourg. We registered (even more) people for the Conference and continued to deal with the final preparations. We caught up with our European projects and are planning the next lunch debate at the European Parliament. We also celebrated World Alzheimer's Day by issuing a joint press release with AGE Platform Europe.



World Alzheimer's Day always seems to spark creativity among our member associations and this year is no exception. So far, we've heard that Spain organised a musical theatre evening and also launched a smartphone app. Bulgaria held a press conference that included traditional singing and dancing by people with dementia. France presented new survey results and an interactive website and also hosted a socio-ethical conference. Memory Walks and Alzheimer Cafés took place in Belgium, Monaco and Portugal - which also held a series of "cinema and debate" events.

This month, we closed the newsletter earlier than usual, in order to have it ready in time for the Conference. You can expect to see more about World Alzheimer's Day in the next newsletter and also in the next issue of our Dementia in Europe magazine.

Other notable member news includes the 30th birthday of the Alzheimer Society of Ireland. Our Irish colleagues also look forward to the 2013 launch of their national dementia plan. France looks at the achievements of its Alzheimer plans and lobbies for continued support of people with dementia. Scotland has launched a new report calling for radical

reform in dementia care while a German report focuses on the growing number of people with dementia.

In EU news, the latest issue of the Health-EU newsletter focused on Alzheimer's disease. This included an interview with Dr. Armelle Leperre-Desplanques, leader of the ALCOVE project. In addition, the European Medicines Agency has named a new head for the CHMP, a group that is very active in approving new drugs in Europe.

September saw considerable media reaction to the announcement of curtailed clinical trials for dementia treatments. This press coverage reminds us yet again that medical research is a slow, laborious and expensive process.

We report on the expansion of a clinical trial of gantenerumab and a new trial for fronto-temporal dementia. There is also a new American report detailing all of the drugs currently being tested to treat dementia.

There are many new resources in this issue. You'll find links to a series of 15 videos for caregivers, courtesy of the Fatebenefratelli research institute. ADI released the 2012 World Alzheimer's Report, which shows that stigma and social exclusion still hamper people with dementia. Finally, a new service from a Dutch university hospital provides factsheets for various psychosocial treatments.

We wish all of our 489 registered delegates a pleasant trip to Vienna and a productive 22nd Alzheimer Europe Conference!

Jean Georges
Executive Director

Alzheimer Europe

21 September: Alzheimer Europe and AGE Platform Europe issue joint press release for World Alzheimer's Day

"Age- and dementia- friendly environments as investment for a sustainable EU"

"Investment in age- and dementia- friendly environments is greatly needed to support the active participation of our ageing populations in society and respond to Europe's demographic challenge in a sustainable way," points out Anne-Sophie Parent on the occasion of World Alzheimer's Day on 21 September 2012, adding that "In creating those environments, we reduce the demand on health and long term care and create healthy environments which benefit everyone, while having a positive financial impact both on public and private expenses."

With the numbers of people with dementia increasing with the ageing of the population and expected to reach 15 million by 2050 - creating environments that empower older people and people with dementia to lead independent lives and take an active part in society for longer must become a priority for EU decision-makers.

This requires a **holistic approach** to Alzheimer's disease and other dementias, which goes beyond medical treatment, and better coordination between all relevant stakeholders, in order to improve the quality of life and dignity of patients and their families. It is essential to **create an environment that favours the inclusion of people with dementia and their relatives in their communities** e.g. by tackling the stigma attached to these diseases, favouring as much as possible community-based care, by supporting families and carers, adapting staff training and housing equipment and design, training bus drivers, salespersons, the police and other members of the public on how to deal with a person with Alzheimer's, etc.

Age- and dementia- friendly measures will **promote everyone's health and well-being**. They will benefit people with Alzheimer's disease and also the growing number of informal carers in charge of older dependent relatives, who will be supported in their caring duties and will be able to continue to remain in paid employment for longer - with a positive impact on their financial stability and family life.

Many initiatives already exist across the European Union, which could inspire further action in other EU Member States. For example, dementia-friendly housing adaptations such as bright open spaces, calming colours and a relaxing atmosphere impact positively on everyone and create living spaces that are better adapted to the needs of all age groups (universal design).

This is why, in the framework of the European Innovation Partnership on Active and Healthy Ageing, AGE Platform Europe and Alzheimer Europe join forces to call for the launch of a **European Covenant of local and regional authorities on demographic change**, whose objective will be to promote age and Alzheimer-friendly environments across the European Union.

Some further examples of good practices across the EU that support age- and Alzheimer-friendly environments:

AAL programme using ICT to improve or sustain the cognitive functions of people with Alzheimer's disease by developing, integrating and testing new technologies in homecare and residential settings.

ALLADIN project to develop an integrated solution for the self-management of people with dementia through innovative tools.

Dementia residential community project in Germany integrating housing, care and everyday services to support independent living of older people in need of assistance.

[World Alzheimer's Day on EY2012 website](#)
[EU Joint Programming Initiative on Alzheimer and other neurodegenerative diseases](#)
[AGE position paper on dementias \(November 2010\)](#)
[AGE call for an age-friendly EU](#)

23 September: "Value of Knowing" survey findings are published in peer reviewed journal

In June 2011, Alzheimer Europe launched the results of the "Value of Knowing" survey at the AAIC Conference in Paris. This joint research project was carried out together with the Harvard School of Public Health, the American Alzheimer's Association and Alzheimer Europe's member organisations in France, Germany, Poland and Spain and was supported by Bayer.

A scientific paper with a sub-analysis of the research results "The Impact of Experience with a Family Member with Alzheimer's Disease on Views about the Disease across Five Countries." has now been published in the peer-reviewed International Journal of Alzheimer's disease.

The objective of the paper is to understand how the public's beliefs may change as more families experience Alzheimer's disease. The data derived from a survey conducted among 2,678 adults in France, Germany, Poland, Spain and the United States.

The paper analyses the beliefs and anticipated behaviour of those who report having had a family member with Alzheimer's disease versus those who do not. In one or more countries, differences were found between the two groups in their concern about getting Alzheimer's disease, knowledge that the disease is fatal, awareness of certain symptoms, and support for increased public spending.

The results suggest that as more people have experience with a family member who has Alzheimer's disease, the public will generally become more concerned about the disease. The public will also be more likely to recognise that Alzheimer's disease is a fatal disease. The findings suggest that other beliefs may only be affected if there are future major educational campaigns about the disease.

The open-access paper is available on the website of the "International Journal of Alzheimer's disease" and on the Alzheimer Europe website.

www.hindawi.com/journals/ijad/2012/903645/
www.alzheimer-europe.org/Research/Value-of-knowing



Alzheimer Europe Networking

- On 5 September (Luxembourg, Luxembourg) Jean met with lawyers to discuss the Alzheimer Europe Foundation.
- On 7 September (Vienna, Austria) Gwladys had a meeting with the conference organiser to finalise preparation of the 22nd Alzheimer Europe.
- On 7, 11 and 19 September (Luxembourg, Luxembourg) Julie met with Jean-Paul Reuland from Binsfeld publishers to discuss issue 12 of the Dementia in Europe magazine.
- On 11 September (Brussels, Belgium) Annette had a meeting with Aino Valtanen, assistant to MEP Sirpa Pietikäinen.
- On 20 September (Vienna, Austria) Jean participated in a press conference with Alzheimer Austria for the 22nd AE Conference in Vienna.
- On 28 September (Brussels, Belgium) Annette met with the EFPIA Think Tank.

European Alzheimer's Alliance

6 September: MEP Werthmann asks the Commission about the availability of a drug to improve the treatment of Alzheimer's disease



Angelika Werthmann, MEP (Austria) and member of the European Alzheimer's Alliance, received an answer to her written question on the European availability of an immune drug to improve treatment of Alzheimer's disease.

Ms Werthmann referred to an American study showing that people with Alzheimer's disease responded well to an immune drug therapy known as IVIG. She wanted to hear whether the Commission intended to build on these findings, and if it will approve the drug for use in the EU.

She also asked the Commission to estimate the drug's impact on both individual patients and social welfare costs within the EU.

The Commission answered that IVIG is the abbreviation used for medicinal products for intravenous use containing an immunoglobulin as an active substance. Currently, the use of IVIG in Alzheimer's disease is in the research stage.

The cost-effectiveness of a medicinal product is usually assessed within the framework of pricing and reimbursement, both of which are done by the Member States. The Commission does not have any data on the impact of this potential treatment on the costs related to the Alzheimer's disease.

www.europarl.europa.eu/sides/getDoc.do?type=WQ&reference=E-2012-007215&language=EN

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). **Belgium:** Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnoc Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP). **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). **Finland:** Jaakonsaari Liisa (S&D), Jäättteenmäki 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 Blinkėvičiūtė (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), Zaboriska Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badia i Cutxet 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

7 September: MEP Rossi questions the Commission on a mobile phone application to help cope with Alzheimer's disease

On 7 September, MEP Oreste Rossi (Italy) sent a question to the European Commission on the subject of "Mobile phone application to help cope with Alzheimer's disease" (question E-007935/2012).

Mr Rossi refers to a virtual application called "Alzheimer's APP" which is now in use in Rome. "Alzheimer APP" is a mobile phone application that can be used by the family of a person with dementia. It provides information on how to care for the person with dementia, how to

respond to their behaviour and where to take them for medical care and assistance.

The application has an "assistance" section with practical suggestions and explanations - such as how to respond to a person's dementia fears and obsessions - and an "Alzheimer" section with specific information on the disease.

As this application can improve the quality of life of people with Alzheimer's disease, how can the Commission support this initiative?

<http://www.europarl.europa.eu/sides/getDoc.do?type=WQ&reference=E-2012-007935&format=XML&language=EN>

17 September: European Medicines Agency names new CHMP chair

The European Medicines Agency (EMA) has named Dr. Tomas Salmonson as the new chair of the Committee for Medicinal Products for Human Use (CHMP).



Dr. Salmonson brings outstanding experience and expertise from a long career in the regulation of medicines both on a national and European level to his new role. A pharmacist by training, he is currently senior scientific advisor at the Swedish Medical Products Agency. He has been a member of the CHMP for more than 12 years, including serving as vice chair since 2007. He has been acting CHMP chair since the departure of the previous chair, Dr. Eric Abadie, in April 2012.

The CHMP is responsible for preparing the Agency's opinions on all questions concerning medicines for human use. The committee plays a particularly vital role in the marketing procedures for medicines in the European Union.

Dr. Salmonson said: "The CHMP has many challenges ahead and as a chair, I am committed to ensuring that we actively shape our own future. The regulation of medicines has become much more proactive over the past few years, and we must embrace the tools we have to shape drug development pre- and post-approval, for example by providing scientific advice to companies developing medicines and agreeing risk-management plans for new medicines coming to the market."

www.ema.europa.eu/ema/

21 September: Dr. Leperre-Desplanques showcases ALCOVE on World Alzheimer's Day



Dr. Armelle Leperre-Desplanques, project leader of ALCOVE (Alzheimer Cooperative Valuation in Europe) spoke about the project and Alzheimer's disease in the 21 September issue of the EU-Health newsletter.

"Sharing knowledge to advance dementia care in Europe"

Alzheimer's disease (AD) and other dementias affect 7 million Europeans and 20 million family carers. These numbers will double between now and 2040. September 2012 marks the first global World Alzheimer's Month, an international campaign to raise awareness and challenge stigma. The theme of this year is "Dementia, Living together".

Given its high prevalence, cost and profound impact on society, dementia is an EU public health priority. Improving care and quality of life for people living with AD and their carers are urgent priorities as well as limiting the burden of the loss of autonomy and encouraging citizen and intergenerational solidarity.

The Joint Action ALCOVE's objective is to share dementia-related knowledge in public health, the organisation of care, clinical care, and ethics. This Joint Action is supported by Member States, health professionals and

patient associations, and complements other EU initiatives on dementia and healthy aging.

In March 2013, ALCOVE's 19 European countries will present their conclusions with knowledge that could benefit each Member State. The ALCOVE toolbox and its benchmarks will facilitate the implementation of public health actions including antipsychotic risk prevention.

As our societies and solidarity systems face the challenge of dementia, the pooling of knowledge and experiences is crucial. European mobilisation around dementia is an expression of this need and mutual interest.

Armelle Leperre-Desplanques (MD, PhD) heads the Department of Pilot Programmes on Clinical Impact at the French National Authority for Health. Since 2004, she has led a team of health professionals that conceives, coordinates and develops public health programmes to improve quality, safety and outcomes. She has led the ALCOVE project since April 2011.

Ms Leperre-Desplanques will be a keynote speaker at the 22nd Alzheimer Europe Conference, which will take place on 4-6 October in Vienna.

http://ec.europa.eu/health-eu/newsletter/96/newsletter_en.htm
www.alcove-project.eu/

21 September: EMA supports World Alzheimer's Month



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

The European Medicines Agency supports World Alzheimer's Month which is taking place throughout September 2012.

World Alzheimer's Month, being held for the first time this year, culminates in World Alzheimer's Day on Friday 21 September. The Month is dedicated to raising awareness of dementia and challenging stigma. In 2012, its theme is 'dementia: living together'.

The Agency plays a key role in the authorisation of medicines to treat dementia. In the European Union (EU), all medicines for the treatment of diseases causing degeneration of the brain and nervous system, including dementia, must be authorised centrally at a European level, rather than in each Member State separately.

The Agency works closely with organisations representing patients with dementia through Alzheimer Europe, an umbrella organisation of 34 national Alzheimer associations from 30 European countries. It also interacts with organisations representing healthcare professionals in the field of dementia, and works with European and international scientific organisations such as the Critical Path Institute.

The Agency's Committee for Medicinal Products for Human Use (CHMP) has issued five qualification opinions on biomarkers for Alzheimer's disease that may enable the diagnosis of the disease before patients show signs of dementia.

The CHMP can issue qualification opinions on the acceptability of a specific use of a method, such as the use of a novel methodology or an imaging method, in the

context of pharmaceutical research and development. Qualification opinions are based on the assessment of data submitted to the Agency and the recommendation of the Scientific Advice Working Party (SAWP).

The Agency also organises regular events and meetings, many of which cover issues related to dementia, as well as providing guidance for companies developing medicines for the treatment and diagnosis of Alzheimer's disease and related illnesses.

www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2012/09/news_detail_001603.jsp&mid=WC0b01ac058004d5c1

Members' News

26 July: Sweden's Demensförbundet publishes architectural guide



The Swedish National Dementia Association (Demensförbundet) has released a new publication called "Guidelines for planning of group living/ nursing homes for people with dementia - buildings that become a language and support for communication when the mind fails."

This is based on a report by architect Ewa Krynicka Storskog (pictured) who conducted research, study visits and interviews with people living with dementia. The publication highlights various aspects such as colour, light and sound as seen in relation to architecture.



The new publication can be purchased on the association's website.

www.demensforbundet.se

4 September: Germany reports 1.4 million people with dementia today



A study commissioned by the Alzheimer's association in Germany shows that the country is home to more than 1.4 million people with dementia. Two thirds of these people are living with Alzheimer's disease.

Barring any breakthrough in prevention or treatment, this number will increase to about three million people with dementia by 2050. This represents an increase of 40,000 cases per year, or more than 100 new cases every day.

The study was led by Dr. Horst Bickel from the Psychiatric Clinic of the Technical University in Munich. The results are based on data originally collected by Alzheimer Europe for the EuroCoDe project.

Heike von Lützu-Hohlbein, who chairs both the German Alzheimer Association and Alzheimer Europe, said: "These alarming figures should motivate us all to do more to ensure that people with dementia and their families can lead a decent life, both today and in the future."

The full report (in German) is available on the association's website.

www.deutsche-alzheimer.de/fileadmin/alz/pdf/factsheets/FactSheet01_2012.pdf

13 September: France Alzheimer launches World Alzheimer's Day website

France Alzheimer has launched a dedicated website for World Alzheimer's Day. The site's theme is "We are all involved" and it contains the latest information on prevalence, tips for family members and carers, a message board and a quiz.

www.alzheimertousconcernes.org



18 September: Alzheimer Scotland launches report on dementia care



Alzheimer Scotland has launched a new report called "Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support". The report calls for a radical reform of the way community care services are delivered to people with dementia, their carers, partners and families.

The 8 Pillars Model of Community Support provides an integrated and comprehensive approach to the support of people with dementia and their families and carers. This will help to enable people with dementia to remain at home for as long as possible with moderate to severe dementia. At a time of demographic change, it delivers a coherent approach in response to increasing dementia prevalence.

The model builds on key developments in post-diagnostic support and will ensure the impact of the investment in early intervention is not lost. It will also form an essential component of "transformational change to deliver world-class dementia care and treatment", a stated aim of the Scottish government.

By tackling the full range of factors that influence the experience of the illness in a coordinated way, it takes a therapeutic approach to enhancing the resilience of people with dementia and their families and carers: equipping and supporting them to cope with the symptoms of the moderate to severe stages of the illness.

The shift towards the integration of health and social care provides an ideal opportunity to transform dementia care in Scotland and to make it of a world-leading standard. The move towards community capacity building and proportionately fewer resources for institutional care requires a coordinated approach to support people with dementia in the community, which is provided by the 8 Pillars Model.

This model provides local authorities and NHS boards with a blueprint for restructuring integrated dementia care so that resources are used to greatest effect. Adopting this model must be a priority for the integration agenda; it will empower families, make effective use of the full range and depth of interventions, provide a coordinated approach to engage with all partners and use their resources and skills to the fullest effect.

The new report is available upon request to alzheimer@alzscot.org

www.alzscot.org

18 September: Spain's CEAFA marks World Alzheimer's Day with a press conference



On 18 September, a joint press conference to mark World Alzheimer's Day was held in Madrid. The conference was designed to inform the public and lobby the government on the importance of developing a national dementia plan. It was hosted by IMSERSO, a government agency serving elderly people, and featured speakers from the CEAFA national Alzheimer association and SEMERGEN, the national association of Spanish GPs.

The speakers (pictured below) are all active players in the effort to create this plan: Mr Arsenio Hueros, President of CEAFA, the Confederation Spanish Associations of Families of People with Alzheimer's and other Dementias; Mr César Antón Beltrán, Director General of IMSERSO; Dr. López Rocha, Spokesperson for SEMERGEN.

Mr Hueros stressed the importance of research to improve early diagnosis. He said that dementia research must have access to similar resources and priorities as other serious diseases. He also pointed out that research funding for heart disease and cancer are respectively 15 and 30 times higher than for Alzheimer's disease.

Dr. Rocha also talked about early diagnosis, especially the need for more education and tools to allow earlier detection by GPs. He said that family doctors must acquire the skills to distinguish between early dementia pathology and memory loss as a normal part of aging. He also said that an effective dementia plan must involve and include family caregivers.

In closing, Mr. Hueros said that CEAFA is committed to play an active role in the planning and development of a national dementia plan in Spain. The association will contribute all of the resources, expertise and knowledge acquired during more 20 years of activity.



Photo: (L-R) Arsenio Hueros, César Antón Beltrán, López Rocha

21 September: German associations issue joint press release for World Alzheimer's Day



A joint press release was issued by three German associations on World Alzheimer's Day: the Alzheimer Association, the Brain League (Hirnliga) and the Association for Geriatric Psychiatry and Psychotherapy (DGGPP).

The press release states that dementia cases in Germany are steadily rising, with about one of three people aged 90+ already affected. There are now some 1.4 million

people living with dementia and this will increase to 3 million by 2050. The related cost will also increase rapidly, especially as dementia is already the most costly disease today.

Heike von Lützu-Hohlbein, chair of the German Alzheimer Association, said that we should all live by the motto "Dementia: living together" - the call to action adopted by Alzheimer associations worldwide in 2012. She explained that dementia is not limited to individuals and their families, but affects all citizens of the community. She added that politicians had recognised this and had recently formed the "Alliance for people with dementia".

Professor Isabella Heuser, Board Member of Hirnliga, said that medical research is proceeding intensively and that there are promising results but also setbacks. She said: "We cannot predict when or even whether a drug for Alzheimer's disease may become available. However, even today it is possible to positively influence the course of the disease through early diagnosis and timely interventions."

Professor Hans Gutzmann, Geriatric Psychiatrist at DGGPP, said: "The inadequacies of health and nursing home insurance mean that Germans with dementia are not being treated as well as they could be. It is essential that tests for early diagnosis and all forms of treatment be covered by insurance." He added that the current system causes undue stress on caregivers, putting them at higher risk of falling ill themselves.

21 September: Alzheimer Bulgaria holds press conference for World Alzheimer's Day



The Alzheimer Bulgaria Association and the Aleksandrovska University Hospital (AUH) held a joint press conference on World Alzheimer's Day. The conference was held in a care home for people with dementia near Sofia.

The conference focused on the necessity of developing a national strategy for Alzheimer's disease, including all the medical, social and psychological aspects related to dementia. The principal message was that Alzheimer's disease is as much a social as it is a medical challenge.

Participants also heard the results of the first Bulgarian research project on the prevalence of dementia: among a total population of seven million, there are 100,000 people diagnosed with dementia in Bulgaria - of which 60,000 are living with Alzheimer's disease. The prevalence rate is similar to other EU countries, but Bulgaria still lags in public awareness of dementia.

Prof Lachezar Traikov, director of AUH, explained that - since February 2012 - some of the most important dementia drugs are fully or partially reimbursed. He praised Alzheimer Bulgaria and the government agencies who worked together to make the reimbursement scheme a reality. The association has also been active in training doctors all around the country to recognise the early symptoms of dementia.

The conference was followed by a performance of traditional Bulgarian dances and songs by the care home residents. There was also a charity sale of handmade craft

objects, made by people with Alzheimer's disease and other forms of dementia. The proceeds will be used for future activities aimed at improving the cognitive abilities of people living with Alzheimer's disease.



Photo: Press conference on 21 September in Bulgaria

21 September: Monaco's AMPA organises Memory Walk on World Alzheimer's Day

The Monaco Alzheimer association AMPA organised its third Memory Walk to celebrate World Alzheimer's Day. The event was very successful as some 250 people turned out for a walk to raise awareness and reduce stigma about dementia.

On the same day, the local Princess Grace Hospital announced that 30 beds would soon be made available exclusively to people with dementia.

www.monacochannel.mc/Chaines/Gouvernement-Princier/Videos/Marche-en-faveur-de-la-lutte-contre-la-maladie-d-Alzheimer

AMPA is not a member of Alzheimer Europe, but we are pleased to cover all World Alzheimer's Day activities.

21 September: Alzheimer Portugal holds week of events for World Alzheimer's Day



Alzheimer Portugal celebrated World Alzheimer's Day with a full week of events across the country.

During 17-20 September, there was a series of "cinema and conference" events with the theme "Alzheimer's disease in the cinema". Four films with dementia themes were shown, followed by interactive discussions between the audience and a panel of expert speakers.

On 21 September, the association held its first Alzheimer Café, a relaxing space where people with dementia, their families and caregivers came together for a unique sharing of experiences, information and support. The Alzheimer Café is a platform for support, information, empowerment and inclusion.



The week's activities ended with the second annual Passeio da Memória (Memory Walk) on 23 September. This year, the popular event was extended to five cities and attracted hundreds of people. Walkers completed a six-kilometre course to raise awareness of the importance of exercise to reduce the risk of developing dementia.

The week's activities ended with the second annual Passeio da Memória (Memory Walk) on 23 September. This year, the popular event was extended to five cities and attracted hundreds of people. Walkers completed a six-kilometre course to raise awareness of the importance of exercise to reduce the risk of developing dementia.

21 September: Brussels hosts an Alzheimer Café Day on World Alzheimer's Day



On 21 September, Belgium's Ligue Alzheimer and the Vlaamse Alzheimer Liga co-hosted a special Alzheimer Café Day in Brussels to commemorate World Alzheimer's Day. This was the seventh occurrence of the popular event and it was held in the name of LINAL, the Belgian national Alzheimer League.

During the event, LINAL announced the creation of a new national group called Dementia Alliance Belgium (DAB). This group will bring together all the Belgian associations and authorities that are active in the dementia cause. DAB intends to consolidate all of its members' resources in order to develop a national dementia plan for Belgium.

22 September: Spain's FAE blends tradition and high-tech for World Alzheimer's Day



Alzheimer's Day.

The Fundación Alzheimer España (FAE) organised a musical theatre evening and also launched a smartphone application to mark World Alzheimer's Day.

"Me olvidé de ti...Alzheimer" (I forgot you, Alzheimer) was the theme of the variety show presented by FAE on 22 September. This was a combination of modern theatre, classical ballet and traditional flamenco, with proceeds going to the association.

On the previous day, FAE launched an application for mobile phones. This app, whose name translates as "Tips for everyday life with your family", offers a wealth of practical advice for daily living with a person with Alzheimer's disease. It includes the "Ten Golden Rules" for caregivers, which have been developed by FAE over the past two decades.

The new app costs Euro 1.39 and is aimed at "e-caregivers", a new generation of Spanish carers that is increasingly familiar with internet technologies and social networks.

www.alzfae.org/index.php/fae360/web/460-ialzheimer

30 September: The Alzheimer Society of Ireland celebrates 30 years of operation



This year, the Alzheimer Society of Ireland celebrates 30 years of helping people with dementia. The organisation was founded in 1982, by a small group of family carers whose initial concern was to offer information, understanding and support to those caring for a loved one with Alzheimer's disease.

This soon grew to a wider aim of increasing awareness and understanding of dementia. Supported by the medical community, the Society held many public information meetings around the country. These inspired the establishment of many of the branch networks which are an integral part of the Society today.

Branches are led by volunteers and operate throughout the country, providing information and support at a local level to people affected by Alzheimer's disease and other forms of dementia. Current statistics show 41,700 people with dementia in Ireland and this figure is expected to reach 147,000 by 2041.

Today, the network includes over 120 dementia specific services throughout the country, including day care centres, home care services, carer support groups, social clubs, respite centres and the Alzheimer National Helpline Service. The response to these actions has been very positive and has raised awareness around caring for loved ones with dementia and also for the carers themselves.

From the beginning, the Society has exerted pressure on the government to take more responsibility for the care of people with dementia and carers. This continues today, with a team focused on lobbying for the implementation of a National Dementia Strategy.

Niamh Sheeran, Head of Fundraising and Communications, said: "The goal of creating a dementia friendly society is still in progress but the Alzheimer Society of Ireland is a lot closer, thanks to the efforts of many people over the last thirty years."

Policy Watch

1 September: Ireland looks forward to launch of national dementia strategy



The Alzheimer Society of Ireland recently presented to the Department of Health a submission on the National Dementia Strategy that represents the voices of people living with dementia in Ireland.

In 2013, the Irish Government will publish The National Dementia Strategy, a plan to respond to the needs of people with dementia and their families. This will be the first time Ireland will have a strategic health plan for dementia, bringing it in line with other EU countries.

The main recommendations of the Society are shown below:

- Develop clinical and policy leadership in dementia
- Develop a strategy with a clear set of principles and values that enshrine social solidarity and interdependency
- Support people with dementia and their carers to have their voices heard
- Develop a new dementia community model
- Reconfiguration of how services are delivered using an integrated care pathway approach
- Dementia education, dementia friendly communities and public awareness must be core to the strategy
- Investment in dementia research.

Following the submission, the Society held an event to thank all those who supported and contributed to the work. Participants were able to hear the presentation of Senator and Professor John Crown, leader of the National Cancer Strategy in Ireland. Prof Crown spoke of the

parallels of dementia with cancer a few years back and the journey Ireland has had to travel to improve cancer care for all. He is pictured below (left), along with Gráinne McGettrick and Maurice O'Connell, respectively Research & Policy Officer and Chair of the Alzheimer Society of Ireland.



21 September: France Alzheimer urges extension of national dementia plan



The third French national dementia plan will officially expire in December 2012. France Alzheimer has released a progress review and also a white paper urging government approval for the fourth edition of the plan.

According to the review, the greatest success of the four year plan was the caregiver training programme: more than 10,000 people attended 850 training sessions all around the country. However, other elements have been less successful, with notable shortfalls in the provision of day care centres and temporary shelters. These have been ascribed to a large budget underspend: at the end of 2011, only EUR 370 million had been spent from a total budget of EUR 1.6 billion.

The white paper includes the ten objectives developed by France Alzheimer to improve the lives of people with dementia and their families. It also features testimonials from these people and the statements made by candidate François Hollande during the presidential election. The paper will be distributed to various French government officials.

For Marie-Odile Desana, Chair of France Alzheimer, the third Alzheimer plan was too short to allow all of its programmes to come to fruition. She said that the need for a fourth plan is evident and added that the new government has already shown interest in improving the quality of life of people with dementia and their families.

www.francealzheimer.org/pages/association/detailActu.php?id=361
www.francealzheimer.org/pdf/espace-presse/LivreBlanc_MaladieAlzheimer.pdf

Science Watch

3 September: MDA7 restores cognition, memory and synaptic plasticity

Scientists at the Cleveland Clinic in Ohio (USA) have found that a new compound called MDA7 restored cognition, memory and synaptic plasticity in rat models. It also improved the removal of amyloid beta from their brains.

The research team was led by Prof Mohamed Naguib, head of Anaesthesiology at Cleveland Clinic. MDA7 was discovered while the team tested another drug to control pain in chemotherapy patients. They found that the compound's anti-inflammatory properties could also be effective in treating other conditions, notably Alzheimer's disease.

www.sciencedirect.com/science/article/pii/S0197458012003478

4 September: High blood sugar may be a risk factor for brain shrinkage

A new Australian study shows that people whose blood sugar is on the high end of the normal range may be at greater risk of brain shrinkage that occurs with aging and diseases such as dementia.

The study - led by Dr. Nicolas Cherbuin, Director of the Neuroimaging and Brain Lab at Australian National University - involved 249 people aged 60 to 64 who had blood sugar in the normal range as defined by the World Health Organization. The participants had brain scans at the start of the study and again an average of four years later. Those with higher fasting blood sugar levels were more likely to have a loss of brain volume in the areas of the hippocampus and the amygdala, areas that are involved in memory and cognitive skills.

Dr. Cherbuin said: "Numerous studies have shown a link between type 2 diabetes and brain shrinkage and dementia, but we haven't known much about whether people with blood sugar on the high end of normal experience these same effects."

www.neurology.org/content/79/10/1019.abstract?sid=77ed0129-f488-4421-bb31-4acb321d92de

5 September: Roche expands size of gantenerumab trial

On 5 September, Roche announced that it recently expanded its phase 2/3 trial of gantenerumab to include 770 participants - approximately twice the original size. The study "SCarlet RoAD" is testing the effects of the compound on people with prodromal Alzheimer's disease. It is due to end in 2015.

Roche is also conducting a phase 2 trial of crenezumab on people with mild to moderate Alzheimer's disease.

www.roche.com/media/media_releases/med-cor-2012-09-05.htm

6 September: Ginkgo biloba does not reduce risk of Alzheimer's disease

A study conducted by the University of Toulouse (France) showed that the herbal remedy ginkgo biloba does not significantly reduce older people's risk of developing Alzheimer's disease.

The study involved 2,854 people in France aged 70 years old or older who had gone to their GP with memory problems. 1,406 people were given ginkgo biloba twice a day for five years while 1,414 people were given a placebo. After five years, 61 people (4%) in the ginkgo biloba group had been diagnosed with Alzheimer's compared to 73 people (5%) in the placebo group.

[www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(12\)70206-5/abstract](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(12)70206-5/abstract)

6 September: Elimination of jnk3 enzyme reduces amyloid beta

Scientists from Ohio State University (USA) have shown that elimination of the jnk3 enzyme from mouse models led to a 90% reduction of amyloid beta in the rodents' brains.

The enzyme stimulates a protein that produces amyloid beta, suggesting that when jnk3 activity is high, amyloid production increases - leading to a higher risk of accumulation and formation into plaques.

The researchers also observed that jnk3 activity in brain tissue from Alzheimer's disease patients increased by 30-40% compared to normal human brain tissue. In a healthy brain, jnk3 activity is typically low, but increases when physiological abnormalities arise.

"These mice are models for the most aggressive form of Alzheimer's disease and produce the highest amount of A-beta peptides. This 90 percent reduction is the biggest drop in A-beta levels that has been reported so far by treating animal models with drugs or genetic manipulations," said Sung Ok Yoon, Associate Professor of Molecular & Cellular Biochemistry at Ohio State University and lead author of the study.

[www.cell.com/neuron/abstract/S0896-6273\(12\)00586-7](http://www.cell.com/neuron/abstract/S0896-6273(12)00586-7)

10 September: TauRx starts phase 3 trial of FTD drug

TauRx Therapeutics, a private pharmaceutical company, has announced the launch of a phase 3 trial of LMTX. This is a compound for the treatment of behavioural-variant fronto-temporal dementia (bvFTD), also known as Pick's Disease.

The double-blind placebo-controlled study will evaluate the safety and efficacy of LMTX, a tau aggregation inhibitor. It aims to confirm the results first seen in pilot cases in a larger controlled clinical trial in bvFTD patients over a 52-week timeframe.

According to the company, LMTX targets a process in the brain whereby a normal form of tau protein begins to self-aggregate due to binding neuronal waste-products. Once the process has started, the aggregates are able to propagate themselves indefinitely, using up normal tau protein and converting it into the toxic aggregates. After destroying the nerve cells where they are initially formed, the aggregates go on to infect nearby healthy neurons, progressively spreading and accelerating the destruction throughout the brain. LMTX stops this aggregation process and releases the trapped tau protein in a form which can be easily cleared by nerve cells.

The study will be led by Prof Claude Wischik, Professor of Old Age Psychiatry at the University of Aberdeen (Scotland) and CEO of TauRx Therapeutics. The trial will take place in Australia, Canada, Germany, The Netherlands, Singapore, the UK and the US. TauRx Therapeutics is based in Singapore and is a spin-off company from the University of Aberdeen.

www.sciencedirect.com/science/article/pii/S1552526008005980

11 September: New nanomolecules bring more drugs to the brain

Researchers from Johns Hopkins Medicine have developed a method to deliver nanoparticles further into the body and to administer higher drug doses when they get there.

Nanoparticles that deliver drugs are made by grouping the drug molecules together with string-like molecules into a tight ball. This ball slowly breaks down when it comes in contact with water, thus delivering the medicine. This system works well when the treatment area is close to the body's surface, but it is harder to deliver the drug package deeper into the body, eg to the brain.

The research team coated nano-sized plastic beads of various sizes with a molecule called PEG (polyethylene glycol). This is known to protect nanoparticles from the body's defence mechanisms and the team reasoned that a layer of PEG might also make the beads more slippery.

The coated beads were injected into slices of rodent and human brain tissue. Results showed that the beads were efficient at penetrating tissue, including larger beads (ie more drug-carrying capacity) than was previously believed. Further tests with a real drug in live rodent brains returned the same results.

Dr. Justin Hanes, Professor of Ophthalmology and Director of the Johns Hopkins Center for Nanomedicine, said: "We are pleased to have found a way to prevent drug-embedded particles from sticking to their surroundings so that they can spread once they are in the brain."

The scientists will continue to optimise the particles, pairing them with drugs to treat brain ailments including Alzheimer's disease.

<http://stm.sciencemag.org/content/4/149/149ra119>

12 September: ARBs may reduce Alzheimer's disease pathology

Researchers from the University of Southern California (USC) recently found that people treated with angiotensin receptor blockers (ARBs) show less Alzheimer's disease-related pathology.

ARBs are used for controlling high blood pressure, treating heart failure and preventing kidney failure in people with diabetes and high blood pressure.

Dr. Ihab Hajjar, a geriatrician at USC, led the team that studied data from autopsy samples of 890 people who had passed away at an average age of 81 years. The team compared vascular injury markers, neuritic plaque and neurofibrillary tangle for those taking ARBs and those treated with other medications and untreated individuals.

The results showed that people treated with ARBs - with or without Alzheimer's disease - showed significantly less amyloid than those treated with other medications.

Dr. Hajjar said: "This autopsy study suggests that treatment with ARBs is associated with less amyloid accumulation and AD-related pathology independent of other AD risk factors."

<http://archneur.jamanetwork.com/article.aspx?articleid=1356776#Abstract>

12 September: Study reveals link between cataracts and dementia

Scientists in Boston University Schools of Medicine and Public Health in Massachusetts have identified a gene linking age-related cataracts and Alzheimer's disease.

This follows previous findings that the protein δ -catenin, which builds up in Alzheimer's brains, also accumulates in the eyes. The researchers examined results from brain MRI scans of 1,249 people that were taken approximately ten years earlier. They found a link between cortical cataracts and various measures of brain degeneration. Specifically, they found increased deposits of δ -catenin in lens tissue from people who had Alzheimer's disease - but not from those who didn't.

The senior author of the study was Dr. Lindsay Farrer, Professor of Medicine, Neurology, Ophthalmology, Genetics & Genomics, Epidemiology and Biostatistics at Boston University. He said: "Though much work remains to be done, a link between cataracts and Alzheimer's disease supports the idea of a systemic rather than brain-limited focus for processes leading to Alzheimer's disease."

www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0043728

17 September: BACE 2 enzyme destroys beta amyloid in rodents

Researchers from the Mayo Clinic in Jacksonville, Florida have discovered that an enzyme called BACE 2 can "cut" beta amyloid, effectively destroying the toxic protein.

BACE 2 is closely related to another enzyme called BACE 1, which is involved in producing beta amyloid rather than destroying it. Beta amyloid is a fragment of a larger protein called APP, which BACE 1 cleaves, or cuts, to produce the fragments. BACE 2 then cleaves these fragments into smaller pieces, which are less likely to accumulate into plaques.

The researchers also found that BACE 2 can cleave APP directly, although this did not take place in the brain. Dr. Samel Abdul Hay, neuroscientist at Mayo and first author of the paper, said: "The fact that BACE 2 can lower beta-amyloid by two distinct mechanisms makes this enzyme an especially attractive candidate for gene therapy to treat Alzheimer's disease."

The project team was headed by Dr. Malcolm Leissring, Assistant Professor of Neuroscience at Mayo. The team will now study whether blocking beta-amyloid destruction by BACE 2 can increase the risk for Alzheimer's disease in a mouse model of the disease.

www.molecularneurodegeneration.com/content/7/1/46/abstract

17 September: Brain network errors may help track the development of Alzheimer's disease

Researchers at Washington University (WU) School of Medicine (Missouri, USA) have mapped the activity of various networks in the brain and how they affect each other in Alzheimer's disease. They found that communications within and between networks are disrupted, but it doesn't happen all at once.

The team led by Dr. Beau Ances, Assistant Professor of Neurology at WU, analysed brain scans of 559 subjects.

Some subjects were cognitively normal, while others were in the early stages of Alzheimer's disease.

According to Dr. Ances, most research into Alzheimer's effects on brain networks has either focused on the networks that become active during a mental task, or the default mode network. This network activates when a person is daydreaming or letting the mind wander - and is also one of the first networks to be impaired by the disease.

However, other brain networks also become active when the brain is "idling". The team examined the effects of Alzheimer's disease on the networks which are active at the same time and also those which require "switching": when one network is active, the other network is quiet. This ability to switch back and forth between networks is significantly diminished in Alzheimer's disease.

Dr. Ances said: "While we can't prove this yet, one hypothesis is that as things go wrong in the processing of information in the default mode network, that mishandled data is passed on to other networks, where it creates additional problems." He concluded that these network breakdowns may help track the development of the disease and aid efforts to better understand its spread through the brain.

www.jneurosci.org/content/32/26/8890.abstract?sid=08b0c584-572e-4112-8a70-6bda0d7a436c

19 September: PET agent detects beta amyloid in live humans

GE Healthcare has announced positive results from a phase 3 study on a PET amyloid imaging agent called [18F]flutemetamol. This agent is being developed for the detection of beta amyloid deposits in the brains of live humans.

The trial involved 180 participants with advanced Alzheimer's disease and 49 people with suspected Normal Pressure Hydrocephalus - a progressive condition associated with dementia. All participants received [18F]flutemetamol injections. The PET images were read by physicians who identified the images as normal or abnormal.

Results showed a strong concordance between the images and Alzheimer's disease brain pathology. Specifically, beta amyloid was detected with a median sensitivity ranging from 75-100% and specificity ranging from 99-100%. In addition, the visual assessment of all images showed a high level of agreement among readers.

Dr. Ville Leinonen, Neurosurgeon and Director of Kuopio University Hospital (Finland), said: "We are encouraged that [18F]flutemetamol PET images accurately and consistently reflected beta amyloid levels in living patients.

"Currently, Alzheimer's disease is confirmed during autopsy studies, but if we can detect beta amyloid earlier, we can help physicians make a more timely clinical diagnosis that can impact disease management and treatment decisions."

These results were presented at the 16th EFNS Congress in Stockholm.

www.genewscenter.com/News/Phase-III-Results-for-Investigational-Imaging-Agent-18F-Flutemetamol-Demonstrate-Ability-to-Accurately-Detect-Beta-Amyloid-in-Living-Patients-3ae6.aspx

20 September: Protein test may help diagnose Creutzfeldt-Jakob disease

A new guideline released by the American Academy of Neurology may help doctors in diagnosing sporadic Creutzfeldt-Jakob disease. The guideline involves testing for a protein called 14-3-3 in cerebrospinal fluid (CSF).

Several tests are available to help diagnose sporadic Creutzfeldt-Jakob disease. A brain biopsy is the most accurate test that can be performed on a person living with the disease, but is also potentially dangerous.

The new guideline examined the diagnostic accuracy of testing for a protein called 14-3-3 in CSF. Researchers reviewed all of the available evidence on the test, which included samples of 1,849 people with suspected sporadic Creutzfeldt-Jakob disease from nine studies.

They found that the test can be helpful in reducing the uncertainty of the diagnosis in cases where doctors strongly suspect Creutzfeldt-Jakob to be the cause of dementia. However, the test is not accurate enough to diagnose the disease with certainty or to rule it out completely.

The guideline determined that the 14-3-3 protein test can be useful when the probability of the person having Creutzfeldt-Jakob disease is between 20-90%.

Dr. Taim Muayqil, a neurologist at Riyadh's King Saud University in Saudi Arabia, said "This means that if the physician considers the likelihood of Creutzfeldt-Jakob disease to be extremely low or extremely high, then testing for 14-3-3 protein would not be useful regardless of the result".

www.neurology.org/content/early/2012/09/19/WNL.0b013e31826d5fc3

Dementia in Society

1 September: Spanish film describes life with Alzheimer's disease

An award-winning short film about Alzheimer's disease has been released in Spain. "Un fuerte abrazo, Carmen" ("A big hug, Carmen") is about a woman who lives with Alzheimer's disease: one day, Carmen finds an old photograph album which revives her memory and sets her on a nostalgic trip through the most significant parts of her life. The 2011 film was directed by Isaiah Lopez Maymó.

www.lomay.es/Fotografia_video_diseno_y_publicidad_TENERIFE/UN_FUERT E_ABRAZO_CARMEN_play.html

7 September: Study shows effects of environmental factors on quality of life

A recent study showed that environmental factors such as temperature and light have a significant effect on the quality of life (QOL) of people with dementia. The study was led by Dr. Josep Garre-Olmo, researcher at the University of Girona.

The study was carried out among 160 residents with severe dementia in eight long-term nursing homes in Spain. Measurements of brightness, temperature, and

atmospheric noise were taken in participants' bedrooms as well as in the dining and living rooms of each residence. The scales used to assess quality of life included mood, physical comfort, social interaction and difficulties with activities of daily living.

The results showed that:

- high temperature in the bedroom was associated with lower QOL.
- high noise levels in the living room were associated with low behavioural signs of social interactions.
- low lighting levels in the bedroom were associated with number of signs of negative affective mood.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2012.04040.x/abstract?sessionid=D1F5D6F1D160B5FFB3A23116D247FC5D.d01102>

17 September: French survey shows public concern and need for education about Alzheimer's disease



On 17 September, France Alzheimer and insurer Groupe Pasteur Mutualité released survey results which showed that 86% of French people are worried about Alzheimer's disease and 41% want to know more about its symptoms. The joint survey was conducted to demonstrate French public perception of Alzheimer's disease on World Alzheimer's Day.

The results show that 86% of people surveyed are worried about Alzheimer's disease. Among them, women (91%) and people aged 65 or over (90%) are particularly worried. Younger people also expressed concern, particularly 24% of those aged 18-24.

More than half of respondents (59%) feel that they are sufficiently informed about Alzheimer's disease, especially those aged 65 and over (66%). These well-informed people cite the media (68%), GPs (24%) and specialist doctors (13%) as their main sources.

Amongst the 41% of respondents who do not feel well-informed, young people aged 18-24 (51%) and men (45%) have the highest knowledge gap. Their preferred sources for obtaining information are GPs (62%), the media (50%) and specialist doctors (32%).

This survey was carried out by Viavoice during 30-31 August 2012 among 1007 people aged 18+ and living in France.

www.francealzheimer.org

21 September: France's EREMA holds annual conference on Alzheimer's disease



On 18-20 September, the French Espace National de Réflexion Ethique Alzheimer (EREMA) organised its annual conference on ethical and social issues around Alzheimer's disease. The 2012 "Université d'été Alzheimer" concentrated on the issues and challenges of living with dementia.

The conference featured presentations from health professionals, government bodies and associations,

including sponsors Fondation Médéric Alzheimer and France Alzheimer.

www.espace-ethique-alzheimer.org/universitedete2012_programme.php

New Publications & Resources

14 September: New reports show the difficulties and progress of dementia drug research

The Pharmaceutical Research and Manufacturers of America (PhRMA) recently released two new reports about dementia drug development during 2012.

"Alzheimer's Research: Setbacks and Stepping Stones", outlines the difficulties of investigating potential new drugs for dementia. The report sites that only three of 104 compounds have advanced to approval for Alzheimer's disease treatments since 1998. This low success ratio is very costly, even if setbacks can eventually contribute to success by putting researchers on a more promising path. The report advocates "a policy framework that supports the long and uncertain process of developing treatments as well as the successes by sustaining a robust research enterprise that encourages innovators to take risks and accept the inevitable setbacks."

"Medicines in Development for Alzheimer's Disease" shows that American biopharmaceutical research companies are currently investigating or developing 93 new medicines for people with dementia. The report contains a detailed table of all the compounds that are in clinical trials or under review by the FDA. This includes a chart showing that developing a new medicine takes an average of 10-15 years and that for every 5,000-10,000 compounds in the pipeline, only one is approved.

John Castellani, PhRMA President and CEO, said: "Confronting this devastating disease of the brain will require continued collaboration in the scientific, medical and patient care communities and a commitment by policymakers to support and reward medical innovation."

<http://phrma.org/sites/default/files/422/alzheimers2012.pdf>
<http://phrma.org/sites/default/files/1864/alzheimersetbacksreportfinal912.pdf>

15 September: Dementia explained in 80 pages



A new book on dementia has been released by John David Baker, a practicing Nurse Specialist in Dementia Care, Care of the Older Person and Nursing Home Practice. Mr Baker was also related to a person that had vascular dementia before she died.

The book is called "The Nurse Explains: Dementia, Alzheimer's Disease and Vascular Dementia". It was written for people with dementia, their relatives, care staff, nurses and people that just wish to learn a little more about dementia. The book is only 80 pages in length and aims to give a sound understanding of what dementia is in a relatively short time.

This book has been published by "John Baker Independent publishing".

17 September: Italian research centre releases educational videos for caregivers



A new series of educational videos on Alzheimer's disease have been released by Fatebenefratelli, the National Centre for Alzheimer's and Psychiatric Diseases in Brescia, Italy. They are freely available in Italian, English and French.



The videos feature a series of interviews and presentations by Dr. Giovanni Frisoni, Neurologist and Deputy Scientific Director of Fatebenefratelli. Dr. Frisoni seeks to help caregivers of people with Alzheimer's disease to manage their loved ones at home; he explains what Alzheimer's disease is and what may be expected after diagnosis has been made.

The videos in English and French are shown on the next page. Videos in Italian can be found at:

www.centroalzheimer.org/sito/video.php

More about Dr. Giovanni Frisoni:

www.centroalzheimer.org/sito/chi_gbf_e.php

21 September: New information service for the care and treatment of dementia



The VU University Medical Center (VUmc) in Amsterdam launched a new information service desk for the effective care and treatment of dementia on World Alzheimer's Day.

The website offers an overview of effective psychosocial treatments in dementia. The methods are organised by the type of assistance they offer (eg dealing with disabilities or maintaining a positive self-image) and also on the target group for whom the treatment has proved to be effective (eg people with dementia who live at home or those who live in an institution).

For each intervention, the most relevant information is summarised in a factsheet. This includes the target group, content of the intervention and the demonstrated effect. It also mentions whether additional materials are available that facilitate the implementation of the treatment, such as brochures and films.

This project was developed by researchers of the research group "Psychosocial care and support for people with dementia" of the Department of General Practice & Elderly Care Medicine and the Department of Psychiatry at VUmc. The Information Desk is part of the Amsterdam Center on Aging.

www.vumc.com/branch/information-desk-dementia-care/

21 September: ADI releases 2012 World Report

Alzheimer's Disease International (ADI) released its 2012 annual report on World Alzheimer's Day.



The World Alzheimer's Report 2012 shows that stigma and social exclusion are major barriers for people with dementia and their carers. 75% of people with

dementia and 64% of family carers believe there are negative associations for those diagnosed with dementia in their countries. In addition, 40% of people with dementia report they have been avoided or treated differently.

The report is based on a global survey of 2,500 people with dementia and family carers across more than 50 countries. The survey aimed to record individual experiences of stigma by people with dementia and family carers and help identify whether national dementia plans have had an impact on reducing stigma.

Nicole Batsch, report author, said: "The report reveals that people with dementia and carers feel marginalised by society, sometimes by their own friends and family members. What they want is to be treated like normal people with a focus on their abilities and not on their impairments. Bringing light to these issues will help improve the quality of life for people with dementia and for their carers."

The report also provides ten key recommendations for governments and societies to include people with dementia into everyday activities.

The World Alzheimer's Report 2012 is available on ADI's website.

www.alz.co.uk/research/world-report-2012

Job opportunities

17 September: Bournemouth University seeks Associate Director



The Bournemouth University Dementia Institute is recruiting an Associate Director. The post is located in the Bournemouth University Dementia Institute (BUDI), School of Health and Social Care. The main role is to work collaboratively with the Director of BUDI to support the development of the institute via collaborative working with colleagues across the University and a range of external stakeholders and to generate external income.

BUDI, launched in May 2012, works with relevant parties from the statutory, private and voluntary sector across the south of England to increase the quality of care and support offered to people with dementia and their families. Applications will be accepted until Wednesday 17 October 2012.

www.bournemouth.ac.uk/jobs/hsc166.html

Contact Alzheimer Europe at:

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

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Educational videos from Fatebenefratelli (see previous page)

Videos in English	Vidéos en français
1. What are the causes of Alzheimer's disease? www.youtube.com/watch?v=ExSjxwhsFE&feature=youtu.be	1. Qu'est-ce qui cause la maladie d'Alzheimer? www.youtube.com/watch?v=1adtgaapFAY&feature=youtu.be
2. Is early diagnosis possible? www.youtube.com/watch?v=TpTsTAJbrcc&feature=youtu.be	2. Alzheimer: un diagnostic précoce est-il possible? www.youtube.com/watch?v=1dunkS641_8&feature=youtu.be
3. Are there any effective treatments? www.youtube.com/watch?v=4e04IOINGpk&feature=youtu.be	3. Alzheimer: existe-t-il des traitements efficaces? www.youtube.com/watch?v=9l4hqvnj5M8&feature=youtu.be
4. Awareness of the disease www.youtube.com/watch?v=KCKR3qMIAI&feature=youtu.be	4. La conscience de la maladie www.youtube.com/watch?v=eJndD_jirCg&feature=youtu.be
5. Obsessions and residual capabilities www.youtube.com/watch?v=BdNLHiiDT4&feature=youtu.be	5. Les fixations et les capacités résiduelles www.youtube.com/watch?v=WFG1c6KjyM&feature=youtu.be
6. Depression, apathy and insecurity www.youtube.com/watch?v=FPHF6yV4I8&feature=youtu.be	6. Dépression, apathie et sentiment d'insécurité www.youtube.com/watch?v=xtYpu93Gxjg&feature=youtu.be
7. Confusion, forgetfulness and mistaking identities www.youtube.com/watch?v=5MRKUtgJ2W8&feature=youtu.be	7. Confusion, manque de mémoire et méprise sur la personne www.youtube.com/watch?v=JzcBhBA28II&feature=youtu.be
8. Anxiety, distress and trouble with everyday tasks www.youtube.com/watch?v=5k4DO44nYSE&feature=youtu.be	8. Anxiété, agitation et difficulté au quotidien www.youtube.com/watch?v=TH4RI3qATY&feature=youtu.be
9. Wandering and attempts to escape www.youtube.com/watch?v=o8yLpOjp9c&feature=youtu.be	9. Vagabondage et tentative de fuite www.youtube.com/watch?v=kGMoYTSUnqU&feature=youtu.be
10. What kind of physical activity and how much? www.youtube.com/watch?v=0kC7pYHSfac&feature=youtu.be	10. Activité physique: typologie et intensité www.youtube.com/watch?v=Q197Clg9BrS&feature=youtu.be
11. Sundowning syndrome and evening confusion www.youtube.com/watch?v=Qw8Ly6k2N9M&feature=youtu.be	11. Le syndrome du coucher de soleil et le désarroi du soir www.youtube.com/watch?v=a9xz0vTRPLw&feature=youtu.be
12. Smoking and alcohol abuse www.youtube.com/watch?v=BncikOllcFQ&feature=youtu.be	12. Tabagisme et abus d'alcool www.youtube.com/watch?v=bY14WyHLP74&feature=youtu.be
13. Drugs and environments against distress www.youtube.com/watch?v=72LMz9G-t9I&feature=youtu.be	13. Les médicaments et le milieu contre l'agitation www.youtube.com/watch?v=WUgioEsU3Xg&feature=youtu.be
14. What next? Progression of the disease and behavior www.youtube.com/watch?v=OMVSEIleWAU&feature=youtu.be	14. Ce qui m'attend: l'évolution de la maladie et du comportement www.youtube.com/watch?v=aZn8JE4w6ks&feature=youtu.be
15. Headaches and complaints for no apparent reason www.youtube.com/watch?v=QI2Uuol6x1I&feature=youtu.be	15. Les maux de tête et les plaintes sans cause apparente www.youtube.com/watch?v=UUfuzAvFDqw&feature=youtu.be



www.irccs-fatebenefratelli.it/sito/pagine/fatebenefratelli.php

AE Calendar

Date	Meeting	AE Representative
1 October	Ligue Alzheimer Workshop 'Dementia Friendly Cities : state of play and perspectives' (Brussels, Belgium)	Annette
1 October	NILVAD Steering Committee meeting (Amsterdam, The Netherlands)	Alex
2 October	European Innovation Partnership on Active and Healthy Ageing – meeting of the Action Group on Age Friendly Cities (Brussels, Belgium)	Annette
3-4 October	Meeting of European Working Group of People With Dementia (Vienna, Austria)	Jean, Dianne
4 October	Alzheimer Europe Board Meeting (Vienna, Austria)	AE Board, Jean
4 October	Alzheimer Europe Annual General Meeting (Vienna, Austria)	AE Board & staff
5 October	Meeting with Alzheimer's Disease International	Jean, Heike
5-6 October	22 nd Alzheimer Europe Conference (Vienna, Austria)	AE Board & staff
7 October	2 nd meeting of Alzheimer Europe's working group on the ethical issues linked to restrictions of freedom (Vienna, Austria)	Dianne
19 October	Sanofi meeting "90 minutes to understand... Alzheimer's disease" (Chilly-Mazarin, France)	Annette
25 October	European Society of Radiology kick off meeting (Brussels, Belgium)	Annette
31 October	Meeting with Novartis (London, UK)	AE Board members and Jean
1 November	Study visit of Lilly's Erl Wood Research Centre (London, UK)	AE Board members and Jean

Future Conferences

Date	Meeting	Place
4-6 October 2012	22 nd Alzheimer Europe Conference "Changing perceptions, practice and policy", www.alzheimer-europe.org/EN/Conferences	Vienna, Austria
7-10 October 2012	137 th Annual meeting of the American Neurological Association, www.aneuroa.org	Boston, USA
10-13 October 2012	6th Croatian Congress on Alzheimer's disease with international participation, www.alzheimer2012.com	Primošten, Croatia
13-17 October 2012	25 th ECNP (European College of Neuropsychopharmacology), www.ecnp-congress.eu	Vienna, Austria
18-20 October 2012	7. Kongress der Deutschen Alzheimer Gesellschaft, www.kukm.de/alzheimer2012	Hanau, Germany
18-20 October 2012	41st Annual Scientific and Educational Meeting: "Aging in a Changing World", www.cagac.ca	Vancouver, Canada
25-26 October 2012	French American Biotech Symposium (FABS), www.fabs2012.com	Nice, France
29-31 October 2012	5th Clinical Trials Conference on Alzheimer Disease (CTAD), www.ctad.fr	Monte Carlo, Monaco
8-10 November 2012	2 nd International Congress on Neurology & Epidemiology (ICNE), http://www.neuro-conference.com/2012/	Nice, France
8-11 November 2012	International Conference on Clinical Practice in Alzheimer Disease (CPAD), www.paragon-conventions.com	Budapest, Hungary
22 November 2012	EMA workshop on access to clinical trial data and transparency, www.ema.europa.eu	London, UK
26-27 November 2012	Developing a Person-Centred Model of care for patients with Dementia, www.pchealthcare.org.uk	London, UK
5-7 December 2012	Nursing Ethics: intensive course on foundational approaches, contemporary and educational issues in the field of nursing ethics, www.masterbioethics.org	Leuven, Belgium
7-10 December 2012	8 th International Winter Conference on Alzheimer's Disease, http://www.ad-zuers.com/	Zuers, Austria
25-27 January 2013	5th European Neurological Conference on Clinical Practices: Neurovascular and Neurodegenerative Diseases, www.enccp.net	Krakow, Poland
29-30 January 2013	EFGCP Annual Conference: Virtual future: what are the ethical dimensions of using emerging technologies in clinical trials and research?, www.efgcp.eu	Brussels, Belgium
6-10 March 2013	11th International Conference on Alzheimer's and Parkinson's Diseases, www.kenes.com/adpd	Florence, Italy
21-23 March 2013	57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), www.dgkn-kongress.de	Leipzig, Germany
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
23-24 May 2013	3 rd International Conference on Neurodegenerative Disorders: Immunotherapy and Biomarkers, http://eventus.trippus.se/immunotherapy_uppsala2013	Uppsala, Sweden
23-27 June 2013	The 20th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
3-5 October 2013	23 rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", www.alzheimer-europe.org/EN/Conferences	Valletta, Malta
17-20 October 2013	8 th International Congress on Vascular Dementia – ICVD 2013, www.kenes.com/icvd	Athens, Greece
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

23rd Alzheimer Europe Conference Living well in a dementia- friendly society

Valletta, Malta/10-12 October 2013

Mark the dates!

www.alzheimer-europe.org/conferences



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