



NEWSLETTER

July-August 2012

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Editorial

We gladly welcome back all our readers after the summer break. The staff at Alzheimer Europe are all well rested and ready to face a very busy autumn season. This newsletter will bring you up to date on the activities that took place over the last two months.



We were sad to hear of the passing of Henk ter Haar, who founded Alzheimer Nederland and was also the second Chair of Alzheimer Europe. We would like to extend our condolences to Dr. ter Haar's family.

In European news, Cyprus took over the EU Presidency in July - with a promise to take us "Towards a Better Europe" via an ambitious health and social programme.

The Commission has launched new consultations about topics to be included in Horizon 2020, which will replace the FP7 programme. There is a new expert panel to improve individual health care systems, as well as an initiative to simplify the administration of clinical trials in the member states.

The European Medicines Agency also plans to improve clinical trials, namely by simplifying access to data and increasing transparency. In the Parliament, a special committee is working to reduce debilitating age-related diseases in women.

Amongst our members, the Polish Alzheimer's Association celebrates 20 years of helping people with dementia. The Slovenian society organised its first Alzheimer Café and Alzheimer Scotland opened a new resource centre and office.

Our Science section is quite large in this issue. This is mainly due to coverage of the 2012 AAC Conference, organised by the U.S. Alzheimer's Association. We would have liked to cover all the topics

presented; instead we were faced with the happy problem of having to choose among the many fine presentations.

One particular highlight is the successful result of Immunoglobulin in a phase 2 trial: participants' cognition, memory and daily function remained stable over the three year trial period. Other notable studies show how gait variations may be linked to cognitive impairment and how a new AD mouse model was derived from human skin cells.

In August, we saw the cancellation of two phase 3 trials for Alzheimer's disease treatments. Unfortunately, bapineuzumab and solanezumab both failed to show significant benefits in cognition and function in their main target groups. However, there is still hope for solanezumab among a certain group of people.

On a positive note, another drug that had failed a phase 3 study has been rehabilitated. Latrepirdine was unsuccessful in a 2010 trial, but recent tests seem to indicate a new potential. There is also good news from the UK, where prescriptions for antipsychotic drugs have seen a remarkable decrease among people with dementia.

World Alzheimer's Day is almost upon us: we wish great success to all of the campaigns and activities of our member organisations and other friends. As always, we'll be glad to report on your activities in our next newsletter and also in the Dementia in Europe magazine.

The Vienna Conference is also coming up soon. The final programme and all of the abstracts are on our website. We now have over 400 registered attendees and online registration will remain open until 28 September. We look forward to seeing you there!

Jean Georges
Executive Director

Alzheimer Europe

19 July: Henk ter Haar, 1922-2012



We regret to announce the passing of Hendrik "Henk" Willem ter Haar on 19 July at the age of 89. Dr. ter Haar founded Alzheimer Nederland in 1984 and was a founding member of Alzheimer Europe. He also served as ADI's Conference Chairman in 1991.

Dr. ter Haar was a delegate at the very first meeting in Leuven (1990) that led to the formation of Alzheimer Europe. He was a member of the Board from 1990 to 1996, serving as Honorary Treasurer (1991-94) and was the second Chairperson of Alzheimer Europe (1994-96).

During his tenure, he continually lobbied the European Institutions: he accomplished the adoption of a report on Alzheimer's disease by the European Parliament and also the establishment of an Alzheimer's budget line.

EU Projects

19 July: DECIDE project begins user training for "Scientist" profile

The DECIDE project has launched a training programme that allows health and research professionals



to freely access the computational facilities of the project's GRID infrastructure.

Training sessions are open to all physicians, scientists and researchers. They are free of charge and are available for each of the EEG, PET and MRI modules. The sessions consist of short presentations, discussions and hands-on instruction on how to use the system. They are conducted as webinars, so that trainees can participate online from their offices or labs. Participants also have the option of attending live sessions in Rome, Italy.

Training events held in March and June focused on the "Physician" profile. The most recent session took place on 19-20 July for the "Scientist" profile and focused on the EEG and SPM modules. Participants learned how to upload resting state EEG datasets and PET/SPECT images and then followed the automatic extraction of candidate markers of Alzheimer's disease.

The next training sessions will take place in October. Applicants are invited to visit www.eu-decide.eu or email info@eu-decide.eu for more information.



www.alzheimer-europe.org/Donation

Alzheimer Europe Networking

On 4 July (Worcester, UK) Dianne attended the ALCOVE work package 5 reference group meeting.

On 4-5 July (Brussels, Belgium) Annette had a European Innovation Partnership on Active and Healthy Ageing meeting (Action Group on Age Friendly Environments).

On 6 July (Luxembourg, Luxembourg) Jean met with representatives of Nutricia.

On 9 July (Stevenage, UK) Alex attended a PharmaCog Steering Committee and EPMT meeting.

On 19 July (Luxembourg, Luxembourg) Julie met with Jean-Paul Reuland from Binsfeld publishers to discuss issue 12 of the Dementia in Europe magazine.

On 23 July (Brussels, Belgium) Annette held a meeting with A. Mitronatsiou, assistant to MEP Angelika Werthmann.

On 23 July (Brussels, Belgium) Annette met with Silvia Botero, EPDA.

On 27-28 August (Valletta, Malta) Gwladys went on a site inspection in preparation for the 2013 Alzheimer Europe Conference.

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:** Cabrnock Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP). **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). **Finland:** Jaakonsaari Liisa (S&D), Jääteemäki 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), Zaborska Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badiá i Cutchet Maria (S&D). **United Kingdom:** Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

EU Developments

1 July: Cypriot EU Presidency presents health and social affairs programme



On 1 July, Cyprus started its Presidency of the Council of the European Union for the second half of 2012. It follows Denmark and precedes Ireland.

The Presidency motto is "Towards a Better Europe". During its term, Cyprus will work towards a better, more relevant Europe for its citizens, meaning a more efficient and sustainable Europe, contributing to a better performing and growth economy. The Presidency has also prioritised growth and job creation, promoting social cohesion and providing hope to its citizens.

The Presidency health priorities will focus on serious cross border health threats and healthy ageing in relation to the European Health Strategy 2008-2013.

Within the framework of 2012 as the European Year of Active Ageing and Solidarity between generations, the Presidency will also take into consideration the current economic crisis and the ageing of population.

The Presidency will further develop work in the area of healthy ageing across the lifetime cycle. This involves collecting evidence and highlighting best practices which prove that healthy ageing is a matter of continuous process, requiring the implementation of health promotion and disease prevention programmes.

The Presidency will also consider the Commission's proposal for a revision of the legislation that regulates clinical trials in Europe, undertake concrete actions in ensuring public awareness on organ donation and transplantation and securing EU funds for the development of programmes in this field.

During the Presidency, work will continue on the revision of the "Transparency Directive" and also on three pillars of priorities, which regard to:

- strengthening social cohesion, placing emphasis on child well-being
- investing in more and better jobs – building new and upgrading current skills; the emphasis will be on tackling youth unemployment
- strengthening the participatory processes and the involvement of local authorities, NGOs and social partners in the implementation of the Europe 2020 Strategy, concentrating on the targets of employment, poverty and social exclusion.

www.cy2012.eu/en/news-categories

6 July: Commission sets up panel of independent experts to improve health care systems

On 6 July, the European Commission adopted a Decision to set up an independent expert panel that will identify effective ways of investing in health and making healthcare systems sustainable.

The panel will support the reflection process in which the Member States have engaged in the field of demographic changes, costly innovation and rising patient expectations. These all put constant pressure on the financial sustainability of European health systems.

The panel will be made up of 17 experts from several areas of expertise, including: primary care, hospital care, pharmaceuticals, research and development, prevention and health promotion, system financing, information systems and patient registers and health inequalities.

The experts will be appointed by the Commission following an open call for interest, which will be launched in the coming weeks.

http://ec.europa.eu/health/healthcare/docs/dec_panel2012_en.pdf

12 July: Parliament Committee discusses report on the prevention of age-related diseases of women

On 12 July, the Committee on Women's Rights and Gender Equality discussed its own-initiative draft report on the prevention of age-related diseases of women. The Rapporteur is European Parliament Vice-President, Roberta Angelilli (EPP, Italy).

The report states that in spite of women's greater longevity, the incidence of debilitating diseases is much higher in their case than among men of the same age. The same applies to the progressive onset of disabilities caused by episodes of mental confusion and dementia (such as Alzheimer's disease), the incidence of which soars with advancing years.

Among other things, the reports calls upon the European Commission to publish a new report on the state of women's health, focusing in particular on the 65+ age group and active ageing indicators.

www.europarl.europa.eu/sides/getDoc.do?type=COMPARE&reference=PE-491.089&format=PDF&language=EN&secondRef=01

17 July: Commission adopts proposal for a new clinical trials regulation

On 17 July 2012, the European Commission adopted a proposal for a new "Clinical Trials Regulation". The aim is to boost clinical research in Europe by simplifying the rules for conducting clinical trials. This regulation will repeal the 2001 "Clinical Trials Directive" that is currently in force in the European Union.

The existing Directive has ensured a high level of patient safety, but divergent transposition and application in the EU Member States has led to an unfavourable regulatory framework for clinical research. This has contributed to a 25% decrease of clinical trials conducted in Europe between 2007 and 2011.

The new Regulation will aim to correct this and will also ensure that rules for conducting clinical trials are identical throughout the EU. Current proposals include:

- an authorisation procedure that will allow a fast and thorough assessment of the application by all Member States and will ensure a single assessment outcome.

- simplified reporting procedures which will spare researchers from submitting largely identical information on the clinical trial separately to various bodies and Member States.
- more transparency on whether recruitment for a clinical trial is still on-going and on the results of the trial.
- the possibility for the Commission to conduct controls in Member States and other countries to make sure the rules are being properly supervised and enforced.
- The legislative proposal will now be discussed in the European Parliament and the Council. It is expected to come into effect in 2016.

http://ec.europa.eu/health/files/clinicaltrials/2012_07/proposal/2012_07_proposal_en.pdf

http://ec.europa.eu/health/files/clinicaltrials/2012_07/press-releases/ip-12-795_en.pdf

http://ec.europa.eu/health/human-use/clinical-trials/index_en.htm

17 July: Commission launches consultations on JTI and PPP in Horizon 2020

On 17 July, the European Commission launched four public consultations on the future of Joint Technology Initiatives (JTIs) and Public Private Partnerships (PPPs) under Horizon 2020.

In particular, the consultation covers the Innovative Medicines Initiative (IMI) - which will become Life Sciences PPP - and the future PPP on bio-based industries.

The consultation document states: "it has been well documented that with the ageing of the European population and a concomitant rise in chronic and degenerative diseases, the challenges for the healthcare sector in Europe are very large.

"The consultation also probes what areas should be addressed in a PPP under Horizon 2020 in order to address the challenges, foster collaboration among entities throughout the innovation cycle from academia to large industry, and including patient organisations and regulators, and among various disciplines".

The consultation deadline is 4 October 2012.

http://ec.europa.eu/research/consultations/life_science_h2020/consultation_en.htm

20 July: EMA to host workshop on clinical trial data and transparency



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

The European Medicines Agency will host a

workshop on access to clinical trial data and transparency on 22 November 2012.

The Agency will proactively publish trial data and enable access to full data sets by interested parties. While the Agency considers clinical trial data not to be commercially confidential, various practical and policy issues need to be addressed before data sets can be made available to a wider audience.

This workshop is a first step in the process. It is intended to elicit the views, interests, and concerns from institutions, groups and individuals. The results will help

the Agency define the modalities of proactive access to clinical trial data, in a way that best serves patients and public health in an open and transparent forum.

The EMA can be reached at ctdataworkshop@ema.europa.eu

www.ema.europa.eu/docs/en_GB/document_library/Other/2012/07/WC500130161.pdf

Members' News

19 July: Polish Alzheimer's Association celebrates 20th birthday



This year, the Polish Alzheimer's Association is celebrating 20 years of operation. Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera was founded in July 1992 by a group of 23 people including family carers, doctors and psychologists.

Amongst the founders were Ms Mirka Wojciechowska, Prof Maria Barcikowska, Prof Tadeusz Parnowski and Dr. Tomasz Gabryelewicz. Remarkably, all are still active members and are still working in the dementia field: they represent the association in the Polish Alzheimer's Coalition, which has developed the Polish Alzheimer's Plan.

Today, the association has grown to 35 local chapters in big and small towns all over the country. They provide active support to people with dementia, their families and caregivers. There are currently some 250,000 people with Alzheimer's disease in Poland.

During its lifetime, the association has provided help, information and education to thousands of people. This includes a key role in raising public awareness of Alzheimer's disease and educating citizens to understand and embrace the needs of people with dementia. Along the way, the volunteers and professionals working with the society have gained invaluable experience and knowledge on how to support people more effectively.

The association has also played an important European role as one of the founder members of Alzheimer Europe. Dr. Gabryelewicz, co-founder and former Chair of the Polish association, was a delegate at the very first meeting in 1990 that led to the formation of Alzheimer Europe. He also served as a member of the Alzheimer Europe Board from 1994 to 2000. Ms Alicja Sadowska, current head of the association, has been on the Board since 2004.

Currently, the main focus of the Polish association is to convince politicians that the implementation of the Polish National Alzheimer's Plan is vital and necessary. According to Alicja, this task is probably the hardest of all. However, she remains optimistic, saying: "We believe that one day we'll succeed, provided that we have the moral and financial support of the government."

24 July: Slovenia organises first Alzheimer Café



The Slovenian Alzheimer Society organised its first Alzheimer Café on 24 July in a nursing home in Ljubljana. It was very well attended, featuring a presentation from Dr. Kogoj, a prominent

local psychiatrist. The society also presented a new book about dementia.

Štefanija Lukič-Zlobec, head of the Slovenian Alzheimer Society, was very pleased with the result. She looks forward to the next meeting of the Alzheimer Café, in cooperation with the Medical Chamber of Slovenia.

7 August: Alzheimer Scotland opens Inverness resource centre



On 7 August, Alzheimer Scotland officially opened a new Dementia Resource Centre in Inverness. The launch was attended by key representatives from NHS Highland and Highland Council, as well as high profile dementia awareness activists.

Garry Coutts, Chair of NHS Highland, said: "This is an absolutely fantastic resource and Alzheimer Scotland is to be applauded for their tireless efforts to raise the profile of dementia and provide support. This will be a vital local point of contact for people with dementia, their families and friends in the Inverness and the surrounding area. There is no question that having such a central location will raise the profile of dementia and help reach and support many more people."

There are almost 4,000 people with dementia in the Highland Council area and this figure is set to double within a generation.

9 August: German association publishes guide for incontinence



The German Alzheimer Society has published a revised edition of the booklet "Incontinence in home care of people with dementia". The booklet explains the different types and causes of incontinence and provides tips on promoting continence. It describes the use of various aid products and includes tips on how they can be reimbursed by health insurance. The 80-page booklet was updated by Dr. Daniela Hayder and Ms Erika Sirsch. It is available for purchase at the association's website.

www.deutsche-alzheimer.de/index.php?id=48&news=131

Policy Watch

13 July: French President Hollande announces plan to address dependency

On 13 July, President Hollande said that he will launch a consultation on the theme of dependency in France in autumn this year. This will be followed by a five year plan to deal with dependency, exclusion and poverty.

This initiative is part of a wider government plan to reform the French social security system. Consultations for both social security and pensions will take place in 2013.

www.agevillage.com/actualite-8476-1-politique-hollande-conference-sur-dependance-en-autonne-elaboration-p%20%20lan-quinquennal.html

13 August: UK allows embryo screening for presenilin

UK couples with a family history of early onset Alzheimer's disease can now screen their embryos for the PSEN-1 and PSEN-2 presenilin genes. Only those found to be free of the genes would be implanted back into the womb. The parents themselves do not need to be tested, or find out if they have the genes.

The decision comes from the Government's fertility regulator, the Human Fertilisation and Embryology Authority (HFEA). In 2007, HFEA had already approved testing for the APP gene, which is the amyloid beta (A4) precursor protein.

Screening, or pre-implantation genetic diagnosis (PGD), is used to test embryos for more than 100 fatal and debilitating conditions, including hereditary breast cancer, cystic fibrosis and muscular dystrophy.

Prof John Hardy, a neuroscientist at University College London, said: "I'm so happy the HFEA has done this. It means families will be free of this scourge for all future generations and will really give people some hope."

Dr. Laura Phipps of Alzheimer's Research UK said screening could give peace of mind but also added that: "The testing could raise some moral issues because, unlike other genetic diseases that can strike at a very young age, people with early-onset inherited Alzheimer's can still have many decades of their life before symptoms start to show."

Science Watch

4 July: Rapamycin improves memory and learning in mouse models

Researchers from the University of Texas (UT) have shown that the drug rapamycin improved learning in young mice as well as memory in older rodents. The findings came after the drug was added to the diet of healthy mice.

The research team was led by Dr. Veronica Galvan, Assistant Professor of Physiology at the UT Health Science Center. She said: "We made the young ones learn, and remember what they learned. Among the older mice, the ones fed with a diet including rapamycin actually showed an improvement, negating the normal decline you see in these functions with age."

The team also found that three "happy, feel-good" neurotransmitters - serotonin, dopamine and norepinephrine - were higher in the mice treated with rapamycin. Dr. Galvan noted that the drug lowered anxiety and depressive-like behaviour in the mice.

Rapamycin is an antifungal agent administered to transplant patients to prevent organ rejection.

www.uthscsa.edu/hscnews/singleformat2.asp?newID=4196
www.ncbi.nlm.nih.gov/pubmed/20376313

12 July: APP mutation may delay or prevent early-onset AD

A research team in Iceland has found a mutation of the APP gene that may delay or prevent early-onset Alzheimer's disease.

Amyloid beta derives from a larger protein called amyloid precursor protein, or APP. Over the last two decades, scientists have identified some two dozen mutations in the APP gene that cause early-onset Alzheimer's disease. The scientists from deCODE Genetics in Reykjavik found a single APP mutation that does the opposite.

The mutation has the effect of halving the amount of amyloid beta peptide produced when APP is broken down. This seems to allow the brain to age without building up to the dangerous levels seen in Alzheimer's patients.

The researchers were led by Dr. Kári Stefánsson, neurologist and CEO of deCODE Genetics. They estimate that carriers have a 47% greater chance of reaching the age of 85 than the majority of people who lack the mutation. Persons 85 or older who have the beneficial mutation were 81% less likely to develop the neurodegenerative disease. The variant also makes developing Alzheimer's disease four times less likely across all age groups.

In a series of follow-up studies, the researchers also found that the DNA sequence protects against the general decline in brain performance that is common in old age. This suggests that Alzheimer's disease and age-related cognitive problems belong to the same family of disorders and share an underlying cause.

www.nature.com/nature/journal/v488/n7409/full/nature11283.html

15 July: Cognitive domains associate with corresponding aspects of gait

Dr. Mohammad Ikram and colleagues at Erasmus University Medical Centre (Rotterdam, the Netherlands) investigated the relationship between cognition and gait in elderly people in a community dwelling.

The researchers studied the gaits of 1,232 individuals aged 49 and older. They performed three types of walks, including placing one foot directly in front of the other (tandem) and making a turn. Scientists measured information processing speed, memory, fine motor speed, and executive function. Gait variables were grouped into seven independent factors.

The results showed that certain cognitive domains were only associated with certain aspects of gait:

- Information processing speed: stride time and cadence
- Executive function: stride length and velocity
- Fine motor speed: errors made during tandem walk

Memory was not associated with any aspect of gait. Dr. Ikram said: "Our results suggest that cognition and gait are tightly linked according to a specified pattern, in which certain cognitive domains only associate with corresponding aspects of gait."

These results were presented at the 2012 AAIC Conference in Vancouver.

www.alz.org/aaic/about/news-highlights.asp

15 July: Coordinated care boosts quality of life and delays death

Researchers from the Johns Hopkins University School of Medicine studied the efficacy of a multidimensional care coordination model to improve quality of care for people with memory disorders. They found that the intervention group had a better quality of life, was less likely to leave home and had a longer life expectancy.

The 18-month trial, led by Dr. Quincy Samus, Assistant Professor of Psychiatry and Behavioral Sciences at Johns Hopkins, included 303 people with cognitive disorders, aged 70+ and living at home. The research team implemented a care coordination protocol which consisted of a multidimensional needs assessment, community resource referrals, memory disorder education, counselling, and problem-solving. These were supported by a web-based application to monitor care progress.

The intervention team included paraprofessionals specially trained in evidence-based dementia care, a psychiatric nurse, and a geriatric psychiatrist. The primary outcomes included unmet needs and time to transfer out of the home. Secondary outcomes were participant quality of life, neuropsychiatric symptoms and depression. The results were as follows:

- Participants had a wide range of unmet needs: home and personal safety issues, general medical care, meaningful activities and legal issues were the most common.
- The intervention group had a greater decrease in total unmet needs from the beginning of the study to 18 months compared to the control group, with the most significant reductions in safety and legal issues.
- Intervention participants were less likely to permanently leave their home or die compared to controls (30.0% vs. 45.6%) and had a significant reduction in time to leaving the home for any reason.
- Self-reported quality of life was better in the intervention group at 18 months.
- No group differences were found on proxy-rated quality of life, neuropsychiatric symptoms or depression.

These results were presented at the 2012 AAIC Conference in Vancouver.

www.alz.org/aaic/about/news-highlights.asp
www.nlm.nih.gov/medlineplus/news/fullstory_127359.html

17 July: DAISY study finds limited benefit in psychosocial intervention

A Danish research team has reported limited benefits from the DAISY study, which tested the efficacy of psychosocial intervention in patients with mild Alzheimer's disease. DAISY - a multicentre, rater blinded, randomised Danish Alzheimer Intervention Study - assessed the efficacy at 12 months of an early psychosocial counselling and support programme for 330 people with mild Alzheimer's disease and their 330 primary care givers.

DAISY was designed to prevent or reduce depressive symptoms, impairments of health related quality of life and loss of social network. Participants received counselling sessions, attended training courses and followed these up with individual discussions.

The journal abstract concludes that "intervention with counselling, education, and support for patients with mild Alzheimer's disease and their care givers did not have any significant effect beyond that with well structured follow-up support at 12 months after adjustment for multiple comparisons. The small positive effect found in the unadjusted primary outcome addressing depressive symptoms in patients may call for further research focusing on patients with Alzheimer's disease and comorbid depression."

www.bmj.com/content/345/bmj.e4693

17 July: Walking speed and variability may track with cognitive impairment

A recent study on gait analysis showed that stride speed and variability may track with cognitive impairment. The research team was led by Dr. Stephanie Bridenbaugh of the Basel Mobility Center, part of Basel University Hospital in Switzerland.

They followed 1,153 elderly participants divided into three groups: cognitively healthy, living with MCI and living with Alzheimer's disease. Over three years, their gaits were measured while walking normally and also while walking and performing mental tasks.

The team found that gait became slower and more variable as cognitive decline progressed. For all groups, walking speeds were slower during dual tasking than during normal walking. People with Alzheimer's disease walked slower than those with MCI, who in turn walked slower than those who were cognitively healthy.

Dr. Bridenbaugh said: "Mobility impairments are often associated with dementia, and some gait changes may even appear before cognitive decline can be detected by traditional testing methods. Gait analysis can simply, quickly and objectively measure walking. When problems emerge, this may provide early detection of fall risk and the earliest stages of cognitive impairment in older adults.

"A gait analysis will not replace a comprehensive neuropsychological assessment to diagnose a patient's cognitive status. Gait analysis, however, may prove to be an important tool to aid diagnosis, and record treatment effects or disease progression."

These results were presented at the 2012 AAIC Conference in Vancouver.

www.alz.org/aaic/about/news-highlights.asp

17 July: New AD mouse model is derived from human skin cells

Researchers from The New York Stem Cell Foundation (NYSCF) have reported the creation of a new mouse model of Alzheimer's disease. The new model was derived from the skin cells of people with the disease that were reprogrammed into Alzheimer's brain cells.

The scientists, led by Dr. Andrew Sproul, a postdoctoral associate at NYSCF, used an induced pluripotent stem cell

(iPSC) approach. This involves taking cells from people with the disease and their unaffected family members, typically skin cells, and reprogramming them by adding genetic factors. The resulting iPSCs can be used to model Alzheimer's in a dish.

Dr. William Thies, Chief Medical and Scientific Officer of the U.S. Alzheimer's Association, said: "Current animal models of Alzheimer's are highly engineered to express elements of the disease, and, while valuable for research, incompletely represent how the disease forms and progresses in people. In order to develop better therapies and eventually prevent Alzheimer's, we need better, more accurate animal and cellular models of the disease. This newly reported research is a significant step forward in that direction."

Looking to the future, Dr. Sproul said: "We have begun to extend this work by collaborating with four different institutions in New York City – the Mount Sinai School of Medicine, Columbia University, New York University, and Rockefeller University. Over the next few years, we expect to provide substantial insight into Alzheimer's and valuable tools to help create the next generation of therapeutics."

These results were presented at the 2012 AAIC Conference in Vancouver.

www.alz.org/aaic/about/news-highlights.asp

17 July: Human stem cells improve mouse memories

Researchers from the University of California (Irvine) and StemCells Inc. have shown for the first time that human stem cells have a significant effect on restoring memory in animals suffering from Alzheimer's disease.

The team injected human stem cells into the brains of two groups of mice models: one group was bred to model the effects of Alzheimer's disease, and the other bred to model the loss of neurons.

After one month, the mice were tested against previous levels and a control group. Tests included a battery of behavioural tasks followed by histological and biochemical analysis. The results showed that animals that received stem cells performed as well as mice without any previous neural pathology.

A common measure in Alzheimer's disease progression is the amount of synaptic loss that is experienced, ie the loss of connections between neurons.

Researchers observed that the mice that received the stem cells had substantially more of these synapses - at times as much as 75% more. The researchers speculate that this is very likely the explanation behind the success of their treatment.

The next step is to translate their work to a human therapy. Specifically, the team hopes to evaluate human stem cells to determine whether they'll work in the same way they do in animal models.

www.stemcellinc.com
www.youtube.com/watch?v=zgvml_vvqq3I

18 July: Immunoglobulin halts mental decline in three year trial

Researchers from Weill Cornell Medical College in New York have reported very good results from an extended phase two trial of intravenous immunoglobulin. The drug successfully halted the mental decline associated with Alzheimer's disease for a period of three years.

The research team, headed by Dr. Norman Relkin, found that 24 patients who had injections every two weeks showed no decline in cognition, memory, daily functioning or mood. The trial initially lasted for 18 months, but was extended to 36 months when beneficial effects were observed.

Immunoglobulin is normally given to patients who suffer from an immune deficiency, but it has also been found to protect the brains of those with early stage Alzheimer's disease. The drug is thought to work by targeting the beta-amyloid protein, sweeping up and removing the small fragments that form amyloid plaque.

Dr. Relkin, of Weill Cornell Medical College, New York, said: "This is the first study to report long-term stabilisation of Alzheimer's symptoms with intravenous immunoglobulin. While the small number of participants may limit the reliability of our findings, we are very enthusiastic about the results."

These results were presented at the 2012 AAIC Conference in Vancouver.

www.alz.org/aaic/about/news-highlights.asp



www.alzheimer-europe.org/Donation

19 July: EVP-6124 shows cognitive benefits in clinical trial

EnVivo Pharmaceuticals has completed a phase 2 trial of EVP-6124. In previous trials, this nicotinic agonist compound has demonstrated cognitive benefits in normal volunteers and in preliminary study participants with Alzheimer's disease or schizophrenia.

Nicotinic agonists amplify the effects of acetylcholine, a brain chemical that is essential for normal brain and memory function. Acetylcholine is greatly reduced in people with Alzheimer's disease.

The trial was a six month, double blind, placebo-controlled, phase 2 study of three doses of EVP-6124 in 409 people with mild to moderate Alzheimer's who were either on stable Alzheimer's therapy (donepezil or rivastigmine) or no therapy.

After 23 weeks of treatment, the researchers found that, compared to the placebo group, one of the treatment groups had statistically significant benefits. EVP-6124 was safe and well tolerated, with some mild to moderate gastrointestinal side effects in a minority of patients. The research team intends to move to a phase 3 trial.

These results were presented at the 2012 AAIC Conference in Vancouver.

www.youtube.com/watch?v=q_FMNkqaqI
www.envivopharma.com/pdf/EVP-6124AAICPressConf.pdf

26 July: MW-151 reduces Alzheimer's symptoms in mouse models

A new study shows that the drug MW-151 reduces Alzheimer's pathology in mouse models. MW-151 suppresses brain inflammation and overproduction of pro-inflammatory molecules from glial cells. Glial cells are non-neuronal cells that provide support and protection for neurons.

The study showed that MW-151 could be effective as a preventive measure - before Alzheimer's pathology appears - as well as after disease symptoms become apparent.

The research team was led by Dr. Linda Van Eldik, director of the University of Kentucky Sanders-Brown Center on Aging and Dr. D. Martin Watterson, Professor in Molecular Pharmacology and Biological Chemistry at the Northwestern University Feinberg School of Medicine.

Dr. Van Eldick said: "Early intervention with MW-151 in an Alzheimer's mouse model reduced the glial activation and proinflammatory cytokine overproduction, which resulted in improvement in neurologic outcomes. The neurological outcomes included protection against the loss of critical nerve cell proteins and functional damage associated with learning and memory impairments."

She added that "The outcomes suggest that therapeutic strategies targeting this pathological process have the potential to attenuate disease onset and progression."

www.jneurosci.org/content/32/30/10201.abstract?sid=51ff835a-8372-4082-96e8-b1f73568505b

31 July: Latrepirdine returns to dementia research labs

A research team from Mount Sinai School of Medicine has demonstrated new potential for latrepirdine in Alzheimer's disease treatment. The drug effectively stopped the progression of memory deterioration and brain pathology in mouse models of early stages of the disease.

Latrepirdine, marketed as Dimebon, was originally sold in Russia as an antihistamine and is still in use there. In the 1990s, researchers found that the compound was effective in treating Alzheimer's disease in animals. They continued their research in humans in several phase 1 and 2 trials, mainly in Russia. All of these showed significant and sustained improvement in cognitive behaviour with minimal side effects. A phase 3 study followed, this time in the United States. The study failed to meet its endpoints and further research was cancelled.

Dr. Sam Gandy, Associate Director of the Mount Sinai Alzheimer's Disease Research Center, said: "The findings from our animal model studies indicated that this drug should not be discarded, and that, if its mechanism of action can be optimized, it still has potential."

Dr. Gandy and his team plan to test latrepirdine in mouse models of protein buildup diseases. This includes

Parkinson's disease, Lewy body dementia and chronic traumatic encephalopathy, the Alzheimer's-like condition that afflicts athletes in violent contact sports.

www.nature.com/mp/journal/vaop/ncurrent/full/mp2012106a.html

1 August: Donepezil brings improvement in dementia with Lewy bodies

A Japanese research team has reported significant improvements in a phase 2 trial of donepezil among people with dementia with Lewy bodies (DLB).

Dr. Etsuro Mori, of the Tohoku University Graduate School of Medicine, led a trial involving 140 patients with DLB who received doses of donepezil hydrochloride or placebo.

He said: "Donepezil at 5 and 10 mg/day produces significant cognitive, behavioural and global improvements that last at least 12 weeks in DLB patients, reducing caregiver burden at the highest dose."

Donepezil is marketed under the trade name Aricept by its developer Eisai and partner Pfizer. It is a centrally acting, reversible acetylcholinesterase inhibitor. Its main use is in the treatment of mild to moderate Alzheimer's disease.

<http://onlinelibrary.wiley.com/doi/10.1002/ana.23557/abstract>

6 August: Janssen and Pfizer will stop bapineuzumab trials

On 6 August, Janssen and Pfizer announced that they would discontinue their joint phase 3 clinical trial of bapineuzumab IV in people with mild-to-moderate Alzheimer's disease. The trial included both carriers and non-carriers of the ApoE4 genotype. People who carry this gene have a far greater risk of developing Alzheimer's disease than those who do not. Bapineuzumab did not meet its endpoints for cognition and function in either group.

"While we are disappointed in the results of the two bapineuzumab IV studies, particularly in light of the urgent need for new advancements in Alzheimer's disease, we believe that targeting and clearing beta amyloid remains a promising path to potential clinical benefits for people suffering from this disease." said Dr. Hussein Manji, Global Therapeutic Area Head for Neuroscience at Janssen.

Dr. Steven Romano, a Senior Vice President at Pfizer, echoed these remarks and added: "These data, and the subgroup and biomarker analyses underway, will further inform our understanding of this complex disease and advance research in this field."

www.jnj.com/connect/news/all/johnson-and-johnson-announces-discontinuation-of-phase-3-development-of-bapineuzumab-intravenous-iv-in-mild-to-moderate-alzheimers-disease
www.pfizer.com/news/press_releases/pfizer_press_release.jsp?guid=20120806006130en&source=2012&page=1

7 August: Anti-epileptic drug restores memory in mice

Scientists from the Gladstone Institutes have shown that an anti-epileptic drug called levetiracetam suppresses abnormal brain activity and restores memory function in laboratory mice.

They found that administering levetiracetam to the mice reduced abnormal network activity in their brains by 50% in less than a day. After two weeks of treatment, the neurons' ability to communicate with each other improved. The mice also showed better learning and memory in a maze test. Finally, the researchers observed that several proteins that are important for healthy brain function returned to normal levels.

The scientists were headed by Dr. Lennart Mucke, Professor of Neurology and Neuroscience at the University of California, San Francisco (UCSF). He said: "This study builds on our earlier findings linking Alzheimer's and epilepsy. It provides new insights into the processes underlying memory loss in Alzheimer's and demonstrates the ability of an anti-epileptic drug to block these processes."

Gladstone is an independent, nonprofit biomedical research organisation that is affiliated with UCSF. Levetiracetam is currently approved as an anti-epileptic drug by the American FDA and the European Medicines Agency.

www.pnas.org/content/early/2012/08/03/1121081109.abstract?sid=7fcc0de-a-c18b-4ef9-9c38-a8f20492b394

7 August: Tesamorelin hormone may slow decline in MCI

A recent clinical trial showed that tesamorelin, a growth hormone-releasing hormone (GHRH), may help slow the decline of memory and mental function in the early stages of Alzheimer's disease. Tesamorelin stimulates the release of human growth hormone from the brain's pituitary gland.

The trial was led by Dr. Laura Baker, Associate Professor of Psychiatry and Behavioral Sciences at the University of Washington Medical School in Seattle. 137 people participated in the five month study: 61 with MCI and 76 healthy controls. In both groups, those taking the hormone fared better than their counterparts who took placebos.

Healthy adults saw their executive function improve by about 200% over their peers who got a placebo. Executive function refers to the brain's ability to manage attention and concentration, to switch between thoughts, and use working memory to plan and prioritise tasks. Adults with MCI still saw their executive function slip over the five months of the study, but their declines were not as large as those in the placebo group.

The research team noted that longer-duration trials will be needed to further examine the therapeutic potential of GHRH on brain health.

Tesamorelin, marketed by Theratechnologies as "Egrifta", is approved by the FDA for the treatment of HIV patients with abnormal distribution of body fat.

<http://archneur.jamanetwork.com/article.aspx?articleid=1306261>

16 August: Scientists discover a new system that drains amyloid from the brain

Scientists at the University of Rochester Medical Center (URMC) have discovered a new network of vessels in the brain that drains waste at a very rapid rate. This network operates like a system of drainage pipes, carrying away

unwanted waste products - including amyloid beta - in a similar way to the lymphatic system in the rest of the body.

The lymphatic system extends throughout the body, filtering cellular waste out of circulating fluids everywhere - except in the brain. It is believed that cerebrospinal fluid (CSF) acts as the brain's lymphatic system.

Dr. Jeffrey Iliff is the first author on the study led by Dr. Maiken Nedergaard, senior investigator at URM. He said: "We showed that the CSF goes into the brain just like people thought, but it does so along very specific anatomical structures. There's a specialized anatomy that allows the CSF to move very quickly and very deeply into the brain, exchanging with fluid that's inside."

The researchers injected tracers into the CSF of mouse models. They saw that the tracers moved in a continual flow, along the outsides of arteries going into the brain and alongside veins to exit the brain. On the way, the fluid swept up waste particles - such as amyloid beta - that were sitting in between the cells. The waste included more than half of the amyloid beta removed from the rodents' brains.

This pathway is dependent on astrocytes: these are glial cells, i.e. non-neuronal cells that provide support and protection for neurons. The astrocytes attach themselves to the blood vessels and form a sort of tunnel around them. The authors have dubbed this the "glymphatic pathway" as it resembles the lymphatic system and depends on glial cells.

The research team is now working to determine whether failure of the glymphatic system may affect the progression of Alzheimer's disease.

<http://stm.sciencemag.org/content/4/147/147ra111.abstract?sid=dca71888-bbcc-405d-9483-368be40c2b12>

22 August: Large mitochondria may cause neuron death

Scientists at Australia's Queensland Brain Institute and Harvard Medical School have established that abnormally large mitochondria in neurons may be the cause of toxic tau build up.

Mitochondria transport and metabolise energy inside the neuron. As such, they are in almost continual movement in the busy intracellular environment. However, if they are very large, their movement is hampered and they are unable to respond quickly when they are needed. This leads to loss of function and eventually death for the neuron.

The scientists were led by Prof Jürgen Götz, Director of Queensland's Centre for Ageing Dementia Research. They were able to successfully treat abnormal mitochondria in fruit flies and mice. Prof Götz said: "By changing their size back to normal it's possible to restore their function and also to prevent the new ones dying."

Prof Perry Bartlett, Director of the Queensland Brain Institute, said that this is the first study to directly link toxic levels of Tau to abnormalities in the mitochondria which starves them of energy and destroys brain cells.

He said: "If they engineer these changed genes into fruit fly or a mouse they find these tangles but they also found

these big mitochondria, so then they ask, well is it the size of the mitochondria that's important? And as it turns out yes it is, because if you reduce the size of the mitochondria, that neuropathology, that toxicity goes away."

[www.cell.com/neuron/abstract/S0896-6273\(12\)00588-0](http://www.cell.com/neuron/abstract/S0896-6273(12)00588-0)

24 August: Lilly announces top-line results on solanezumab phase 3 clinical trials

Eli Lilly and Company announced on 24 August that the primary endpoints, both cognitive and functional, were not met in either of the two Phase 3, double-blind, placebo-controlled solanezumab EXPEDITION trials in patients with mild-to-moderate Alzheimer's disease.

However, a pre-specified secondary analysis of pooled data across both trials showed statistically significant slowing of cognitive decline in the overall study population of patients with mild-to-moderate Alzheimer's disease. In addition, pre-specified secondary subgroup analyses of pooled data across both studies showed a statistically significant slowing of cognitive decline in patients with mild Alzheimer's disease, but not in patients with moderate Alzheimer's disease.

An ongoing, open-label extension study, EXPEDITION-EXT, is fully enrolled and will continue as planned.

"We recognise that the solanezumab studies did not meet their primary endpoints, but we are encouraged by the pooled data that appear to show a slowing of cognitive decline," said John C. Lechleiter, Ph.D., Lilly's CEO. "We intend to discuss these data with regulatory authorities to gain their insights on potential next steps."

Jan Lundberg, Ph.D., President of Lilly Research Laboratories, said: "We believe the pooled data support the amyloid hypothesis, as these are the first Phase 3 data with an anti-beta amyloid agent that appear to show a slowing of cognitive decline."

The next steps for solanezumab have not yet been decided and will be determined after discussions with regulators.

The complete press release is available on Lilly's website.

<http://newsroom.lilly.com/releasedetail.cfm?releaseid=702211>

24 August: Study shows that men resist dementia better than women

A review of data from 15 studies shows that men might resist the progression of dementia more than women. The analysis of studies, involving 828 men and 1,238 women, discovered that men with Alzheimer's disease consistently and significantly outperformed women with the disease across five cognitive areas.

Men with Alzheimer's consistently outperformed women in tests of episodic and semantic memory. They were also better at verbal skills, where women normally have the advantage among healthy people.

The study was led by Keith Laws, Professor of Cognitive Neuropsychology at the University of Hertfordshire, UK. He said: "Unlike mental decline associated with normal aging, something about Alzheimer's specifically

disadvantages women. Men's cognitive reserve appears to compensate for the disease process.

"Other research using scans shows men can have brains that are badly damaged yet their skills are not as impaired as they should be. For whatever reason, and it's not about greater intellect, men are better able to stave off the effects for longer."

www.tandfonline.com/doi/abs/10.1080/13803395.2012.712676

Dementia in Society

3 July: UK report shows large variations in time to dementia diagnosis

A new report published in the UK by the All-Party Parliamentary Group on Dementia (APPG) shows that people with dementia are facing considerable variations in the time it takes to receive a diagnosis.

The report, entitled "Unlocking Diagnosis: The key to improving the lives of people with dementia", found that waiting times for memory services – a key component of the diagnosis process – varied from just a few weeks to over a year. The average wait was reported to be at least three months. The APPG is calling for improvement of these services, with more investment, compulsory accreditation and better accountability.

Across the UK, it is estimated that only 43% of people with the disease have a formal diagnosis. Scotland has the highest rate with 64.5%. Northern Ireland follows with 61.5% and then England at 41%. The diagnosis rate is lowest in Wales, with 37.4%.

The report is available on the Alzheimer's Society website.

www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1457

9 July: Gabriel García Márquez can no longer write due to dementia



The Nobel prize winning author Gabriel García Márquez is suffering from dementia and is no longer able to write. Mr. Márquez has been fighting lymphatic cancer since 1995; it is thought that cancer treatment has accelerated his mental decline.

The announcement was made by his brother Jaime, who said: "Dementia runs in our family and Gabriel is now suffering the ravages prematurely due to the cancer that put him almost on the verge of death. Chemotherapy saved his life, but it also destroyed many neurons, many defences and cells, and accelerated the process. But he still has the humour, joy and enthusiasm that he has always had."

The 85-year-old Colombian writer won the Nobel prize in Literature in 1982. He is best known for novels such as *One Hundred Years of Solitude* (1967), *Chronicle of a Death Foretold* (1981) and *Love in the Time of Cholera* (1985). His last novel, *Memoirs of My Melancholy Whores*, was published in 2004.

17 July: Antipsychotic drug use falls by half in UK

On 17 July, the UK National Health Service (NHS) reported that the number of prescriptions of antipsychotic drugs

for people with dementia have fallen by half in the last 3 years.

This figure comes from an audit conducted in 2006-2011 among more than 130,000 people with dementia in the UK. The audit also showed a steady increase in the number of people diagnosed with dementia.

Andrew Chidgey, Director of External Affairs for the UK Alzheimer's Society, said: "Given that we know most prescriptions of antipsychotics have been inappropriate and harmful, this is an excellent result. There is still plenty more to do but this shows how practice can change through determined effort."

The audit results are available on the NHS website.

www.ic.nhs.uk/services/national-clinical-audit-support-programme-ncasp/audit-reports/dementia

31 August: Online petition calls for support of U.S. dementia plan



The American Health Assistance Foundation (AHAf) has launched the "Stop Alzheimer's Petition" online. This calls on the President and Congress to dedicate all resources necessary to fulfil the commitment of the new American national plan to address Alzheimer's disease.

According to AHAf, five million Americans are living with Alzheimer's disease and they are cared for by 15 million family caregivers. The petition is available on AHAf's website.

www.ahaf.org/help/advocate/sign-the-petition-to-help-end-alzheimers.html

New Publications & Resources

6 July: Report highlights concerns about medicating people with dementia

A new Irish research report finds considerable uncertainty and variation in the medicines doctors say they would prescribe for people with dementia at the end of life when presented with clinical scenarios.

"Medication use in patients with dementia at the end of life" was published by the Centre for Ageing Research & Development in Ireland (CARDI). It shows that GPs and hospital physicians indicate they would continue with dementia medications and statins and actively prescribe antibiotics when there is limited evidence of benefits to patients with dementia at end of life.

There is also a lack of consistency in how doctors say they would prescribe medication. In particular, advance directives often appear to have little impact in the medicines proposed for people with dementia at the end of life.

The report concludes that publication of specific guidelines for medication for people with dementia at the end of life would be beneficial to people living with dementia, their families and health professionals working in this area.

This project was funded by CARDI and led by Dr. Carole Parsons from Queen's University Belfast. There were additional researchers from University College Cork and the voluntary, statutory and private sectors. Altogether

662 doctors (593 GPs and 69 hospital physicians in Northern Ireland and the Republic of Ireland) answered questions about which drugs they would continue with or withdraw when presented with four different scenarios.

www.cardi.ie/userfiles/Dementia%20medication%20research%20brief.pdf

19 July: Commission publishes a new brochure: "Health in the EU: what is in there for you?"



The European Commission has published a new brochure that outlines recent EU achievements in the health field. "Health in the EU: what is in there for you?" includes information and news about:

- Increasing consumer safety and public health by assessing scientific risks
- Strengthening the safety and quality of medicines
- Promoting active and healthy ageing.

The new brochure is available on the Health-EU website.

http://ec.europa.eu/health/strategy/docs/recent_achievements_2012_en.pdf

24 July: Arts-based education benefits people with dementia

An education project based on painting has shown considerable benefits for people with moderate or advanced dementia.

The research study was implemented at a care home in Toronto, Canada and engaged ten participants in painting classes that met once a week for one hour over a ten-week period.

All ten participants in the program responded positively to the opportunity to paint and half excelled. Several participants demonstrated acquisition of new skills and developed a distinctive painting style. These participants also openly shared their work, praised their accomplishments and stated that they felt they had learned something new.

The programme also built mutual trust and reciprocity with and among the participants. They enjoyed sharing and talking about their work with their fellow learners. In turn, these qualities contributed to the expression of positive feelings, improved self-esteem, sense of purpose and communication.

The programme was led by Ms Kathleen Downi, artist and researcher in adult education.

www.mindsetmemory.com/Client_Files/Arts_Based_Education_Guide.pdf

1 August: Alzheimer Scotland publishes guide for proxy decision making in dementia



Alzheimer Scotland has published a new guide called "Dementia: making decisions. A practical guide for family members, partners and friends with powers of attorney, guardianship or deputyship". The guide is part of a research and development project led by Ms Jan Killeen (pictured), who recently retired from Alzheimer Scotland

as Director of Policy. The project was funded by the Nuffield Foundation.

Carers are frequently faced with stressful situations, for example, when the person they care for is unaware of the risks they are taking, is refusing help or making decisions about end-of-life care. Family members also face difficulties in dealing with bureaucracy, professional differences or family conflicts.

The guide is based on the experiences of over 100 family members across Scotland, England, the Netherlands and Germany. It provides practical advice and information on how to weigh up options and information for action when faced with challenging situations. There is also a checklist to follow in reaching decisions. Finally, the guide shows how the principles within incapacity laws can be used to uphold the rights of the person with dementia and help lay proxies to assert their authority.

The accompanying report, "Research summary and recommendations for policy and practice", is intended as a resource for those campaigning to improve support for families who take on this additional duty of care.

Both publications can be freely downloaded from the Alzheimer Scotland website at www.alzscot.org/decisions. Paper copies can be ordered via email to alzheimerscot@alzscot.org with a charge for postage and packing for overseas requests.

6 August: Young musician donates profits from memorial song to dementia research

Rupert Brooke, a professional singer and songwriter, has written and released a song in memory of his grandmother, who passed away with Alzheimer's disease. "Always" is available globally for download from Rupert's official charity website and all profits will be donated to Alzheimer's Research UK.

www.rupertstroudforaruk.com
www.youtube.com/watch?v=JQUbjmAkISY

31 August: A new French book explores the ethical and societal challenges of Alzheimer's disease

A new book entitled "Alzheimer, éthique et société" has been published (in French) by a team headed by Dr. Fabrice Gzil and Prof Emmanuel Hirsch.

Fabrice Gzil is the Research Programme Manager at the Fondation Médéric Alzheimer. Emmanuel Hirsch is a Professor of Medical Ethics at the Université Paris-Sud. He is also the Director of Espace National de Réflexion Ethique Alzheimer (EREMA).

The book is a collection of articles by over 60 authors - including Dianne Gove, Information Officer for Alzheimer Europe. The authors seek to demonstrate the diversity and complexity of the ethical and societal challenges posed by Alzheimer's disease.

They point out that people living with the disease must be actively and continually involved in all activities involving their care, for as long as they are able. The authors also highlight the many problems faced by family members and other caregivers of people living with dementia - and advocate recognition and support for their efforts. They also show how European governments and other

organisations are working to raise awareness of dementia and to make it a national priority. Dementia, they conclude, is a challenge for all of society - not just for the doctors and scientists who are looking for a cure.

Dianne Gove's article, entitled "The Ethics of Dementia Research", is a summary of the work produced by Alzheimer Europe's Ethics Working Group.

More details about "Alzheimer, éthique et société" can be found at:

www.espace-ethique-alzheimer.org/encarts_details.php?n=248&e=1



www.alzheimer-europe.org/Donation

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AE Calendar

Date	Meeting	AE Representative
7 September	Meeting with conference organiser to finalise preparation of the 22nd Alzheimer Europe Conference (Vienna, Austria)	Gwladys
20 September	Press conference for the 22 nd Alzheimer Europe Conference (Vienna, Austria)	Jean
28 September	EFPIA Think Tank (Brussels, Belgium)	Annette
1 October	NILVAD Steering Committee meeting (Amsterdam, The Netherlands)	Alex
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
5-6 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

Future Conferences

Date	Meeting	Place
5-7 September 2012	7th International conference on creative expression, communication and dementia, www.cecd-society.org	Worcester, UK
8-11 September 2012	16th Congress of the European Federation of Neurological Societies (EFNS), www2.kenes.com/efns/pages/home.aspx	Stockholm, Sweden
11 September 2012	10th ERA-AGE Forum Meeting, ERA-AGE: from 2004 to 2020, www.era-age.group.shef.ac.uk	Brussels, Belgium
19-20 September 2012	4 th International conference - "Senior's training and non-pharmacological interventions for Alzheimer's disease", www.alzheimer.sk/informacie/kontakty.aspx	Bratislava, Slovakia
7-10 October 2012	137 th Annual meeting of the American Neurological Association, www.aneuroa.org	Boston, USA
4-6 October 2012	22 nd Alzheimer Europe Conference "Changing perceptions, practice and policy", www.alzheimer-europe.org/EN/Conferences	Vienna, Austria
10-13 October 2012	6th Croatian Congress on Alzheimer's disease with international participation, www.alzheimer2012.com	Primošten, Croatia
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.cagacg.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
8-11 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
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
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, adi2013@mci-group.com	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
23-27 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

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.