Editorial

In April, we were very pleased to welcome three new members to the European Alzheimer’s Alliance, which now has a total of 63 members.

The undoubted highlights in April were two important meetings which we cover in more detail in this newsletter:

- We organised the first meeting of the European Working Group of People with Dementia which brought together people with dementia and representatives from 12 European countries and which served as a true inspiration for our cause.
- Alzheimer Europe was invited to attend the Steering Committee of ALCOVE, the European Joint Action on Dementia and we signed a memorandum of understanding highlighting the areas for collaboration.

April also saw considerable activity from the European Commission:

- launch of the European Citizens’ Initiative, a tool that allows citizens to make legislative proposals for health services
- launch of the "Marketplace for innovative ideas", an element of the European Innovation Partnership on Active and Healthy Ageing
- presentation of the "Employment Package" that focuses on job creation, with an emphasis on the health sector.

Together with our member organisations, we provided input to the Council of Europe for its consultation on the collection and use of health-related data by insurance companies.

We also contributed to the European Commission’s reflection process on Chronic Diseases. This is part of the Commission’s ongoing discussions on how to address chronic diseases and related issues at European, national and local levels.

On the national level, the German Ethics Council declared that dementia is one of the major health and social challenges of our time. In addition, our member organisations report on their numerous activities. In Greece, there was a workshop on legal and social issues and also a conference dedicated to caregivers. The first group of Dementia Champions has been deployed in Scotland and the Swiss Alzheimer Association is preparing to repeat a series of popular seminars dealing with taboos in dementia.

Our newsletter also covers the recent report by the World Health Organization and Alzheimer’s Disease International which examines the worldwide impact of dementia, including best practices and case studies.

We continue to prepare for the 22nd Alzheimer Europe Conference in October. We are very glad to have received 160 abstracts – more than the two previous years. These will be reviewed during May by the Programme Committees. We are no longer accepting abstracts, but the early bird rates for conference registration are available until the end of June.

Finally, our website updates are progressing, albeit at a somewhat slower pace than anticipated. The section on the European Alzheimer’s Alliance is now up to date, including all of our members’ recent activities. We will continue to report on updates as they happen.

Jean Georges
Executive Director
Alzheimer Europe

30 March: Iva Holmerová and Sigurd Sparr attend ELTECA conference

On 30-31 March, Dr. Iva Holmerová and Dr. Sigurd Sparr, respectively Vice Chairperson and Honorary Treasurer of Alzheimer Europe, participated in the first ELTECA conference on long-term care medicine in Prague.

ELTECA (Exchange of Experience in Long-term Care) attracted 80 European and American delegates, all experts in long-term care from academic and private organisations. The conference aimed to share knowledge and promote cooperation among health care professionals, patient organisations and the community at large. The following topics were covered:

- the future of nursing homes
- the numerous models of long term care in use today
- follow-up of after-care and palliative care in long-term care facilities
- barriers in providing long-term care
- the need for adequate symptom management in geriatric patients
- the importance of diagnosis and the diagnostic process
- psychosocial intervention for people with dementia

Dr. Holmerová, who also heads the Czech Alzheimer’s Society, said: “Long-term care is an issue of increasing importance in all ageing countries. Each country tackles this problem according to its local conditions but there are some common issues and experiences that can be shared.”

ELTECA was organised by the Czech Alzheimer’s Society and the Centre of Expertise in Longevity and Long-term care of the Charles University in Prague (CELLO), with support from Zentiva, a Sanofi company. Conference presentations and videos will soon be available on ELTECA’s website.

11-12 April: Alzheimer Europe signs memorandum of understanding with ALCOVE, the Joint Action on Dementia

On 11 and 12 April, Heike von Lützau-Hohlbein and Jean Georges, the Chairperson and Executive Director of Alzheimer Europe were invited to attend the Steering Committee Meeting of ALCOVE, the European Joint Action on Dementia.

ALCOVE stands for ‘ALzheimer’s COoperative Valuation in Europe’. It is a two year Joint Action (JA), which is co-financed by the European Commission and is managed by the Executive Agency for Health and Consumers (EAHC) within the framework of the Community’s 2008-2013 public health programmes.

The Joint Action brings together 30 partners from 20 countries (Belgium, Cyprus, Czech Republic, Finland, France, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Portugal, Slovakia, Slovenia, Spain, Sweden and the UK), with the Haute Autorité de Santé (HAS) in France acting as coordinator.

Within ALCOVE, there are four core questions to be addressed:

1. How to improve data for better knowledge about dementia prevalence?
2. How to improve access to dementia diagnosis as early as possible?
3. How to improve care for people living with dementia and particularly those with behavioural disorders?
4. How to improve the rights of people with dementia, particularly with respect to advance declarations of will?

In order to answer these questions, the work of the project is divided into seven Work Packages. The desired anticipated main outcomes are:

- The establishment of a sustainable European network for the exchange of experiences and knowledge at the level of health care institutions in order to improve quality of care and services.
- To inform and advise decision-makers, health care professionals, care givers and citizens in general through convergent recommendations in terms of health policy, and
- A reduction in the risks associated with psychotropic drugs, with a common focus on the use of psychotropic drugs, in particular antipsychotics.

At the meeting in Paris, Alzheimer Europe and the ALCOVE network signed a memorandum of understanding outlining the areas of collaboration.

15-17 April: Alzheimer Europe organises first meeting of the European Working Group of People with Dementia

From 15 to 17 April, Alzheimer Europe brought together people with dementia and representatives of national
Alzheimer associations in Glasgow. The meeting which was organised together with the Scottish Dementia Working Group and Alzheimer Scotland aimed at exchanging best practices between countries on how best to involve people with dementia and providing guidance to Alzheimer Europe for the setting up of its European Working Group of People with Dementia.

The inspirational meeting was attended by people with dementia from the Czech Republic, England, Germany, Ireland, the Netherlands and Scotland who shared both their personal experiences of being diagnosed with Alzheimer’s disease or another form of dementia, as well as their involvement in the work of the national Alzheimer associations. In addition, representatives of Alzheimer associations from Austria, Bulgaria, Norway, Slovenia and Spain participated in the meeting to learn from the experiences of those organisations which were already more advanced on the issue of involving people with dementia.

Amid laughter and tears, the participants shared the many good examples of how national Alzheimer associations involve people with dementia and provide unique services for both people with dementia and their carers. All participants agreed on the importance of early diagnosis and the absolute right of people with dementia to be told their diagnosis as prerequisites for involving people with dementia. In addition, post diagnostic support including access to peer support was identified as a priority for all countries.

The interesting meeting was rounded off by a relaxed and varied social programme with a welcome reception in the sumptuous City Hall of Glasgow on the invitation of the Glasgow Mayor.

As a next step, Alzheimer Europe will provide a detailed report of the meeting highlighting the many innovative initiatives undertaken at national level. The next meeting of the European Working Group will take place in Vienna prior to the Alzheimer Europe Conference.

23 April: Alzheimer Europe responds to Council of Europe consultation

Alzheimer Europe was amongst the organisations invited by the Council of Europe to take part in the consultation on “predictivity, genetic testing and insurance” which was launched by the Committee on bioethics of the Council of Europe in February 2012.

The questionnaire on this topic was prepared and then circulated for comment amongst the board members of Alzheimer Europe and the member organisations attending AE’S Public Affairs meeting in February. The completed questionnaire was submitted on 23 April.

The consultation was not limited to genetic predictive tests but included non-genetic predictive data and the use of family histories. Many of the topics addressed were relevant to dementia. For example, issues related to the actuarial basis covered scientific validity and the positive predictive value of tests, whether they are used in clinical practice and the proper interpretation of data/relevant expertise. Discussions around the underwriting process focused on transparency regarding reasons for refusal and the systematic inclusion of individual data on factors positively affecting health risks. Other issues addressed included data collection, storage and accessibility.
Alzheimer Europe Networking

On 3 April 2012 (Brussels, Belgium) Annette attended the European Commission's conference on "European Innovation Partnership on Active and Healthy Ageing. From Plan to Action".

On 11-12 April 2012 (Paris, France) Heike and Jean attended the Meeting with ALCOVE.

On 13 April 2012 (London, United Kingdom) Jean went to the GSK Health Advisory Board.

On 15-17 April 2012 (Glasgow, Scotland) Dianne, Henry and Jean attended the First meeting of the European Working Group for People with Dementia.

On 18 April 2012 (Brussels, Belgium) Annette represented Alzheimer Europe at the European Patients' Forum General Assembly Meeting.

On 23-25 April 2012 (Copenhagen, Denmark) Jean attended the Global Forum on Incontinence.

On 26-27 April 2012 (Brussels, Belgium) Dianne attended the Workshop “Finding the right balance between autonomy and protection of the person with dementia: advance directives and competence assessment”.

EU Projects

1 April: PharmaCog project team announces personnel changes

Our last newsletter mentioned the appointment of Régis Bordet as the new Academic Coordinator, replacing Alexandra Auffret. Since then, there have been several other changes:

• due to Régis’s new role, a new co-leader for Work Package (WP) 3 will be named. Pierre Payoux is the other co-leader.
• Joelle Micallef will take over from Alexandra to co-lead WP1, along with David Bartès-Faz.
• Darrel Pemberton replaces John Atack as co-leader of WP4. Esther Schenker remains the other co-leader.
• Bruno Boutouyrie, co-leader of WP10, has left the project. Lesley Stubbins will step in as co-leader and will also help lead the Ethics Advisory Board meetings until a replacement is identified.

PharmaCog Work Packages mentioned in this article:

• WP1: Development and validation of translatable cognitive impairment models
• WP3: Development and validation of translatable pharmacodynamic markers (clinical)
• WP4: Development and validation of translatable pharmacodynamic markers (non-clinical)
• WP5: Identification of biomarkers sensitive to disease progression
• WP10: Communication, dissemination and ethics

www.pharmacog.org

European Alzheimer’s Alliance

18 April: Three MEPs join the European Alzheimer’s Alliance

The European Alzheimer’s Alliance is very pleased to welcome three new members: Philippe Juvin, MEP (France), Gilles Pargneaux, MEP (France) and Marc Tarabella, MEP (Belgium).

Philippe Juvin is a member of EPP, the Group of the European People’s Party. He sits on the Committee on the Internal Market and Consumer Protection and is a substitute on the Committee on the Environment, Public Health and Food Safety. He is also a medical doctor, specialising in anaesthesia and resuscitation as well as forensic medicine. Mr Juvin was a member of the Commission led by Professor Menard to identify the priorities of the current Alzheimer Plan in France.

Gilles Pargneaux is with S&D, the Group of the Progressive Alliance of Socialists and Democrats. He is on the Committee on the Environment, Public Health and Food Safety and is a substitute on the Committee on Transport and Tourism.

Marc Tarabella is also affiliated with S&D and sits on the Committee on Agriculture and Rural Development and the Committee on Women’s Rights and Gender Equality. He is a substitute on the Committee on the Internal Market and Consumer Protection.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 63, representing 21 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),
Belgium: Brepeols Frieda (Greens/EFA), Ries Frédérique (ALDE),
Bulgaria: Parvanova Antoniya (ALDE),
Cyprus: Triantaphyllides Kyriacos (GUE-NGL),
Czech Republic: Cabrnoch Milan (ECR), Kohíček Jaromír (GUE-NGL), Roithova Zuzana (EPP),
Danmark: Christensen Ole (S&D), Rohe Jens (ALDE),
Dáidilseach Christel (S&D),
Finland: Jääskeläinen Liisa (S&D), Jääätteenmäki Anneli (ALDE),
France: Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE),
Greece: Chountis Nikolaos (GUE-NGL), Kopka Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP),
Ireland: Aylward Liam (ALDE), Childers Nessa (S&D), Crowley Brian (ALDE),
Italy: Panzeri Pier Antonio (S&D), Toia Patrizia (S&D),
Lithuania: Vilija Blinkėvičiute (S&D),
Luxembourg: Engel Frank (EPP), Lulling Astrid (EPP),
Netherlands: De Lange Esther (EPP), van Nistelrooij Lambert (EPP),
Poland: Ninehmer Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP),
Portugal: Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL),
Romania: Antonescu Elena Oana (EPP), Borozi Cristian (ALDE),
Slovakia: Mikolásik Miroslav (EPP), Zaborska Anna (EPP),
Slovenia: Peterle Aljaz (EPP),
United Kingdom: Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D),

EU Developments

1 April: European Commission launches Citizens’ Initiative

1 April, the European Commission launched the European Citizens’ Initiative (ECI), a tool that allows groups of citizens to make legislative proposals.

The ECI enables EU citizens to participate directly in the development of EU policies, by calling on the European Commission to make a legislative proposal. A citizens’ initiative has to be backed by at least one million EU citizens coming from at least seven Member States. Initiatives are possible in any field - such as public health - where the Commission has the power to propose legislation.

A minimum number of signatories is required in each of the 7 Member States. The number of statements of support has to be certified by the competent authorities in the Member States. The Commission will then have three months to examine the initiative and decide how to act on it.

The ECI is one of the major innovations of the Treaty of Lisbon. The rules and procedures governing the new instrument were agreed by the European Parliament and the Council following a proposal from the Commission: Regulation (EU) n. 211/2011 of the European Parliament and of the Council on 16 February 2011.

3 April: European Commission opens EIP AHA Marketplace

On 3 April, the European Commission launched the “Marketplace for innovative ideas” as part of the implementation of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA).

This is an interactive website designed to help like-minded stakeholders work together and develop innovative ideas, in line with the six priorities identified in the Strategic Implementation Plan (SIP). The Marketplace helps stakeholders to:

• be identified as potential partners
• share information on ageing and innovation
• participate in the discussion forum
• promote events related to active and healthy ageing.

This website complements the “Invitation for Commitment” launched at the end of February. This enables all stakeholders to submit a commitment to be an active partner in the implementation of the SIP.

17 April: European Parliament welcomes Croatian observer MEPs

At the plenary session of 17 April, EP President Martin Schulz welcomed twelve Croatian observer MEPs. The observers will take part in group and committee meetings. Croatia is due to join the EU on 1 July 2013.

The Croatian observer MEPs are:

• Ms Ingrid ANŢIĆEVIĆ MARINOVIC (S&D)
• Ms Biljana BORZAN (S&D)
• Mr Davor BOŽINOVIC (EPP)
• Mr Boro GRUBIŠIĆ (NI)
• Ms Romana JERKOVIC (S&D)
• Mr Frano MATLUSHIĆ (EPP)
• Mr Tonino PICULA (S&D)
• Mr Andrej PLENKOVIĆ (EPP)
• Mr Milorad PUPOVAC (S&D)
18 April: European Commission presents the “Employment Package”

On 18 April, the European Commission presented its new “Employment Package”, a set of concrete measures to tackle unemployment, boost jobs and beat the grim economic outlook for the months ahead in Europe. The package was presented as a Communication to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, “Towards a job-rich recovery”.

The package focuses on job creation and underlines the need for a stronger employment and social dimension to EU governance. Health services, the green economy and ICT are identified as areas with the biggest job potential for the future. The package sets out the following steps to strengthen the national employment policies of Member States:

- create the right conditions for job creation and labour demand
- exploit the big job potential areas for the future, including health services
- improve planning and forecasting of the health workforce to match the demand and supply of health professionals
- support an increase in highly qualified ICT labour and the promotion of digital skills across the workforce.

The Communication also presents key areas for reform so that labour markets become more dynamic and inclusive and more resilient to economic change:

- draw on the lessons learned from the crisis, such as stimulating internal flexibility to reduce job insecurity and fiscal costs
- establish decent and sustainable wages and avoid low-wage traps
- ensure appropriate contractual arrangements to prevent the excessive use of non-standard arrangements. This includes the need to deliver on opportunities for young people and developing lifelong learning.
- provide more investment in skills to address the mismatches in Europe’s labour markets, as well as better anticipation of skills needs.

The ultimate aim of the “Employment Package” is to create a genuine EU labour market by:

- improving labour mobility: removal of legal and practical obstacles to the free movement of workers; inviting governments to lift restrictions on labour market access to some workers; allowing nationals from other Member States to access jobs in the public service
- improving the matching of jobs with job-seekers: transform the EURES job seeker portal into a true European placement and recruitment tool by 2013.

24 April: EU Council agrees to delay transposition of EMF Directive

A new directive postponing the transposition of electromagnetic fields directive 2004/40/EC1 entered into force on 24 April. This follows the European Parliament and Council decision to delay the transposition by 18 months. The new deadline for transposition is 31 October 2013.

This will allow more time to discuss the Commission’s 2011 proposal for a new directive on electromagnetic fields. The new directive will repeal directive 2004/40. On 29 March, the European Parliament agreed to extend the April 2012 implementation deadline of EMF Directive 2004/40 until October 2013. The Council had to formally adopt the extension before 30 April.

Directive 2004/40/EC was adopted together with other measures intended to protect workers from the health effects of noise, vibration and optical radiation. Soon after its adoption in 2004, the medical community working with magnetic resonance imaging claimed that the strict exposure limits of the Directive would seriously hamper its activities.


30 April: Alzheimer Europe contributes to Commission’s reflection process on Chronic Diseases

On 30 April, Alzheimer Europe finalised its contribution to the European Commission reflection process on Chronic Diseases. This is in response to a series of questions that were put forward to the public:

- what should be done on health promotion and disease prevention?
- how does healthcare deal with prevention, treatment and care of chronic diseases?
- how does research contribute to the prevention and treatment of chronic diseases?
- how can information and information technology contribute?
- what should be the roles of Members States, the EU and stakeholders?
- what are other areas to consider when dealing with chronic diseases?

In its response, Alzheimer Europe extended the Commission’s definition of chronic diseases to include the idea that chronic diseases of a neurodegenerative nature, such as Alzheimer’s disease and other forms of dementia, are unpreventable and do not benefit from any curative treatment. The ageing of the population and the increase in age-related diseases (such as dementia) will follow this trend. It is therefore important to include these diseases in the reflection process.

Alzheimer Europe advocates early diagnosis of dementia, awareness campaigns, multi-sectorial policies that will respond to the need of people with dementia and their carers. This includes social, care, education, health, work and research policies.

EU Joint Actions are important instruments that facilitate the collection and sharing of best practice across Europe and support both national and EU policy work. This can be
illustrated by ALCOVE, the current Joint Action on dementia.

National Plans on dementia that include health promotion, reduced exposure to risk factors and early diagnosis as key elements should become a reality all over Europe.

In the field of research, the Joint Programming of Neuro-Degenerative research (JPND) is a promising instrument that must be further supported by the current Framework Programme for Research and the next research programme Horizon 2020.

Alzheimer Europe also advocates the establishment of a European Dementia Observatory to collect and maintain data on the prevalence of dementia.

Additional actions should: 1) target individuals who are at risk of developing dementia, 2) the identification of European Guidelines for quality assurance in dementia screening and diagnosis and 3) lead to the implementation of a European specialist dementia unit accreditation scheme that would enable people with dementia and their carers to identify which dementia units in Europe meet the quality standards.

Alzheimer Europe also invites the European Commission to set up a Chronic Diseases Task Force with EU and national policy makers, healthcare professionals and patient representatives covering both preventable and unpreventable chronic diseases.

All too often, young people with dementia are not considered in the discussions or strategies put in place. Activities such as Corporate Social Responsibility must support young people with dementia to be active and participate in society for as long as possible.

Patient and carer organisations have a broad grass-roots understanding of peoples’ expectations and experience, including stigma. These organisations must be recognised as full partners and receive the necessary financial and logistical support to contribute to the discussions.

The European Commission (DG SANCO) launched the reflection process on the growing challenge of chronic diseases in response to the Council conclusions on “Innovative approaches for chronic diseases in public health and healthcare systems” of the Employment, Social Policy, Health and Consumer Affairs of December 2010. This was reinforced by the conclusions of the UN High Level Meeting on non-communicable diseases in 2011 which confirmed that addressing chronic diseases is now a global priority.

The Commission intends to launch a further, targeted discussion with key stakeholders involved in European work with the European Commission in the areas of chronic disease and related issues.

http://ec.europa.eu/health/major_chronic_diseases/docs/eu_reflection_cd_i
nuitationletter_032013_en.pdf
18282.pdf

Members’ News

9 March: Alzheimer Hellas holds workshops on legal and social issues

Alzheimer Hellas has initiated a series of workshops for 2012 which aim to inform professionals and caregivers about legal and social issues that are specific to dementia. The first workshop took place in Thessaloniki on 9-11 March.

The event was officially opened by Deputy Health Minister Markos Bolaris and attracted nearly 200 people, mainly health care professionals and carers of people with dementia. Delegates provided input for a proposed legal framework for people with dementia and also attended seminars on best practices for home care.

18 March: Athens Alzheimer Association hosts Caregiver’s Day 2012

The Athens Association of Alzheimer Disease and Related Disorders held its third annual Caregiver’s Day on 18 March in Athens. The main focus of the event was to address the specific challenges faced by caregivers of people with Alzheimer’s disease and other forms of dementia. Caregiver’s Day 2012 was attended by 1,000 caregivers and 400 people with dementia.

Caregivers had access to numerous training seminars, such as pharmacological and non-pharmacological treatments for dementia and psychiatric and behavioral symptoms. There were also sessions on daily care issues like communication skills, personal hygiene and reduced mobility. Delegates could also attend counselling sessions to share their everyday concerns with doctors, psychologists and other health professionals.

Attendees with dementia were also able to participate in the event, mainly in activities based on cognitive stimulation. There are an estimated 160,000 people with dementia in Greece, of which 80% are cared for at home.

10 April: Scottish Dementia Champions will improve standards of care

The first 100 Dementia Champions have started work across Scotland to improve standards of care for people who live with dementia.

This is a group of NHS professionals including nurses, dieticians and physiotherapists. They are all graduates of the first Dementia Champions programme, a specialised training programme designed by Alzheimer Scotland and the University of the West of Scotland.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: “The new Dementia Champions are a vital component in delivering meaningful change to people with dementia and their families. We are greatly impressed by their commitment and enthusiasm. They will complement the work done by Alzheimer Scotland Dementia Nurse Specialists/Consultants: both those
already appointed and those who will come into post over the next few months as part of the jointly-funded investment made by Alzheimer Scotland and the Scottish Government."

The second group of Dementia Champions will be twice the size of the first and will also include Social Services staff. The group will begin training in May 2012.

http://vimeo.com/38449657

28 April: Alzheimer Romania colleagues attend General Practitioner Conference

On 28-29 April, several colleagues of Societatea Alzheimer attended the Romanian General Practitioner Conference in Bucharest. The title of this event was "The delicate balance between science, art and communication". Maria Moglan, Executive Director of Societatea Alzheimer, along with colleagues Letitia Dobranici and Carmen Busneag held an hour-long seminar on 29 March. They gave presentations on memory loss, the role of family doctors in diagnosing and treating Alzheimer's disease and a call to action for a national Romanian dementia plan.

30 April: Swiss Alzheimer Association defies taboos in dementia

Due to popular demand, the Swiss Alzheimer Association will organise further sessions of its seminar entitled "Taboos and Dementia". The first session attracted more than 350 participants and covered topics that remain hidden in the lives of many people who live with dementia.

These topics, including negligence, abuse, aggression and sexuality, were openly discussed among health professionals and caregivers. Their aim was to determine the causes and to develop ways of managing these forms of behaviour. The new seminars will take place in Lausanne and Olten.

Policy Watch

24 April: German Ethics Council names dementia as a major challenge of our time

On 24 April, the German Ethics Council published an opinion on "Dementia and Self-determination" that identifies dementia as one of the major health and social challenges of our time.

The opinion points out that people with dementia live with diminished mental, emotional and social resources. Therefore, it is essential to preserve "each remaining independence and self-determination" for as long as possible.

Heike von Lützau-Hohlbein, chairperson of the German Alzheimer Society, said: "I am very pleased that the German Ethics Council has made this extensive study on dementia. It is very important to recognise that people with dementia have a right to self-determination and a right to participate in society. "The members of the Ethics Council also expressed their support for the German national dementia plan, but pointed out that the plan could not develop without additional funding. I would urge all the Members of Parliament to read the Ethics Council report before they discuss care reform next week."

www.ethikrat.org

Science Watch

1 April: CERE-110 gene therapy begins Phase II trial

Ceregene, an American biotech company, has begun a Phase II clinical study of CERE-110. This gene therapy product is designed to deliver nerve growth factor (NGF) to the brain for the treatment of Alzheimer’s disease. NGF is known to promote survival of cholinergic neurons. These neurons produce acetylcholine and degenerate during the course of Alzheimer’s disease. The clinical trial involves direct delivery of CERE-110 into the brain, specifically to an area called the Nucleus Basalis of Meynert that is rich in acetylcholine. The trial will be conducted with 50 patients at 11 US research sites.

http://adcs.org/Studies/NGF.aspx

5 April: SORL1 gene may be the cause of early onset Alzheimer’s disease

A research team from INSERM has shown that mutations of the SORL1 gene seem to contribute to the development of early-onset Alzheimer’s disease. The research team, led by Dr. Dominique Campion and Prof Didier Hannequin, studied the genes from 130 families living with early-onset forms of Alzheimer’s disease. 116 of these families presented mutations on the known genes. In the 14 remaining families, no mutation was observed.

A DNA study of the genome of the 14 families showed evidence of mutations on the SORL1 gene. This is a coding gene for a protein involved in the production of beta amyloid and is known to affect neuron function.

Two of the identified mutations are responsible for a decrease in SORL1, resulting in increased production of beta amyloid. Dr Campion said: "The mutations observed on SORL1 seem to contribute to the development of early-onset Alzheimer’s disease. However, we still need to identify more clearly the way in which these mutations are transmitted on the SORL1 gene within families."

www.nature.com/mp/journal/vaop/ncurrent/full/mp201215a.html

5 April: Memory declines faster in the last 2.5 years of life

A new study shows that a person’s memory declines at a faster rate in the two- and-a-half years before death than at any other time after memory problems first appear.
The project was led by Dr. Robert Wilson, neuropsychologist at Rush University Medical Center in Chicago.

For the study, 174 Catholic priests, nuns and monks without memory problems had their memory tested yearly for six to 15 years before death. After death, scientists examined their brains for beta amyloid plaques and tau tangles.

The study found that, at an average of two-and-a-half years before death, different memory and thinking abilities tended to decline together. The rates of decline were eight to 17 times faster than before this terminal period. Higher levels of plaques and tangles were linked to an earlier onset of this terminal period, but not to the rate of memory decline during the period.

Dr. Hiroko Dodge, Associate Professor of Neurology at Oregon Health and Science University, made the following comments but was not involved in the study:

"The findings suggest that the changes in mental abilities during the two to three years before death are not driven directly by processes related to Alzheimer’s disease, but instead that the memory and other cognitive decline may involve some biological changes in the brain specific to the end of life. The study by Wilson and his co-authors deepens our understanding of terminal cognitive decline."

www.neurology.org/content/78/15/1116.abstract?sid=c558bace-7004-4b16-a2cb-33fb501d331e

9 April: New test detects amyloid plaques in people with MCI

On 9 April, the American FDA approved a new protein detection test developed by Eli Lilly. It is an imaging test performed on living people using a chemical called florbetapir. This radioactive agent settles on clumps of beta amyloid and can then be detected with PET scans.

The imaging test - known as Amyvid - aims to detect Alzheimer’s disease earlier and more accurately in people with slight memory loss. For people who already have some symptoms of cognitive decline, a positive scan suggests that moderate to frequent amyloid plaques are present in the brain. If the scan is negative, indicating no or few clumps of amyloid, “that gives the clinician a clue that Alzheimer’s is less likely to be the cause of those symptoms,” said Eli Lilly’s Daniel Skovronsky.

www.fda.gov/Drugs/NewsEvents/ucm130961.htm

9 April: Bapineuzumab may reduce CSF tau levels

Researchers have found that treatment with the antibody bapineuzumab significantly lowered levels of phosphorylated tau (P-tau) in the cerebrospinal fluid (CSF) of people with Alzheimer’s disease. Dr. Kaj Blennow, Professor of Clinical Neurochemistry at the University of Gothenburg in Sweden, led the project that pooled results from two earlier Phase II studies.

These studies showed that P-tau levels fell significantly for those people on bapineuzumab compared with controls. There was also a trend toward diminished total tau levels in these people. However, there were no changes in levels of beta amyloid, the protein that bapineuzumab is designed to remove. People with Alzheimer’s disease typically have lower levels of beta amyloid and higher levels of tau in their CSF.

These findings may indicate that the antibody has some downstream effects on the degenerative process. It remains to be seen whether these effects translate to clinical improvements. Bapineuzumab is currently being evaluated in a Phase III trial.

http://archneur.ama-assn.org/cgi/content/full/archneurol.2012.90v1

11 April: APP fragment can regulate production of beta amyloid

A research team led by the University of South Florida (USF) has found that a fragment of the amyloid precursor protein (APP) known as sAPP-α can regulate production of beta amyloid.

In its healthy state, APP is thought to be involved in synaptic formation and repair. In Alzheimer’s disease, APP degenerates and produces beta amyloid (the primary component of amyloid plaque) and also sAPP-α.

Clearly, high levels of beta amyloid are toxic. However, high levels of sAPP-α appear to be beneficial: the researchers showed that reduction of sAPP-α led to an increase of beta amyloid activity.

This is due to the interaction between sAPP-α and the BACE1 enzyme. BACE1 (beta-secretase) initiates the formation of beta amyloid, while sAPP-α reduces or blocks this activity.

The research team, led by Dr. Jun Tan, Professor of Psychiatry, continues to investigate ways of monitoring and adjusting sAPP-α levels, as well as enhancing its association with BACE1.

www.nature.com/ncomms/journal/v3/n4/full/ncomms1781.html

15 April: Piramal buys Bayer’s florbetaben rights

On 15 April, Piramal Healthcare announced that it has signed an agreement to acquire worldwide rights to the molecular imaging research and development portfolio of Bayer. This includes the rights to florbetaben, a PET tracer for the detection of beta-amyloid plaque deposition in the living brain.

Florbetaben (BAY 94-9172) is in the final stages of a Phase III clinical trial and the first results are expected soon.

www.thelancet.com/journals/laneur/article/PIIS1474-4422(11)70077-1/abstract

16 April: Hippocampal shrinkage is accelerated by four gene variants

A new international study shows that four gene variants may speed shrinkage of the hippocampus in healthy humans. Scientists found that shrinkage in people with these variants accelerates by about four years on average. If such a person were to develop Alzheimer’s, the disease would attack an already compromised hippocampus - leading to a more severe condition at a younger age.

"This is definitely a case of "bigger is better," said Dr. Charles DeCarli, co-leader of the study and Professor of Neurology at the University of California in Davis. "We already know that Alzheimer’s disease causes much of its damage by shrinking hippocampus volume. If someone loses a greater-than-average amount of volume due to the gene variants we’ve identified, the hippocampus is more vulnerable to Alzheimer’s."
"With this study, we have new evidence that aging, the hippocampus and memory are influenced by specific genes. Understanding how these genes affect the development and aging of the hippocampus may give us new tools to delay memory loss with advanced age and possibly reduce the impact of such diseases as Alzheimer's disease."

The research team hopes to find ways to protect the hippocampus from premature shrinkage or slow its decline by studying the normal regulation of the proteins coded by these genes.

This project involved more than 80 scientists at 71 institutions in eight countries. The study used a very large assemblage of genetic and disease data called the Cohorts for Heart and Aging Research in Genomic Epidemiology Consortium, or CHARGE. The consortium brings together several population-based cohorts in the United States and Europe.
countries. This leads to stigmatisation and barriers to diagnosis and care, which in turn affect people on physical, psychological and economic levels.

“WHO recognises the size and complexity of the dementia challenge and urges countries to view dementia as a critical public health priority,” said Dr. Shekhar Saxena (Director, Department of Mental Health and Substance Abuse, WHO). “Right now, only eight of 194 WHO member states have a national dementia plan in place, and a few more are in development.”

Dr. Margaret Chan (WHO Director-General) called the report “a major contribution to our understanding of dementia and its impact on individuals, families and society.” She said the report “provides the knowledge base for a global and national response to facilitate governments, policymakers and other stakeholders to address the impact of dementia as an increasing threat to global health.”

Marc Wortmann (ADI Executive Director) said: “Around the world a new case of dementia arises every four seconds. That’s a staggering growth rate, equivalent to 7.7 million new cases of dementia every year. Our current health systems simply cannot cope with the explosion of the dementia crisis as we all live longer. The report shows that a lot can be done to improve the lives of people with dementia and their carers. The entire dementia community, and indeed the world, owes a huge debt of gratitude to the WHO to have taken the leadership in the creation of the report. The WHO is the singular organization globally capable of such a critical role in matters of public health.”

www.alz.co.uk/WHO-dementia-report

30 April: Two new books on dementia written by Prof Julian Hughes

Two new books on dementia are available, both written by Professor Julian Hughes, Consultant in old age psychiatry and Honorary Professor of Philosophy of Ageing, Northumbria Healthcare NHS Foundation Trust and Institute for Ageing and Health, Newcastle University.

"Thinking Through Dementia" (ISBN 978-0-19-957066-9) offers a critique of the main models used to understand dementia-the biomedical, neuropsychological, and social constructionist. It discusses both clinical issues and cases, together with philosophical work that might help us better understand and treat this illness. Drawing on philosophical critique of models of dementia, as well as empirical data and clinical experience, the book unifies the biological, psychological, and social accounts of illness and disease. A sample chapter is available at http://fds.oup.com/www.oup.com/pdf/13/9780199570669.pdf

"Alzheimer’s and other Dementias: The Facts" (978-0-19-959655-3) provides an overview of all the different types of dementia (including younger-onset dementias), from the most-recognized - Alzheimer’s - to the less-frequent types, such as those caused by inherited metabolic disorders or HIV. The book guides the reader step-by-step through how the brain works, and explains in clear and simple language the effect of dementias on the brain, and the impact on an individual’s cognitive function.

The author can be reached at julian.hughes@ncl.ac.uk

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AE Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tr>
<td>10-11 May</td>
<td>PharmaCog interim review (Brussels, Belgium)</td>
<td>Alex</td>
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<tr>
<td>16 May</td>
<td>Meeting with IE Perfect Eagle to talk about the organisation of the our annual conference</td>
<td>Gedalyss</td>
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<td>22 May</td>
<td>Symposium AMPA Ethique et Recherche Toulouse organised by the Association Monégasque pour la Recherche sur la Maladie d’Alzheimer (Toulouse, France)</td>
<td>Dianne</td>
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<tr>
<td>24 May</td>
<td>Presentation at the Symposium AMPA Ethique et Recherche Toulouse (Toulouse, France)</td>
<td>Dianne</td>
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<tr>
<td>6 June</td>
<td>Annual IMPACT Consortium Meeting (Trondheim, Norway)</td>
<td>Dianne</td>
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<tr>
<td>19-20 June</td>
<td>Symposium &quot;Biobanks and biomedical collections – an ethical framework for future research&quot; organised by the Council of Europe (Strasbourg, France)</td>
<td>Dianne</td>
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<tr>
<td>25-27 June</td>
<td>Alzheimer Europe Board, Company Round Table, European Parliament lunch debate on &quot;Alzheimer’s disease in the new European public health and research programmes&quot; and AE Members’ meeting (Brussels, Belgium)</td>
<td>Board &amp; Staff</td>
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Future Conferences

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>16-19 May 2012</td>
<td>7th World Congress for Neuro-rehabilitation 2012 (WCNR 2012), <a href="http://www.dcconferences.net.au/wcnr2012">www.dcconferences.net.au/wcnr2012</a></td>
<td>Melbourne, Australia</td>
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### Upcoming Conferences 2012

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>28 May-1 June 2012</td>
<td>IFA 11th Global Conference on ageing, <a href="http://www.braidproject.eu">www.braidproject.eu</a></td>
<td>Prague, Czech Republic</td>
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<tr>
<td>11 June 2012</td>
<td>Creative Dementia Arts Conference, <a href="http://www.creavance-gnse.co.uk">www.creavance-gnse.co.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>12-13 July 2012</td>
<td>International Academy on Nutrition and Aging (IANA), <a href="http://www.iagg.info">www.iagg.info</a></td>
<td>Albuquerque, New Mexico</td>
</tr>
<tr>
<td>8-11 September 2012</td>
<td>16th Congress of the European Federation of Neurological Societies (EFNS), <a href="http://efns2012@kemes.com">efns2012@kemes.com</a></td>
<td>Stockholm, Sweden</td>
</tr>
<tr>
<td>4-6 October 2012</td>
<td>22nd Alzheimer Europe Conference “Changing perceptions, practice and policy”, <a href="http://www.alzheimer-europe.org/EN/Conferences">www.alzheimer-europe.org/EN/Conferences</a></td>
<td>Vienna, Austria</td>
</tr>
<tr>
<td>29-31 October 2012</td>
<td>5th Clinical Trial Conference on Alzheimer Disease (CTAD), <a href="http://www.ctad.fr">www.ctad.fr</a></td>
<td>Monte Carlo, Monaco</td>
</tr>
<tr>
<td>8-11 November 2012</td>
<td>International Conference on Clinical Practice in Alzheimer Disease (CPAD), <a href="http://www.paragon-conventions.com">www.paragon-conventions.com</a></td>
<td>Budapest, Hungary</td>
</tr>
<tr>
<td>5-7 December 2012</td>
<td>Nursing Ethics: intensive course on foundational approaches, contemporary and educational issues in the field of nursing ethics, <a href="http://www.masterbioethics.org">http://www.masterbioethics.org</a></td>
<td>Leuven, Belgium</td>
</tr>
<tr>
<td>6-10 March 2013</td>
<td>11th International Conference on Alzheimer’s and Parkinson’s Diseases, <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a></td>
<td>Florence, Italy</td>
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<tr>
<td>21-23 March 2013</td>
<td>57. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Leipzig, Germany</td>
</tr>
<tr>
<td>20-23 March 2014</td>
<td>58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Berlin, Germany</td>
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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.