



NEWSLETTER

April 2013

Highlights in this issue

4 April: Formation of the Mediterranean Alzheimer Alliance	9
4 April: Dutch government commits funds to dementia plan	7
8 April: European Alzheimer's Alliance welcomes new member	3
12 April: EWGPWD holds third meeting	4
17 April: DECIDE project holds successful final review	3



Table of contents

Editorial	1
Alzheimer Europe.....	2
AE Projects	3
European Alzheimer's Alliance	3
Alzheimer Europe Networking 2013 ...	4
EU Developments.....	4
Policy Watch.....	7
Members' News	8
Science Watch	10
Dementia in Society	13
New Publications & Resources.....	14
Education Opportunities	15
AE Calendar 2013	16
Future Conferences.....	16

Editorial

In April, we went to the ADI Conference in Taipei and an EMA Scientific Advice meeting. We also attended the GSK Advisory



Board meeting and hosted visitors from Lilly and Piramal in Luxembourg. In Brussels, we went to an EFPIA meeting and joined the EU conferences on frailty and the European Month of the Brain.

The European Working Group of People with Dementia also met in Brussels, in preparation for our Annual Conference in October. We were very pleased to receive over 160 abstract proposals for the Conference! These are now in the hands of the Scientific Committee, which will announce its selections by the end of May.

The DECIDE project held a successful final review and our other projects are proceeding smoothly. In addition, we are in talks to participate in three new potential EU projects beginning in 2014.

The European Alzheimer's Alliance was pleased to welcome Romanian MEP Tanasescu to its ranks. We would also like to thank former MEP Mario Mauro, who left the EAA after winning an election to the Italian Senate.

In policy news, the Dutch government has agreed to participate in a new dementia plan and the Welsh government pledged its support to develop dementia-friendly communities. Meanwhile, Croatia has elected its first MEPs and the new EU Commissioner for Consumer Protection also hails from the new EU Member State.

Amongst our members, the top story is the creation of the Mediterranean Alzheimer Alliance. This initiative, conceived by Monaco's AMPA, aims to increase awareness of dementia and assist in making a national priority in all countries on the Mediterranean Sea. Our members from France, Greece, Malta and Portugal are all involved.

Alzheimer Portugal is also part of a new partnership at home, with a similar goal of improving the lives of people with dementia. Our Norwegian colleagues have launched a new awareness campaign along with their government. The German association published a new guide on nursing care and the UK Alzheimer's Society released a report that explores the quality of life of people with dementia. Finally, Alzheimer Uniti Italy held a very popular poetry workshop.

The EMA released two new interesting publications in April: the first is a survey of the origin of people in clinical trials and the locations of these trials. The other is a glossary that contains all the terms used in the regulatory process of approving drugs.

We've also included two calls for awards, one for young neurologists and the other for projects that improve involvement of people with dementia and their carers in the local community.

Finally, this month we have a special section on education opportunities. This contains calls for participants in upcoming courses on Nursing Ethics and Grid & Cloud Computing.

Jean Georges
Executive Director

Alzheimer Europe

12 April: EWGPWD holds third meeting in Brussels

The European Working Group of People with Dementia held its third meeting on 12 April in Brussels. Ten of the eleven members of the group were in attendance, along with their carers and a representative from Alzheimer Europe. Led by Chairperson Helga Rohra, the group covered a busy agenda that included updates on recent activities, the election of a new Vice-Chair and planning for the Malta conference.

The meeting began with an update from the AE board meeting in February 2013. During this discussion, the EWGPWD decided to make several proposals during the next AE board meeting in June. The members also agreed that their Board should prepare a document listing the objectives of the EWGPWD.

The group then held elections for the vacant post of Vice-Chairperson, following the resignation of Jan Frederik Meijer in January 2013. Three candidates agreed to stand and Nina Balackova won the election on the second round. She joins the EWGPWD Board alongside Jean-Pierre Frognet and Agnes Houston, the other two Vice-Chairs of the group.

Alzheimer Europe's 23rd Annual Conference will take place in Malta in October. The EWGPWD will be represented in several ways and these were all discussed during the

meeting. Nina Balackova will be a keynote speaker during the third plenary session: as the youngest member of the group, she intends to raise awareness that young people can have dementia too. Stig Atle Aavik has agreed to be her stand-by if needed. The group also discussed the possibility of having a poster, while AE agreed to produce a leaflet on behalf of the group. This year, the Conference will feature a special session organised by the EWGPWD. The group is still discussing the content of this session, which will be open to all delegates.

The next meeting of the EWGPWD will take place on 9 October 2013 in Malta.

www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia

30 April: Alzheimer Europe closes call for abstract submissions

The call for abstracts for the 23rd Alzheimer Europe Conference is now closed. Alzheimer Europe is very pleased to have received more than 160 abstracts. These are being reviewed by the members of the Scientific Committee and acceptance or rejection will be based on an average mark. All submitting authors will be informed of the Committee's decision by 30 May 2013.

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

Impressions from the EWGPWD meeting



Schtroumpf, the official mascot of the meeting



Helga and Stig



Agnes, Donna and Dermod



Nina with Helga and Jean-Pierre



Ingegård and Rolf



Ranveig and Stig

AE Projects

17 April: DECIDE completes a successful final review



On 17 April, the DECIDE project team held a successful final review in Rome. The project achieved all of its objectives and also demonstrated sustainability beyond the project lifetime.

The review was held at the premises of GARR, the Italian research and educational organisation that also acted as Project Coordinator. The Commission's review team was headed by Ms Athina Zampara and included Ms Juliane Jark, Mr Kamen Beronov and Mr Michal Mozdzonek. After hearing presentations, seeing a demonstration of the service and holding discussion sessions with the project team members, they concluded that the project accomplished what it set out to do.

The reviewers specifically cited the scientific and technological excellence of the project. They also pointed out various areas for improvement; these will be addressed in the final report that will be delivered in the coming weeks.

DECIDE is an operational service that assists in the earlier diagnosis of Alzheimer's disease and other forms of dementia. Fortunately, the service will continue to operate after the end of the project life. This is mainly due to the Italian Ministry of Health, which has already approved funding for several follow-on projects involving DECIDE.

The project partners are also seeking a role for the service in various European FP7 projects. In addition, there has been a formal offer for the DECIDE diagnostic service for daily clinical practice to a group of leading European memory clinics. It is hoped that these efforts will ensure that the service will remain available for at least the next several years.

DECIDE was funded by the European Commission within the 7th Framework Programme.

www.eu-decide.eu



European Alzheimer's Alliance

31 March: Mario Mauro leaves the EAA

Mario Mauro, MEP (Italy) and EAA member, has resigned from the European Parliament. This follows his successful election to the Italian Senate.

Alzheimer Europe would like to thank Mr Mauro for his support and wishes him all the best for the future.

8 April: MEP Claudiu Tanasescu joins the Alliance



The European Alzheimer's Alliance is pleased to welcome a new member: Claudiu Ciprian Tanasescu, MEP (Romania). This brings EAA membership up to 70 MEPs from 23 countries.

Mr Tanasescu belongs to the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament (S&D). He sits on the Committee on the Environment, Public Health and Food Safety and is a member of the Delegation for relations with Canada. He joined the Alliance on 8 April.

16 April: EPP Group elects MEP Mairead McGuinness as new Vice-Chairwoman



On 16 April, the EPP Group in the European Parliament completed its Presidency team by electing Irish MEP Mairead McGuinness as Vice-Chairwoman at its Group meeting. The seat became vacant when former MEP Ioannis Kasoulides was nominated as Minister of Foreign

Affairs in Cyprus.

Ms McGuinness sits on the Committee on Agriculture and Rural Development and is a substitute on the Committee on the Environment, Public Health and Food Safety. She has been a member of the European Alzheimer's Alliance since September 2009.

14 April: Commission replies to MEP Werthmann's question about research in Alzheimer's disease

On 14 April, the European Commission (DG Research) responded to Angelika Werthmann, MEP (Austria) and member of the European Alzheimer's Alliance, about how the EU supports research on Alzheimer's disease and other forms of dementia.

The Commission said that FP7, the 7th Framework Programme for Research and Technological Development, has allocated EUR 200 million to research on Alzheimer's disease. The next Framework Programme for Research, Horizon 2020, will very likely provide further opportunities to support research on Alzheimer's.

Regarding national programmes, the Joint Programming Initiative on Neurodegenerative Diseases (JPND) carried out in 2011 a mapping exercise of the main national research programmes and funding support in Europe in this area.

In its response, the Commission added that encourages the alignment and coordination of institutional and

competitive funding that has been committed under national research programmes. This funding accounts for 88% of the public research investments in Europe.

In terms of international cooperation, Canada joined the JPND in 2012 and the JPND organised a meeting on 9 November 2012 to exchange views with the United States. The Commission provides support to the JPND and, under the Health programme, to the Joint Action Alzheimer cooperative Valuation in Europe (ALCOVE). The Commission is also organising a European Month of the Brain in May 2013. This will provide a framework to raise awareness on brain research and health care issues.

Finally, the Commission response mentions the European Innovation Partnership on Active and Healthy Ageing. This

should enable EU citizens to lead healthy, active and independent lives while ageing and to improve sustainability and efficiency of social and health care systems.



Alzheimer Europe Networking 2013

On 3 April (London, UK) Jean attended the EMA Scientific Advice Meeting and had a meeting with Maria Carrillo from US Alzheimer's Association.

On 4 April (Luxembourg, Luxembourg) Jean met with Piramal.

On 9 April (Brussels, Belgium) Annette had an EFPIA dinner with Think Tank representatives to discuss pharmaceutical industry transparency.

On 12 April (Brussels, Belgium) Dianne attended the EWGPWD meeting.

On 16-20 April (Taipei, Taiwan) Jean attended the Alzheimer Disease International Conference.

On 17 April (Rome, Italy) Alex attended the DECIDE final project review.

On 18 April (Brussels, Belgium) Annette attended the European Commission conference 'Frailty in old age: a public health concern at EU level'.

On 23 April (Brussels, Belgium) Annette attended the STOA 'European Month of the Brain' meeting on 'What does it mean to have a brain disease?'

On 25 April 2013 (Luxembourg, Luxembourg) Jean met with Lilly.

On 26 April (London, UK) Jean attended the GSK Health Advisory Board (London, United Kingdom).

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at 70, representing 23 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:** Demesmaeker Mark (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabella Marc (S&D). **Bulgaria:** Parvanova Antonia (ALDE). **Cyprus:** Triantaphyllides Kyriacos (GUE-NGL). **Czech Republic:** Cabrnoc Milan (ECR), Kohlíček Jaromír (GUE/NGL), Roithova Zuzana (EPP). **Denmark:** Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D). **Finland:** Jaakonsaari Liisa (S&D), 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:** Panzeri Pier Antonio (S&D), Toia Patrizia (S&D). **Lithuania:** Vilija Blinkeviciute (S&D). **Luxembourg:** Engel Frank (EPP), Lulling Astrid (EPP). **Malta:** Simon Busuttil (EPP), Joseph Cuschieri (S&D). **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), Tanasescu Claudiu Ciprian (S&D). **Slovakia:** Mikolasik Miroslav (EPP), Zavorska Anna (EPP). **Slovenia:** Peterle Alojz (EPP). **Spain:** Badiá i Cutchet Maria (S&D), Estaràs Ferragut Rosa (EPP). **United Kingdom:** Anderson Martina (GUE-NGL), Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), McCarthy Arlene (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

10 April: Parliament and Council agree on text for MRI derogation

On 10 April, the European Parliament and the Council reached an agreement on a final text of the draft directive on electromagnetic fields, including the MRI derogation.

The plenary vote in the Parliament should take place in June 2013. The Council will formally adopt the draft directive before the summer break and the implementation date has been set for July 2016.

From July onwards, the European Commission will start working on a practical guide regarding the Annexes of the Directive. This guide will also contain working procedures as well as specific information and training measures for MRI workers exposed to electromagnetic fields and will be implemented through a delegated act.

<http://eu2013.ie/news/news-items/20130328emfpr/>

14 April: Croatia elects Members of the European Parliament

On 14 April, Croatia held its first elections for the European Parliament, with twelve MEPs elected.

The coalition list consisting of 3 (of 4) ruling parties will have 5 MEPs within S&D, the Progressive Alliance of Socialists and Democrats in Europe. They are Marino Baldini, Biljana Borzan, Sandra Petrović Jakovina, Tonino Picula and Oleg Valjalo.

The opposition coalition list will have 6 MEPs from EPP, the European People's Party: Zdravka Bušić, Ivana Maletić, Andrej Plenković, Ruža Tomašić, Davor Ivo Stier and Dubravka Šuica.

The Croatian Labour Party will be represented by Nikola Vuljanić, as soon as his political affiliation is confirmed.

The elected MEPs will be in office until next year's European elections, at which time their number will be reduced from 12 to 11. Turnout for this election was just 20.75% – the lowest ever in any election in the country and one of the lowest in any member state for elections to the European Parliament.



Croatia applied for EU membership in 2003 and negotiations ended in 2011. The country of 4.3 million people will become the 28th EU Member State on 1 July. Currently, the European Parliament has 12 Observers appointed by the Croatian parliament, reflecting the political composition in the national assembly.

<http://libraryeuroparl.wordpress.com/2013/04/20/croatias-european-elections-14-april-2013/>

17 April: Commission presents report on chronic diseases and economic activity among older working people

On 17 April, the European Commission presented a report of the Dutch National Institute for Public Health and the Environment (RIVM) entitled "Europeans of retirement age: chronic diseases and economic activity".

RIVM prepared this report in 2012 in response to a call by the European Commission's Directorate-General for Health and Consumers. It is a review of the impact of chronic diseases on the population of pre- and post-retirement age in the EU.

The report primarily focuses on five chronic diseases (cardiovascular diseases, cancers, diabetes, chronic lung diseases and depression) but also includes some neurodegenerative diseases (such as dementia) because of their importance among older age groups.

The findings are:

- The burden of chronic diseases for Europeans of retirement age is substantial and increases with age in both men and women.
- The burden of chronic diseases will increase due to the ageing of the population and lifestyle risks.
- Only five EU countries can expect their citizens to reach retirement age without activity limitations: Bulgaria, Ireland, Greece, Malta and Sweden.
- Each year, approximately three million productive life years are lost due to premature mortality from chronic diseases among older Europeans of working age.

- There are large differences in the burden of chronic diseases among EU Member States and also among social economic groups or regions within the States.
- Chronic disease prevalence and mortality vary considerably among EU Member States. The differences in mortality are the main cause of the differences in life expectancy at birth among Member States.

The authors of the report recommend the following actions for the EU and Member States:

- The EU and Member States should stimulate the use of effective interventions for the prevention and treatment of chronic diseases.
- The EU and Member States should use an integrated and intersectoral approach to combat the growing and unequally distributed burden of chronic diseases. Health should be an issue in all policies.
- Member States should learn from each other's experiences by an exchange of best practices.
- The EU and Member States should invest further in sustainable and harmonised data collection in the area of chronic diseases.
- The EU will take responsibility for improving current data in Europe by stimulating joint data collection and facilitating the central coordination of data harmonisation and quality control and the exchange of best practices in data collection.

Another chapter deals with the relationship between chronic diseases and economic activity. A relevant health outcome measure, especially in view of dementia and Alzheimer's disease, is cognitive functioning. The authors report some studies that found no significant effect of retirement on problems with cognitive functions.

http://ec.europa.eu/health/major_chronic_diseases/docs/rivm_report_retirement_en.pdf

18 April: Commission holds conference on frailty

On 18 April, the European Commission organised a high-level conference entitled "Frailty in old age: a public health concern at EU level". This was part of the European Innovation Partnership on Active & Healthy Ageing, where prevention of functional decline and frailty has been identified as a concrete action.

The objectives of the conference were to initiate a policy debate on frailty guidelines, showcase the commitments being implemented in the frailty action group and discuss the latest evidence that can feed into the work of the Partnership.

Tonio Borg, Commissioner for Health and Consumer Policy, opened the conference by reminding the audience that innovation is the key to Europe's future success and must be at the very core of all efforts. He acknowledged that many people currently experience significant functional decline in old age. To mitigate this decline, we need to identify and implement targeted interventions to postpone the onset of disability where possible and ensure that people can lead meaningful and contented lives.

Mr Borg also mentioned that the Commission is collaborating with the WHO and the OECD to develop a

global agenda to address functional and cognitive decline and dependence. He said that we must now highlight the main challenges posed by frailty and define common approaches that could be adopted by different actors across Europe.

The Commissioner praised the work of the Partnership and highlighted the emergence of common drivers such as screening, anticipatory care and prevention of functional decline in older people. Another driver is the increased use of innovative, co-ordinated and comprehensive community based prevention, delivered within an integrated health and care system. This will dramatically improve the quality of life of old people and reduce both the number and the length of hospital stays.

Kathleen Lynch, Irish Minister for Disability, Equality, Mental Health and Older People, also stressed that we should see the opportunities of old age and that we were working for our future. As an example, she cited Ireland's "Mental Capacity Bill". This Bill protects the rights of people with disabilities to make decisions about their lives. It is important that their preferences be taken into account: people know what is good for them and they do not want others to tell them what to do or how to do it.

The policy implications of preventing frailty, understanding and tackling frailty and key ideas for EU action were discussed during the plenary sessions. Four workshops addressed: 1) risk conditions, early diagnosis and prevention, 2) malnutrition and frailty, 3) functional and cognitive decline and 4) the impact of frailty on health and social services.

http://ec.europa.eu/commission_2010-2014/borg/docs/speech_18042013_en.pdf
http://ec.europa.eu/dgs/health_consumer/dyna/enews/enews.cfm?al_id=1365

23 April: Parliament's STOA conference addresses brain diseases

On 23 April, the STOA Unit (Science and Technology Assessment Options) of the European Parliament organised a conference entitled "What does it mean to have a brain disease?" The conference was held within the context of the European Month of the Brain and was chaired by Antonio Correia de Campos, MEP (Portugal) and Chairman of the STOA Bureau.

Mr Correia de Campos started the event by setting the scene: by 2025, one in five Europeans will be 65 or older. The increase in life expectancy and the consequent ageing of the population will lead to an increase in the number of people having neurodegenerative or brain diseases like Alzheimer's disease and Parkinson's disease. Less than one in two Europeans currently receives some form of medical attention.

Brain diseases cost Europe EUR 800 billion in 2010 - more than the total cost of cardiovascular disease and diabetes - and this will increase drastically in the coming years. Out of this EUR 800 billion, 37% accounted for direct health care costs, 23% for direct non-medical costs and 40% for indirect costs. Indirect costs include disability support and lost earnings for people with brain disorders.

Elena Becker-Barroso, Editor of The Lancet Neurology journal, advised to move from the alarmist conceptions that neurodegenerative diseases are a threat to the

health systems toward a more positive attitude fostering technological developments and innovation. She called for a better research network and multidisciplinary systems for long-term care.

Colin Blakemore, School of Advanced Study, University of London and University of Oxford, gave a very comprehensive speech about neuroscience. He praised the EU for having a great tradition in neuroscience and wished this would continue. He told the audience that most neurons could not be replaced and that it was essential for an individual to retain as many cells as possible during lifetime. However, there are some limited areas of the brain where nerve cells can be replaced. Some research in mouse models has shown that neurons in the hippocampus can be created based on exercise. Mr Blakemore cited this as evidence for the importance of physical exercise.

Monica di Luca, from the Federation of Neuroscience Societies and the European Brain Council, talked about the economic and social revolution triggered by the ageing of the population. She mentioned the dependency ratio that will reach 20% of the population over 65 by 2020 and that two-thirds of the people who reach 65 live alone. This has an impact on the structure of society and how care is provided: there are fewer people to cope for an increasing number of people. She added that delaying the onset and progression of the disease by five years would significantly reduce its cost.

Audrey Craven, representing the European Federation of Neurological Associations (EFNA), called for a "coalition of the willing" at EU level to help reduce the impact of neurodegenerative diseases. She thus launched EFNA's pledge asking all stakeholders to put neurology patients first and support essential investment in neuroscience research.

All presenters agreed that brain research was important, as there is currently no treatment or cure for brain diseases. They called for more support for research to understand brain functions and diseases, develop new treatment and preventive strategies, improve health and social care and alleviate the economic and social burden of brain diseases.

They also called for the creation of a strong European platform for both basic and clinical brain research. In addition, healthcare strategies should be coordinated between member states in order to create an all-encompassing European system.

www.europarl.europa.eu/news/en/headlines/content/20130426STO07641/html/Month-of-the-Brain-experts-warn-MEPs-over-expected-rise-in-brain-diseases

25 April: Croatia names EU Commissioner for Consumer Protection

On 25 April, Croatia named Neven Mimica as Commissioner-designate. President Barroso has met Mr Mimica and has confirmed his agreement for this candidacy. Mr Barroso also indicated his intention to assign Mr Mimica the portfolio of consumer protection.

The Council will appoint the new Commissioner after consultation with the European Parliament. Mr Mimica is due to take his post on 1 July 2013, when Croatia becomes the 28th EU Member State. He is currently

Croatia's Deputy Prime Minister for Foreign Affairs and European Integration, with a long-standing commitment to European integration and extensive experience as a Minister and diplomatic adviser.

30 April: European Commission presents the "European Month of the Brain"

On 30 April, the European Commission presented a Question & Answer memo to explain the "European Month of the Brain".

This initiative is not just about health: brain research also involves genetics, cell biology, physiology, imaging, bioinformatics, anatomy, ICT, nanotechnology and nutrition. In addition, a wide range of services and products could stem from unlocking the secrets of how the brain works.

The EU's FP7 research programme has already invested EUR 1.9 billion in brain research and innovation. More than EUR 750 million has funded research for brain functions and processes and more than EUR 400 million for neurodegenerative disorders - including EUR 202 million for Alzheimer's disease. Research for neurological disorders has been funded with EUR 400 million and public health with EUR 75 million.

EU-supported brain research comes in various formats, including international collaborative projects, frontier research through the European Research Council (ERC), public-private partnerships (Innovative Medicines Initiative), networks (European Stroke Network), global co-operations (International Initiative for Traumatic Brain Injury Research), training and mobility schemes for young researchers and the large-scale "Human Brain Project".

The EU also supports national research efforts through the State-led Joint Programming Initiative on Neurodegenerative Diseases (JPND), the recently completed EU Joint Action ALCOVE (Alzheimer Cooperative Valuation in Europe) and the European Innovation Partnership on Active and Healthy Ageing.

On a wider scale, the EU is co-operating with the US National Institute of Neurological Disorders and Stroke and the Canadian Institute of Health Research. Canada also participates in the JPND and the US recently announced the "Brain through Advancing Innovative Neurotechnologies" (BRAIN) project.

Finally, the memo presents how the next EU research programme (Horizon 2020) for the period 2014-2020 will cover brain disease.

http://europa.eu/rapid/press-release_MEMO-13-390_en.htm?locale=en

30 April: EMA receives interim court decisions on access to clinical and non-clinical information



Following interim rulings by the General Court of the European Union, the EMA has been ordered not to provide documents as part of two access-to-documents requests until a final ruling is given by the court.

These rulings were made as part of court cases brought by pharmaceutical companies AbbVie and InterMune. The companies are challenging the Agency's decisions to grant access to non-clinical and clinical information (including clinical study reports) submitted by companies as part of marketing-authorisation applications in accordance with its 2010 access-to-documents policy. According to an EMA press release, this is the first time that the policy has been legally challenged. The agency is considering whether to appeal the interim decisions.

The press release is available on the EMA website.

www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2013/04/news_detail_001779.jsp&mid=WC0b01ac058004d5c1

Policy Watch

4 April: Dutch government commits funds to a new dementia plan

On 4 April, the Dutch Ministry of Health, Welfare and Sport announced that it will allocate EUR 32.5 million to the fight against dementia over the next four years. This money is intended for the "Deltaplan Dementia". This plan - analogous to the Dutch water works - is intended to limit the consequences of the foreseen explosive rise in people with dementia.

The contribution of the government will be used to initiate a research program that concentrates on (1) rapidly improving the efficiency of healthcare, so today's patients can benefit of the results and (2) fundamental research into the origins of the dementia to improve diagnostics and find ways to prevent or cure dementia. The second objective will receive two thirds of the research budget and aims to improve the situation of tomorrow's patients.

The Deltaplan Dementia is a public-private partnership; a number of private partners have shown interest to support the financing of research projects and also the other two pillars of the plan. One of these is a registry that will monitor diagnosis and received care of Dutch patients, thereby contributing to a high national standard of care. The other pillar is an online portal that will help patients, cares and professionals to receive or provide the best possible care.

Alzheimer Nederland, one of the Deltaplan initiators, is delighted with the contribution of the government. Maria van der Hoeven, Chairman of the Supervisory Board of Alzheimer Nederland, said: "The financial contribution of the Ministry of Health, Welfare and Sport in a time of budget cuts is a strong signal that dementia is recognised as a major social issue. Moreover, the financial support of dementia research is testament to the proactive and long-term vision of the ministry. This problem requires a joint effort of government, private sector and the public to find solutions. The impact of the explosive growth of dementia cases in the future would otherwise be unmanageable and unaffordable for Dutch society. A dam is needed to turn the tide - while we still can."

Alzheimer Nederland will support the Deltaplan Dementia with EUR 12.5 million over the next four years. Director Gea Broekema-Prochazka said: "With the contributions of the Ministry of Health, Welfare and Sport and Alzheimer

Nederland, the first 50% of the research money for the first four years of the Deltaplan is already secured. This is an important first step to fulfil our ambition. It is important that more private partners and private donors give their support to the Deltaplan Dementia".

23 April: Wales declares support for dementia-friendly communities



First Minister Carwyn Jones recently unveiled a programme which he hopes will help to create dementia supportive communities in Wales.

The aim of the programme - which is supported by the Alzheimer's Society - is to make people in Wales more aware of dementia and how it affects the day to day lives of people living with the syndrome. There are some 44,500 Welsh people with dementia and that number is predicted to rise to 56,000 by 2021.

The Alzheimer's Society, the Welsh Government and the Older People's Commissioner will work together on a number of initiatives to build awareness of dementia and build dementia supportive communities.

Sue Phelps, director of Alzheimer's Society in Wales, said: "We seek nothing less than the creation of a social movement to change quality of life for people with dementia and their families. A dementia supportive community requires a change in attitudes and behaviours towards dementia. We want people in the local community to have a better understanding of dementia, and the problems people face."

Gwenda Thomas, Deputy Minister for Social Services, said that building dementia friendly communities is about much more than investing in health and social care services. She added: "While this is essential and something the Welsh government will continue to work to deliver, all of us - individuals, businesses, statutory services, the voluntary sector, and government at all levels - have a role to play."

29 April: Finland publishes English text of its National Memory Programme



The Finnish Ministry of Social Affairs and Health has published an English language version of the text of Finland's National Memory Programme 2012-2020.

The programme launched in May 2012 and aims to create a "memory-friendly Finland" through four main areas of activity:

- 1) The promotion of lifelong brain health and the prevention of memory-related diseases. Brain health will be promoted both on a personal level and on a very broad level across society, including social and health services and education.
- 2) The ageing of the population is causing a marked increase of memory-related diseases in Finland. The plan will promote positive attitudes towards people with dementia in

order to guarantee their basic human rights, including the right to self-determination.

- 3) Good care and rehabilitation is essential. It is important that memory-related diseases be recognised, diagnosed and treated as early as possible. There will be a particular focus on the entire care chain and its quality.
- 4) Support for high quality research and competence of professionals are important. Research efforts must be adequately resourced, in order to support the areas above and to ensure further development. This includes developing the knowledge and competencies of health care professionals.

The new English translation is available on the websites of the Ministry and Alzheimer Europe.

www.stm.fi/julkaisut/raportteja-ja-tyoryhmuistioita/nayta/_julkaisu/1800855#en
www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/Finland#fragment-1

Members' News

3 April: Norway launches dementia awareness campaign



On 3 April, Norway's Department of Health launched a new public awareness campaign about dementia called "Talk about it" during an event

hosted by the Norwegian Alzheimer's Association. The campaign aims to increase openness about dementia and to encourage people who suspect they may have dementia to seek advice from their GP.

Openness about the early symptoms of dementia increases the opportunity of an early diagnosis. In turn, diagnosis allows the person with dementia to plan for the future, talk with their family and live as well as possible with dementia. Recent research has shown that nearly three quarters (74%) of Norwegians say it would be difficult to talk about dementia with someone they suspect might have it.

The Norwegian Minister of Health and Care and Alzheimer Norway's Director of Health both spoke at the event. They underlined the importance of keeping the focus on the person - not the diagnosis - and emphasised the vital roles of relatives and volunteers in supporting and caring for people with dementia in Norway.

The Norwegian association often receives complaints from people with dementia and their relatives who experience a long wait when inquiring about dementia diagnoses from their GP. Lisbet Rugtvedt, General Secretary, pointed out in the national media that GPs must pay more attention to concerns from relatives about memory loss and changes in behaviour, and also start their inquiries at an earlier time.



4 April: New Mediterranean Alzheimer Alliance issues declaration of collaboration



On 4 April, nine organisations from countries adjoining the Mediterranean Sea joined together to form the Mediterranean Alzheimer Alliance (MAA). These countries (France, Greece, Lebanon, Malta, Monaco, Morocco, Portugal, Spain and Tunisia) are united by historical, geographical and cultural links, but more importantly by common values of solidarity. The partners, including eight national Alzheimer associations, established the MAA as an alliance in the struggle against Alzheimer's disease.

This initiative was conceived by Monaco's AMPA Alzheimer Association and stems from the fact that Alzheimer's disease is much more than a health issue; it also has a huge impact on social, cultural and economic sectors of each society. The only solution is an integrated package of diagnosis along with sufficient support for people with dementia, their caregivers and families.

During the conference, which was attended by over 70 people, the signatories issued the Marrakech Declaration. This calls for associative, scientific and professional organisations across the Mediterranean involved in dementia to collaborate towards the following aims:

- Create a Mediterranean Alzheimer expert network and incite exchanges between organisations involved in dementia.
- Improve and increase knowledge by identifying the needs and emerging issues of Alzheimer's disease in the Mediterranean region.
- Promote and diffuse the best local experiences, good practice and innovative initiatives in the Mediterranean.
- Issue recommendations and enforce plans on a local and international level to ensure that dementia becomes a priority in the Mediterranean area.
- Extend this network with experts or research teams specialised in issues concerning the Mediterranean.
- Encourage associative and scientific collaboration and partnerships in the Mediterranean.
- Develop and support training for professionals in Mediterranean countries.

This first conference was seen as a great success by delegates; for some, it was an important first step toward making dementia a priority in their respective countries. Dr. Charles Scerri, Secretary of the Malta Dementia Society, said: "MAA is still in its early stages, but has a huge potential for moving forward. The next step is meeting in Malta in October to continue discussing the way forward and getting more Mediterranean countries involved and signing the Declaration."

For more information about the Mediterranean Alzheimer Alliance, please contact Federico Palermi, AMPA Monaco: fpalermi@ampa-monaco.com



16 April: German Alzheimer Society releases new guide to nursing care



The German Alzheimer Society has released the 14th edition of its "Guide to Nursing Care". The guide provides detailed information on long-term care benefits, such as how to apply for the benefits and the conditions of the authorisation. It specifically addresses the provisions of the new care restructuring law that was enacted in January 2013.

The German-language guide is available for sale at EUR 6 on the Society's website.

<http://shop.deutsche-alzheimer.de/broschueren/>

19 April: Alzheimer Uniti Italy organises poetry workshop for people with dementia



On 19 April, Alzheimer Uniti Italy held a poetry workshop called "Caproni and me" at the Alzheimer Day Center of Fondazione Roma. This featured poetry readings and then a poem writing session, all under the close guidance of a contemporary poet.

She first read a poem by the famous Giorgio Caproni, who lived in the same borough of Rome as the Day Center. Next she read one of her own poems, which had been inspired by that same Caproni poem. Then the two poems were "dismantled" and "reassembled" by the participants in the group who were encouraged to speak freely about emotions, memories and thoughts that came to mind. The resulting words were written down and then rearranged into new verses by the group.

Reading and writing poetry has a positive effect on persons with dementia, bringing out creativity, language and autobiographical memory and encouraging verbalisation.

The verses written at the Alzheimer Day Center will be read in a theatre in the near future, along with the poetry of other writers.

The verses written at the Alzheimer Day Center will be read in a theatre in the near future, along with the poetry of other writers.

22 April: Alzheimer Portugal supports community actions for dementia



Alzheimer Portugal, along with various partners, is developing a new project called "CuidarMelhor" - Taking Better Care. The main goals of the project are:

1. to determine the prevalence of dementia in the Cascais, Sintra and Oeiras municipalities
2. to open CuidarMelhor centres that will support people with dementia and their carers in these municipalities

3. to raise public awareness of the various issues related to dementia
4. to train dementia carers
5. to adapt and develop the Memory Café concept in Portugal.

The first CuidarMelhor centre opened to the public on 22 April in Cascais and another is due to open in several weeks. The centres employ multidisciplinary, person-tailored approaches that aim to inform and provide social, psychological and legal support to people with dementia and their carers.

The staff is highly specialised and can offer advice on the causes and signs of dementia, as well as diagnosis and intervention. In addition, a group of lawyers working on a voluntary basis provides legal support.

During April, Alzheimer Portugal also organised two Memory Cafés - the first to take place in the country. Both events were very well attended by people with dementia together with their carers. The Memory Cafés aim to provide emotional support and information to people with memory problems or dementia and to promote the sharing of experiences. They are also useful tools to raise awareness of the issues surrounding dementia and to encourage people in the local community to become actively involved. The Memory Cafés are scheduled to take place twice a month.



The other partners in CuidarMelhor are the Gulbenkian Foundation, the MontepioFondation, the Institute of Social Sciences of the Portuguese Catholic University, private company Sonae Sierra and the municipalities of Cascais, Sintra and Oeiras.



Science Watch

1 April: Cardiovascular and stroke risk tools are also effective for dementia

A new cohort study shows that the standard risk prediction tools for heart disease and stroke may be better at predicting declining mental powers than a specific dementia risk score.

French scientists found that higher risks on the widely used Framingham cardiovascular disease and stroke scores were strongly associated with declines on four out of five cognitive tests.

They also found that higher risk on the recently proposed Cardiovascular Risk Factors, Aging and Dementia (CAIDE)

score was less strongly associated with declines and only on three of the five tests.

The research team was led by Dr. Sara Kaffashian, a doctoral fellow at the French National Institute of Health and Medical Research. The study involved 7,830 participants in the Whitehall II study, who had an average age of 55 when they entered the longitudinal British cohort.

The researchers compared the performance of the CAIDE test with the Framingham cardiovascular tool in 4,374 participants who were free of cardiovascular disease. They also compared the CAIDE test with the stroke tool in 5,157 people free of strokes and transient ischemic attacks.

Participants were tested three times in four cognitive domains over ten years. On both the Framingham tools, higher scores at baseline were associated with greater decline on all tests except memory, they found. On the other hand, a higher CAIDE risk was associated with greater decline in reasoning, vocabulary, and global cognition.

Dr. Kaffashian said: "Cardiovascular risk scores may have an advantage over the dementia risk score for use in prevention and for targeting changeable risk factors since they are already used by many physicians."

Dr. Michael Rafii, Adjunct Professor of Neurosciences at the University of California (San Diego), commented that the varied outcomes might reflect differences in the type of dementia being measured. He was not involved in the study, but said: "The measures that are being looked at with the stroke measures are more reliable in predicting vascular dementia than Alzheimer's disease" and added that the "dementia tool seems to be less correlated with vascular dementia down the road".

www.neurology.org/content/80/14/1300.abstract



www.alzheimer-europe.org/Donation

2 April: Hormonal hunger signalling may help reduce AD plaque

A new study shows that hormonal hunger signalling may represent a new way to fight Alzheimer's disease. A research team from the University of Alabama in Birmingham (UAB) demonstrated improved memory and reduced amyloid plaque buildup in mouse models that were kept in a hungry state.

The researchers, led by Dr. Inga Kadish, Assistant Professor at UAB's School of Medicine, argue that hormonal signals are the middlemen between an empty gut and the perception of hunger in the brain. Manipulation of these signals may effectively counter age-related cognitive decline in the same way as caloric restriction.

Caloric restriction is a regimen where an individual consumes fewer calories than average. Studies in various species have suggested that this could protect against neurodegenerative disorders and extend lifespans.

However, the effect has never been confirmed in human clinical trials. The research team theorises that feeling hungry creates mild stress. In turn, this stress activates metabolic signalling pathways that inhibit plaque buildup in Alzheimer's disease.

This study examined the long-term effects of a synthetic form of the ghrelin hormone in three types of Alzheimer mouse models. More specifically, it looked at whether or not the feeling of hunger could counter Alzheimer's pathology in the absence of caloric restriction.

The ghrelin hormone is known to create hunger signals by interacting with the arcuate nucleus in the brain's hypothalamus, which sends out signals that help the body sense and respond to energy needs.

Study mice were divided into three groups: one that received synthetic ghrelin, a second that underwent caloric restriction and a control group. Study measures looked at each group's ability to remember, their degree of Alzheimer's pathology and their level of related, potentially harmful immune cell activation.

Results showed a 67% reduction of AD pathology in caloric-restricted mice as compared to control mice and a 48% reduction of plaque deposits when comparing the ghrelin-treated mice with the control group. They also showed that the treated mice had reduced levels of microglial activation compared to the control group.

Dr. Kadish said: "This is the first paper, as far as we are aware, to show that the sensation of hunger can reduce Alzheimer's disease pathology in a mouse model of the disease. If the mechanisms are confirmed, hormonal hunger signaling may represent a new way to combat Alzheimer's disease, either by itself or combined with caloric restriction."

www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0060437

4 April: APOE gene is linked to elevated tau levels

Researchers at Washington University School of Medicine in St. Louis have identified a new set of genetic markers for Alzheimer's disease. These are based on the tau protein and seemingly point to a second pathway through which the disease develops.

The team - headed by Dr. Alison Goate, Professor of Neurology and Genetics and Dr. Carlos Cruchaga, Assistant Professor of Psychiatry - performed a genome-wide association study (GWAS) on tau in cerebrospinal fluid. They analysed the genomes of 1,269 individuals who had undergone spinal taps as part of ongoing Alzheimer's research.

Results showed several genes that are related to high levels of tau and higher risk for Alzheimer's disease. Three genes have no known effect on amyloid beta, suggesting that they operate through a completely different pathway.

Another gene, APOE, is known as an Alzheimer's risk factor through its association with amyloid beta. However, in this study it also seemed to be connected to elevated tau levels. The finding that APOE influences more than one pathway could help explain why the gene has such a big effect on Alzheimer's disease risk.

Prof Goate said: "It appears APOE influences risk in more than one way. Some of the effects are mediated through amyloid-beta and others by tau. That suggests there are at least two ways in which the gene can influence our risk for Alzheimer's disease." Dr. Cruchaga added: "We know there are some individuals with high levels of amyloid-beta who don't develop Alzheimer's disease. We don't know why that is, but perhaps it could be related to the fact that they don't have elevated tau levels."

In addition to APOE, the research team found that the GLIS3, TREM2 and TREML2 genes also affect tau levels and Alzheimer's risk.

www.sciencedirect.com/science/article/pii/S0896627313001840

4 April: Study shows beneficial effects of beta amyloid and tau proteins

Two recent studies from the Stanford University School of Medicine have uncovered new, beneficial effects of amyloid-forming proteins.

The first study, published in August 2012, showed that the beta amyloid protein could reverse the symptoms of a variant of multiple sclerosis in mouse models. The second study, from April 2013, determined that small fragments of several amyloid-forming proteins, such as tau and prions, can also quickly alleviate symptoms in mice. This is despite the fact that the fragments form the long tendrils, or fibrils, that are thought to be harmful to neuron health.

Taken together, the studies suggest that amyloid-forming proteins may be produced by the body as a protective rather than destructive force. In particular, the proteins may function as molecular chaperones, escorting and removing molecules involved in inflammation from injury sites.

Dr. Lawrence Steinman, Professor of Neurology and Neurological Sciences at Stanford, was involved in both studies. He said: "We began this research because these molecules are present in the brains of people with multiple sclerosis. We expected to show that the presence of beta amyloid made the disease worse in laboratory animals. Instead, we saw a great deal of benefit."

"What we're finding is that, at least under certain circumstances, these amyloid peptides actually help the brain. We know the body makes a lot of amyloid-forming proteins in response to injury. I'm doubtful that that's done to produce more harm. For example, the prion protein exists in every cell in our bodies. What is it doing? It's possible that any therapeutic maneuver to remove all of these proteins could interfere with their natural function."

"The lessons we learn from our study of amyloid-forming proteins in multiple sclerosis could be helpful for stroke and brain trauma, as well as for Alzheimer's disease."

<http://stm.sciencemag.org/content/5/179/179ra42.abstract?sid=b728e6db-2f3b-4b32-a1ab-9e49668c3025>

<http://stm.sciencemag.org/content/4/145/145ra105.abstract>

10 April: New rat model mimics AD symptoms better than mice

Researchers at the University of Southern California (USC) have developed a genetically modified rat that is the first

rodent model to exhibit the full range of brain changes found in Alzheimer's disease.

In recent years, drug companies have developed several Alzheimer's drugs that seemed to work in animals - especially mice - but did not help people. This led to experimentation with rats: the new TgF344-AD model comes from a line that is known to develop some of the same health problems as humans when they get older. In addition, rats are 4-5 million years closer evolutionarily to humans, so their brains are more like ours.

The researchers were led by Dr. Terrence Town, Professor of Physiology and Biophysics at USC. They confirmed the presence of both amyloid plaque and tau tangles in the new rats. The scientists also discovered specialised glial cells (neural support cells) before the development of amyloid plaque. While mouse models do develop plaque, they cannot have tau tangles or specialised glial cells.

Dr. Town reported: "The big shocker came when we started counting numbers of neurons in their brains. It turns out that they lose up to about 30 or 35 percent of the neurons in brain regions that are classically associated with Alzheimer's disease.

"The rats also began to lose their ability to do mental tasks, like navigate a maze. And as the animals get older, they perform even worse, much as you would see in a human being that would have these mutations".

He hopes that the new transgenic rats will also help researchers uncover principles applicable to other neurological diseases, such as amyotrophic lateral sclerosis (ALS) and Parkinson's disease.

www.jneurosci.org/content/33/15/6245.abstract?sid=eb16f873-af98-4494-872c-0289ff5cecd3

10 April: Gene mutation increases dementia risk in African Americans

American researchers have identified a new mutation in the ABCA7 gene that nearly doubles the risk of developing Alzheimer's disease in African Americans.

ABCA7 is involved in producing cholesterol and lipids, which suggests that these may be a more important pathway to Alzheimer's disease in blacks than in whites. High cholesterol and lipid levels - which are more common in blacks - can lead to vascular disease, heart attacks and strokes. Therefore, treatments that lower these levels may potentially be an effective way to reduce or delay Alzheimer's in people with the gene variant.

"The first thing this tells us is there are probably many different ways to get Alzheimer's" said Dr. Richard Mayeux, lead author of the study and Professor of Neurology, Psychiatry and Epidemiology at Columbia University Medical Center. "It might be like some forms of cancer where the type of cancer you have dictates the type of treatment you receive."

Several gene mutations have been linked with increased Alzheimer's risk with APOE-e4 as the most significant in both whites and blacks. This study shows that both ABCA7 and APOE-e4 are major genetic risk factors in blacks.

Dr. Neil Buckholtz, Director of Neuroscience at the National Institute on Aging, said: "This is a major finding because it shows that blacks have an additional risk factor

compared to whites. It's a highly significant risk that doesn't exist in other populations. In order to find interventions, we need to explore all the various risks." The National Institute on Aging is part of the NIH, the agency that funded the study.

<http://jama.jamanetwork.com/article.aspx?articleid=1677372>

11 April: AMPK enzyme triggers synaptic loss in mice

A recent study has linked overactivation of the AMPK enzyme to the typical synaptic loss of early Alzheimer's disease in mouse models.

The study was led by Prof Franck Polleux from The Scripps Research Institute in California. His team established that the presence of amyloid beta signals certain neuronal receptors to accept an influx of calcium ions into the neurons. This calcium influx triggers the activation of an enzyme called CAMKK2, which seems to be the main activator of AMPK in neurons.

Amyloid beta also causes the destruction of neurons' dendritic spines, which act as communications paths to other neurons via synaptic connections. The researchers showed that dendritic spine loss can only occur when AMPK is overactivated - and also that AMPK overactivation on its own can cause the damage. When the scientists blocked AMPK, the mouse models were protected from synaptic loss.

Prof Polleux said: "These findings open up many new avenues of investigation, including the possibility of developing therapies that target the upstream mechanisms leading to AMPK overactivation in the brain."

Dr. Simon Ridley, head of research at Alzheimer's Research UK, said: "This study suggests AMPK could be an important link between the build-up of amyloid in the brain and the breakdown of communication between nerve cells in mice, leading the way towards further studies in people. As AMPK is involved in many biological processes, much more work would be needed to know whether it could be a target for new Alzheimer's drugs." Alzheimer's Research UK was not involved in the study.

www.cell.com/neuron/retrieve/pii/S0896627313001335

15 April: A wrong signal from APP causes neuron death

Researchers at Ruhr-Universität in Bochum (Germany) have developed a new hypothesis on the development of Alzheimer's disease, based on the interaction of the APP and FE65 proteins.

The amyloid precursor protein APP is already known as a player in Alzheimer's disease. It spans the membrane of a neuron and anchors FE65 to that membrane. From there, FE65 moves into the nucleus, where it plays a role in DNA replication and repair.

In Alzheimer's disease, APP's activity is modified. The scientists believe that this modification also changes the behaviour of FE65 when it moves into the nucleus. Instead of regulating DNA replication, it acts to instruct the entire neuron to replicate. However, neurons cannot normally divide so they degenerate and die.

<http://jcs.biologists.org/content/early/2013/04/09/jcs.121004>

15 April: Sanofi cuts back on Alzheimer's research

French drug maker Sanofi has announced that it will no longer commit major resources toward a therapy for Alzheimer's disease.

According to CEO Chris Viehbacher, more research needs to be done before taking drugs into expensive, later-stage trials. He said: "We have to do a lot more basic science work to understand what's going on. We really, at best, partially understand the cause of the disease. It's hard to come up with meaningful targets. Unless we've got better targets, we're not really making any progress."

29 April: CD33 gene exhibits radical differences in behaviour

American scientists have determined that controlling the activity of the CD33 gene may reduce amyloid build-up in the brain.

The team headed by Dr. Rudolph Tanzi, Professor of Neurology at Harvard Medical School, first identified CD33 in 2008. They found that a subset of brain cells known as microglia showed high levels of CD33 and deduced that the gene acts as a molecular housekeeper. It patrols the nervous system and removes materials that don't belong and could impair normal brain function - such as amyloid protein deposits. However, under certain conditions the gene dramatically changes its activity and destroys the same cells it is meant to protect.

When the team looked at the brains of people who had died of Alzheimer's disease, they found that CD33 appeared in high quantities along with very large amounts of dead neurons. Instead of engulfing and removing amyloid, the microglia with CD33 were targeting healthy cells. To confirm this, the researchers conducted tests in culture and mouse models.

They found that when microglia were stripped of CD33, they went back to performing their original cleaning duties. Alzheimer mouse models without CD33 showed lower levels of amyloid than animals with the gene, suggesting that CD33 was clearing the protein away.

Dr. Tanzi said: "At some point, as the amyloid is making the cells sick, and forming tangles as lots of neurons are dying, the microglia put on their battle gear and turn radical, killing whatever they think is attacking the brain. The result is friendly fire, and they start to kill so many neurons that the microglia are now detrimental; they are no longer clearing but they're rounding up nerve cells and shooting out free radicals and causing a lot of damage."

"We just need to take advantage of the housekeeping functions of CD33 and entice them to stay helpful and not go crazy."

www.cell.com/neuron/retrieve/pii/S0896627313003164



Dementia in Society

4 April: US annual cost of care exceeds USD 50,000

A study in the New England Journal of Medicine shows that the average annual cost of care for a patient with dementia can exceed USD 50,000 (EUR 38,000) in the United States.

Researchers determined the annual costs to be between USD 41,689 and 56,290. This adds up to between USD 159-215 billion (EUR 121-164 billion) in American health care dollars, of which USD 11 billion (EUR 8.4 billion) is paid for by Medicare.

The authors also projected that the aging of the US population will result in an increase of nearly 80% in total societal costs per adult by 2040.

This study was funded by the National Institute on Aging.

www.nejm.org/doi/full/10.1056/NEJMsa1204629

8 April: Margaret Thatcher passes away at age 87



Former UK Prime Minister Baroness Margaret Thatcher passed away on 8 April at the age of 87 after suffering a stroke.

It was well known that Baroness Thatcher lived with dementia during the last years of her life. This was originally revealed by her daughter in 2005 but never officially confirmed.

Baroness Thatcher (13 October 1925 – 8 April 2013) was Conservative Prime Minister from 1979 to 1990 and the first woman to hold the post. While serving as Education Secretary, she successfully challenged former Prime Minister Edward Heath for her party's leadership in 1975. She won general elections in 1979, 1983 and 1987.

Margaret Hilda Thatcher is survived by her daughter Carol, her son Mark and two grandchildren.

20 April: ADI organises successful 28th International Conference in Taipei



Alzheimer's Disease International (ADI) organised its 28th International Conference in collaboration with the Taiwanese Alzheimer's Disease Association (TADA Chinese Taipei) from 18 to 20 April.

Held under the motto "Dementia: Action for Global Change", the conference was attended by over 1,000 participants and brought together people with dementia, professional and family carers, researchers, clinicians, scientists and staff of national Alzheimer associations.

The conference also provided an opportunity for ADI to organise a meeting of its Elected Board and a Council Meeting bringing together the representatives of its national member organisations. The ADI Board approved the new partnership agreement with Alzheimer Europe which aims at improving the communication and collaboration between the two organisations.

The organisers of the conference also commemorated the occasion by organising an International Memory Walk.

More than 3,000 participants joined the walk, including the Taiwanese President Ma Ying-Jeou and the Mayor of Taipei who announced their continued commitment to supporting people with dementia and their carers.



30 April: British police will use GPS to track people with dementia

A British police force has announced plans to begin tracking people with dementia using GPS locators. The aim is to quickly locate people who are at high risk of becoming lost around the Sussex area in south-eastern England. GPS locators are already in wide use by British health and social services agencies, but this is the first time a police force is involved.

The devices are worn around the neck or attached to a keychain and send a person's location to a website every four minutes. This information can be accessed by the police and the person's family. Tanya Jones, Chief Inspector of the local police force, described this as a cost-effective strategy that would save police time and resources by not having to frequently search for lost people.

However, the National Pensioners Convention on Wednesday called the initiative inhumane, arguing that patients could be stigmatised and made to feel like criminals. Dot Gibson, General Secretary of the group, said: "Dementia patients need human interaction, not tagging." She added that dementia patients haven't committed any crime and that this was more about saving money than treating people with dignity.

On the other hand, some experts said the GPS technology can be enormously helpful if used properly. Dr Julia Botsford, head researcher for the Dementia UK charity, said: "This could empower people to be freer in terms of their movement and give families peace of mind, but the challenge is to ensure the patients' civil liberties are being respected." She added that such devices could allow dementia patients to live longer on their own.

Similarly, Chris Quince from the Alzheimer's Society said: "It's vital that consent is always sought from a person with dementia, unless their carer or family member has power of attorney and makes decisions on their behalf. Any attempt to determine what is best for an individual who does not have capacity to consent would require careful inquiry and judgment. Any tracking system must support and never replace good quality care."

New Publications & Resources

4 April: EFID issues call for 2014 award proposals

The European Foundations' Initiative on Dementia (EFID) has issued a second open call for proposals for its 2014 award.

The award is designed to reward initiatives promoting the integration, support and involvement of people with dementia and their carers in the local community through a large range of activities. It is available to groups and communities in all EU member states.

The following are examples of project elements that could win the award:

- support encounters between people with and without dementia
- support daily and practical tasks, and encourage neighbourly assistance, to allow people with dementia and their relatives to continue taking part in community life and reduce their isolation
- give people with dementia a stronger "voice" and greater empowerment, respecting their autonomy and citizenship
- raise public awareness about the topic in order to reduce stigmatisation, and change the societal perception of dementia by informing and educating, and by conveying different, more balanced views of dementia.

EFID is an initiative of the Network of European Foundations (NEF) under the chairmanship of the King Baudouin Foundation of Belgium. It consists of several foundations that have joined forces to fight stigmatisation and work towards changing the societal perception of dementia, through an awareness-raising campaign and the support of local projects. The other foundations participating in EFID are The Atlantic Philanthropies (USA), Robert Bosch Stiftung (Germany) and Fondation M d ric Alzheimer (France).

More information and applications can be found on the NEF website.

www.nef-europe.org/call-for-proposals/
www.nef-europe.org/wp-content/uploads/2013/05/FAQ.pdf

9 April: UK Alzheimer's Society releases a report on loneliness

The Alzheimer's Society has released a new report that explores the quality of life of people with dementia.

"Dementia 2013: The hidden voice of loneliness" reveals that nearly two thirds (62%) of more than 250,000 people with dementia who live on their own are lonely, compared to just 24% of people over the age of 55. In addition, over half of the general public (54%) believe that people with dementia have a bad quality of life. This was echoed in feedback from people with dementia, with 70% saying they had stopped doing things they used to do because of lack of confidence. The majority of people with dementia also felt anxious or depressed (63%) and a third of people (35%) said they'd lost friends after a diagnosis.

Jeremy Hughes, Chief Executive of Alzheimer's Society, said: "This report reveals the stark truth that too many

people with dementia, especially the thousands who live alone, are truly isolated. We need to put a stop to this epidemic of loneliness, not only to improve quality of life but also to save thousands from reaching crisis point and being admitted to hospital unnecessarily or care homes early.

"The Prime Minister's Challenge has put dementia in the spotlight. However, the reality is that many people still feel disconnected from society. It's time for all of us to play a part in helping people with dementia live well with the condition."

The report is available free of charge on the Alzheimer Society website.

www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1542

9 April: EMA publishes a glossary of regulatory terms

The European Medicines Agency (EMA) has released a new website containing a glossary of the main regulatory terms that are currently used by the agency. The website also provides useful links to related terms. The glossary has been developed to help users understand regulatory terminology, but definitions may differ from those given in European Union legislation.

www.ema.europa.eu/ema/index.jsp?curl=pages/document_library/landing/glossary.jsp&mid=WC0b01ac05800973d7

10 April: EMA publishes report on clinical trial participation

The European Medicines Agency (EMA) has released a report detailing the origins of patients in clinical trials connected to EMA marketing authorisations. The report covers the period 2005-2011 and also shows the geographical locations of these trials. In 2005, some 87,000 people participated in clinical trials, compared to nearly 143,000 people in 2011.

Results show that only 38.1% of trial participants were from EU/EFTA/EEA countries. More than 34% of patients were enrolled in North America and the regions Central/South America and Middle East/Asia/Pacific each accounted for 9.4% of patients. Smaller numbers were recruited in the CIS region (4.4%), Africa (2.6%), Australia-New Zealand (1.5%) and Eastern Europe-non EU (0.5%). Central/South America had the strongest growth in number of patients, followed by the CIS and Middle East/Asia/Pacific.

The locations of clinical trials show a similar trend: the highest numbers of sites were located in North America (42.4%) and EU/EEA/EFTA (36.2%), followed by Middle East/Asia/Pacific (6.6%) and Central/South America (6.0%). The Middle East/Asia/Pacific and CIS regions saw the biggest growth in clinical trial sites during the period, closely followed by Central/South America. The report is available on the EMA website.

www.ema.europa.eu/docs/en_GB/document_library/Other/2009/12/WC50016819.pdf

16 April: Eppendorf & Science issue call for annual neurobiology prize

The Eppendorf & Science Prize for Neurobiology is awarded annually for the most outstanding

neurobiological research by a young scientist of 35 years of age or younger, as described in a 1,000 word essay based on research performed during the past three years.

This prize acknowledges the increasingly active and important role of neurobiology in advancing our understanding of the functioning of the brain and the nervous system - a quest that seems destined for dramatic expansion in the coming decades. The prize was established in 2002 and encourages the work of promising young neurobiologists by providing support in the early stages of their careers.

The winner of the Eppendorf and Science Prize for Neurobiology is awarded USD 25,000 and publication of his or her essay in the journal *Science*. The essay and those of up to three finalists are also published on Science Online. The award is announced and presented at a ceremony concurrent with the annual meeting of the Society for Neuroscience in the USA. Eppendorf provides financial support to help enable the grand prize winner and finalists to attend the event.

The application deadline is 15 June 2013. More information is available on the Science website.

www.sciencemag.org/site/feature/data/prizes/eppendorf/howto.xhtml

Education opportunities

29 April: Join the summer school on Grid and Cloud Workflows and Gateways

The organisers of a weeklong study course on European grid and cloud infrastructures are looking for participants to attend the course and/or to be speakers about Workflow Interoperability.

The course will take place during 1-6 July 2013 in Budapest, Hungary. It is organised by the SZTAKI Cloud project and two current FP7 projects called SCI-BUS and ER-flow.

Participants will most likely be application and workflow developers, science gateway developers, system administrators and staff members of companies who would like to establish and use company level private clouds or other commercial clouds via a high-level gateway service.

There are already several well established grid and cloud infrastructures in Europe. The next issue is how to exploit these infrastructures, how to port and develop application for these infrastructures and how to extend their user communities. The main goal of this summer school is to give answers for these questions and to promote best practice examples for potential application developers and users of e-science infrastructures.

The registration deadline is 27 June 2013. Applicants are invited to visit www.lpds.sztaki.hu/summerschool2013/ for more information.

30 April: University of Leuven seeks applicants for Nursing Ethics course

The Centre for Biomedical Ethics and Law of the University of Leuven (Belgium) is accepting applications for an English-language course on Nursing Ethics in December 2013.

This intensive, three-day course will focus on foundational approaches as well as contemporary and educational issues in the field of Nursing Ethics. It is based on an interdisciplinary perspective and will include philosophical, theological, nursing and clinical-ethical aspects.

The course is part of the Erasmus Mundus Master of Bioethics programme. It is intended for participants from diverse professional backgrounds, such as nursing, medicine, philosophy and theology, health care administration and PhD students undertaking courses of study in these areas. Additional information is available on the University's website.

<https://med.kuleuven.be/nl/erasmus-mundus-bioethics/documents/nursing-ethics>



www.alzheimer-europe.org/Donation



Contact Alzheimer Europe:

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

Alzheimer Europe Board

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

Alzheimer Europe Staff

Executive Director: Jean Georges; **EU Public Affairs Officer:** Annette Dumas; **Administrative Assistant:** Kate Ellis; **Editor – Dementia in Europe Magazine:** Julie Fraser; **Information Officer:** Dianne Gove; **Conference and Event Coordinator:** Gwladys Guillory; **Communications Officer:** Alex Teligadas; **Administrative Assistant:** Grazia Tomasini.

AE Calendar 2013

Date	Meeting	AE Representative
13 May	IMI Stakeholder Forum (Brussels, Belgium)	Annette
13-14 May	NILVAD project meeting (Hohenkammer, Germany)	Alex
14 May	European Commission "Month of the Brain" conference "European brain research : successes and next challenges" (Brussels, Belgium)	Annette
15 May	S&D discussion in the European Parliament on 'Access to quality long-term care : a right for all' (Brussels, Belgium)	Annette
16 May	Ethics work on restrictions of freedom at the Identity and Belonging workshop at the Edinburgh School of Law (Edinburgh, UK)	Dianne
16 May	EMIF project meeting (Barcelona, Spain)	Alex
22-24 May	European Patients' Forum General Assembly Meeting, EPF Annual Conference "10 Years of active involvement: how far have we come, where do we need to go?" and EGAN conference on "Effective healthcare requires good nutritional care" (Dublin, Ireland)	Annette
28 May	22nd Annual Conference of La Ligue Alzheimer (Libramont, Belgium)	Alex
29 May	European Commission D4 Action Group meeting (European Innovation Partnership on Active and Healthy Ageing) (Brussels, Belgium)	Annette

Future Conferences

Date	Meeting	Place
23-24 May 2013	3 rd International Conference on Neurodegenerative Disorders: Immunotherapy and Biomarkers, http://eventus.trippus.se/immunotherapy_uppsala2013	Uppsala, Sweden
5-6 June 2013	Pioneers in healthcare, info@researchmedia.eu	Brussels, Belgium
8-11 June 2013	23 rd ENS 2013 meeting, www.congrex.com	Barcelona, Spain
13-14 June 2013	EU Summit on active and healthy ageing: An action agenda for European cities and Communities, http://www.ahaconference2013.ie	Dublin, Ireland
23-27 June 2013	The 20th IAGG Congress of gerontology and geriatrics, www.iagg2013.org	Seoul, Korea
1-2 July 2013	NeuroConnection, www.neuroconnection.eu	Marseille, France
21-26 September 2013	XXI World Congress of Neurology, www.oegnt.at	Vienna, Austria
5-9 October 2013	26 th ECNP (European College of Neuropsychopharmacology), www.ecnp-congress.eu	Barcelona, Spain
10-12 October 2013	23 rd Alzheimer Europe Conference: "Living well in a dementia-friendly society", www.alzheimer-europe.org/EN/Conferences	St. Julian's, Malta
17-20 October 2013	8 th International Congress on Vascular Dementia – ICVD 2013, www.kenes.com/icvd	Athens, Greece
11-14 December 2013	The 16 th Asia Pacific regional Conference of Alzheimer's disease international, www.aprc2013-hongkong-macau.com	Hong Kong & Macau
20-22 March 2014	58 th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), www.dgkn-kongress.de	Berlin, Germany
20-23 March 2014	30 th International Congress of Clinical Neurophysiology of the IFCN (ICCN), www.iccn2014.de	Berlin, Germany
26-29 March 2014	13th Int. Geneva/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Geneva, Switzerland
5-9 July 2014	9 th FENS Forum of Neuroscience, http://forum.fens.org/2014	Milan, Italy

23rd Alzheimer Europe Conference
Living well in a dementia-
friendly society
St. Julian's, Malta, 10-12 October 2013
Mark the dates!

www.alzheimer-europe.org/conferences



The Alzheimer Europe newsletter arises from the 2013 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.