Welcome to this first newsletter of 2012.

I am delighted that we were able to successfully conclude the negotiations about the continuation of our operating grant with the Executive Agency for Health and Consumers in December. This newsletter and our other dissemination and information activities thus continue to be made possible thanks to the support of the European public health programme.

Our 22nd Annual Conference in Vienna will also receive funding from the public health programme and the preparations for this conference are now well underway. This month, we launched the call for abstracts and we hope that many people want to share information on their projects and studies, as well as best practices on the care and treatment of people with dementia and the support of their carers.

We have also been able to negotiate very favourable room rates with the conference venue and it is already possible to book with the Eventhotel Pyramide via our website. The registration facilities for the conference will also open shortly.

The motto of the conference is “Changing perceptions, practice and policy” and I am confident that this year’s conference will attract a similar number of participants as our very successful Warsaw Conference. Please mark the dates of 4 to 6 October 2012 in your calendar. We hope to see you in Vienna.

January was also another important month for PharmaCog, the project which brings together 13 academic institutions, 12 global pharmaceutical companies, 5 small and medium-sized enterprises and Alzheimer Europe with the aim of speeding up the drug discovery process for treatments against Alzheimer’s disease. Some 110 delegates met in Marseille to share the progress and achievements of this important research consortium and we report on this meeting in our newsletter.

On a European level, January was also particularly busy as the European Parliament elected a new President, Vice-Presidents, Quaestors, heads of political groups and chairs of parliamentary committees. We were delighted to see a number of members of the European Alzheimer’s Alliance take on important new posts and welcome Richard Ashworth, MEP (United Kingdom) as the 59th member of the Alliance.

Heike von Lützau-Hohlbein and Annette Dumas attended an award ceremony organised by the European Foundation Initiative on Dementia. This innovative initiative rewarded ten community based projects as good practices for helping people with dementia and carers to live well and participate actively in their local community.

Out of the great number of policy developments and research news in this newsletter, I want to recommend that you read about the UK court case, where a care home tried to stop a husband from taking his wife with dementia on holiday. Thankfully, the court found in favour of the couple, but the story clearly shows that we still have a long way to go in changing the image of dementia.

Jean Georges
Executive Director
Alzheimer Europe

9 January: Alzheimer Europe issues call for 2012 Conference abstracts

Alzheimer Europe and Alzheimer Angehörige Austria have opened the call for abstracts for the 22nd Alzheimer Europe Conference.

We welcome abstracts - in English only - on the topics listed below.

The 22nd Alzheimer Europe Conference will take place in Vienna on 4-6 October 2012.

- Assistive technologies
- Care services
- Carer support
- Consent, advance directives and guardianship systems
- Diagnosis
- End-of-life issues
- Epidemiology
- Involving people with dementia
- National dementia strategies
- Perceptions of dementia
- Prevention
- Psycho-social interventions
- Quality of life
- Socio-economic cost of dementia
- Stigma and discrimination
- Treatment.

www.alzheimer-europe.org/Conferences/Vienna-2012/Call-for-abstracts

25 January: Dianne Gove attends forum for good clinical practice

On 24-25 January, Dianne Gove (Information Officer, Alzheimer Europe) attended the Annual Conference of the European Forum for Good Clinical Practice (EFGCP) entitled “Informed consent – How less could be more: effecting a paradigm shift so we do inform participants.”

A recurring theme at the conference was the inappropriateness and inadequacy of the informed consent procedure for research. Delegates clearly felt that this procedure responded more to the needs of lawyers than research participants. The need to consider informed consent as a process rather merely a signed document was emphasised.

The conference included a workshop on adopting a risk-based strategy for consent to participation in clinical trials of new drugs. Participants settled on the following priorities for such a document:

- organising the information into different levels of detail, giving participants the freedom to choose how much information they want
- ensuring that they have a copy for future reference
- structuring the information in such as way as to ensure that people easily find the exact information they need.

The participants also agreed that informed consent documentation should not be unnecessarily long; current participant information sheets can be up to 30 pages long.

Another conference issue which provoked lively debate was that of consent to research in emergency situations when the patient is unable to give consent or is unconscious.

DECIDE

2 January: DECIDE applications are ready for user testing

The DECIDE distributed e-infrastructure and service is up and running. It will now be released for user testing by a panel of selected early adopters. They will undergo dedicated training sessions in Rome for the GridSPM, GridANN4ND and GridEEG applications to allow them to make the best use of the tool.

PharmaCog

16 January: PharmaCog holds second Annual General Assembly

On 16-17 January, PharmaCog held its second Annual General Assembly in Marseille, France. The assembly was attended by around 110 delegates and chaired by Elisabetta Vaudano (Principal Scientific Manager), Jill Richardson (EFPIA Coordinator) and Alexandra Auffret (Academic Coordinator).

During the first day, delegates heard presentations by the Work Package leaders, showing 2011 achievements and 2012 objectives of the ten work packages that make up the PharmaCog project. This was followed by an exhibit of 36 posters, showing the diverse methodologies used and results obtained by PharmaCog researchers in some 20 academic and commercial labs in Europe.

The second day was devoted to round-table sessions. Participants of each work group sat together to discuss current progress, potential setbacks and how to proceed in 2012, which will be the third of five years in the PharmaCog project lifetime.
Alzheimer Europe Networking

On 5 January 2012 (Brussels, Belgium) Annette met Erick Tyssier (Sanofi) following Sanofi’s meeting “Alzheimer’s disease: the future alongside patients and their carers” with patient representatives in December 2011.

On 9 and 10 January (Luxembourg, Luxembourg) Jean met with representatives of PricewaterhouseCoopers for an audit of the organisation’s participation in the PharmaCog project.

On 9 and 25 January (Luxembourg, Luxembourg) Julie met with Jean-Paul Reuland from Binsfeld publishers to discuss issue 10 of the Dementia in Europe magazine.

On 11 January 2012 (Brussels, Belgium) Annette had a meeting with Richard Ashworth, MEP (UK) to discuss the European Alzheimer’s Alliance.

On 12 January 2012 (Brussels, Belgium) Annette had a meeting with Maria Iglesias Gomes (DG Sanco) to discuss the European Innovation Partnership on Active and Healthy Ageing.

On 13 and 14 January (Miami, USA) Jean participated in a Lexicon Steering Committee Meeting organised by Pfizer.

On 16 January (Marseille, France) Alex attended the 2nd PharmaCog General Assembly.

On 16 January 2012 (Brussels, Belgium) Annette attended the EFID Award ceremony.

On 19 January (Luxembourg, Luxembourg) Jean met with Sophie d’Alayer and Serge Tabery of Fondation Roger de Spoelberch.

On 20 January (Luxembourg, Luxembourg) Jean had an exchange of information with Armelle Lepere-Desplanques on the areas of collaboration between Alzheimer Europe and ALCOVE, the Joint Action on Dementia.

On 24 and 25 January 2012 (Brussels, Belgium) Dianne attended the Annual Conference of the European Forum for Good Clinical Practice entitled “Informed consent – How less could be more: effecting a paradigm shift so we do inform participants”.

On 25 January 2012 (Brussels, Belgium) Annette attended the MRI Alliance informal meeting and MRI reception in the European Parliament.

On 30 January (Luxembourg, Luxembourg) Jean had an exchange with Jan Killeen from Alzheimer Scotland for the organisation of the first meeting of the European Working Group of People with Dementia.

European Alzheimer’s Alliance

11 January: Richard Ashworth joins the European Alzheimer’s Alliance

Richard Ashworth, MEP (UK) joined the European Alzheimer’s Alliance on 11 January. Mr Ashworth is a member of the European Conservatives and Reformists (ECR) Group, sits on the Budgets Committee and is a substitute on the Agricultural and Rural Development Committee.

23 January: European Alzheimer’s Alliance members take up new Parliament posts

In the wake of the election of the European Parliament Committee Chairs, Vice Chairs, Quaestors and political group leaders, some European Alzheimer’s Alliance members have taken on new roles:

- Brian Simpson (UK) was elected Chair of the Transport and Tourism Committee
- Elisabeth Morin-Chartier (France) was elected Vice-Chair of the Women’s Committee
- Patrizia Toia (Italy) and Jens Rohde (Denmark) were elected Vice-Chairs of the Industry, Research and Energy Committee
- Bart Staes (Belgium) was elected Vice-Chair of the Budgetary Control Committee
- Astrid Lulling (Luxembourg) was re-elected as Quaestor.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 59, 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), Brepeols Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA).
- **Bulgaria**: Parvanova Antoniya (ALDE), Cyprus: Triantaphyllides Kyriacos (GUE-NGL), Czech Republic: Cabrnouch 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), Jäätteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP), France: Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossête Française (EPP), Morin-Chartier Elisabeth (EPP), 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 Blinkkeviciute (S&D), Luxembourg: Engel Frank (EPP), Lulling Astrid (EPP), Netherlands: De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP), Poland: Lukacijewska Elżbieta (EPP), Portugal: Carvalho Maria da Graça (EPP), Ceofilo Carlos (EPP), Mattas Marisa (GUE-NGL), Romania: Antonescu Elena Oana (EPP), Slovakia: Mikolásik Mikoslav (EPP), Žaborska Anna (EPP), Slovenia: Piterle Alcoz (EPP), United Kingdom: Ashworth Richard (ECR), Hall Fiona (ALDE), Lynne Liz (ALDE), McAvon Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).
European developments

1 January: Denmark takes over EU Presidency

On 1 January, Denmark took over the Presidency of the Council of the European Union from Poland. The six-month Presidency will concentrate on jobs, economic growth, budget talks and the global financial crisis.

In the health field, the Presidency will work on:

• anti-microbial resistance: promoting a more rational use of antibiotics and strengthening and improving the surveillance and use of, and resistance to, antibiotics
• the EU Action Programme “Health for Growth” (2008-2013)
• the amendment of the Tobacco Directive
• the amendment of the Transparency Directive, which encourages transparency in the measures that Member States establish to control prices and limit public reimbursement for medical products
• the Health Threats Package, which ensures better coordination of crisis responses and crisis handling of major cross-border health threats.

This Presidency is part of the ”Trio Presidency” that consists of Poland, Denmark and Cyprus. Denmark will hand over to Cyprus at the end of June 2012.

10 January: MEP Sârbu questions the Commission on neurodegenerative disease

On 10 January, MEP Daciana Sârbu (Romania) submitted the following written questions to the Commission about support for combating of neurodegenerative illnesses:

• What budget will the Commission allocate to research into neurological diseases, particularly Alzheimer’s, after 2013?
• What campaigns for the prevention of neurodegenerative illnesses might the Commission support in the future?

Approximately 7.3 million Europeans suffer from forms of dementia, the most common of which is Alzheimer’s disease.

The number of people suffering from dementia in the EU is increasing and it is estimated that in the future the number of people with Alzheimer’s will rise from 85 million, as it was in 2008, to 151 million in 2060.

The European Commission provides funding for research in the field of neurodegenerative illnesses through the Programme for Research and Technological Development (2007-2013).

17 January: European Parliament names new chairs of political group

The election of Martin Schulz (Germany) as the new President of the European Parliament (EP) has changed the composition of the Conference of Presidents, the body that brings together the EP’s president and political group leaders. The new heads of the political groups are:

• Lothar Bisky (Germany): GUE/NGL, Confederal Group of the European United Left - Nordic Green Left
• Martin Callanan (UK): ECR, European Conservatives and Reformists Group
• Joseph Daul (France): EPP, Group of the European People’s Party (Christian Democrats)
• Rebecca Harms (Germany) and Daniel Cohn-Bendit (France): Greens/EFA, Group of the Greens/European Free Alliance
• Francesco Enrico Speroni (Italy) and Nigel Farage (UK): EFD, Europe of Freedom and Democracy Group
• Hannes Swoboda (Austria), replaces Martin Schulz: S&D, Group of the Progressive Alliance of Socialists & Democrats in the European Parliament
• Guy Verhofstadt (Belgium): ALDE, Group of the Alliance of Liberals and Democrats for Europe.

17 January: Martin Schulz is the new president of the European Parliament

On 17 January, Martin Schulz was elected President of the European Parliament for a mandate of two and a half years with 387 votes.

MEP Schulz (Germany) has served in a number of committees, including the sub-committee on Human Rights and the Committee on Civil Liberties and Home Affairs. He led the SPD MEPs from 2000 and was subsequently elected Vice-Chair of the Socialist MEPs. He was also Chairman of the S&D Group from 2009 until the recent election.

18 January: EP elects new Vice Presidents and Quaestors

After the election of the European Parliament (EP) President on 17 January, all 14 Vice-Presidents were elected in the third round with a simple majority of the valid votes cast. The Quaestors were elected on the same day.

The 14 Vice-Presidents elected are: Gianni Pittella (Italy), Miguel Angel Martinez Martinez (Spain), Anni Podimata (Greece), Alejo Vidal-Quadras (Spain), Georgios Papastamkos (Greece), Roberta Angelilli (Italy), Othmar Karas (Austria), Edward McMillan-Scott (UK), Isabelle Durant (Belgium), Alexander Alvaro (Germany), Rainer Wieland (Germany), Oldřich Vlasak (Czech Rep.), Jacek Protasiewicz (Poland), László Surjan (Hungary).

The 5 Quaestors elected are: Astrid Lulling (Luxembourg), Jim Higgins (Ireland), Lidia Geringer de Oedenberg (Poland), Boguslaw Liberadzki (Poland), Jiří Mastalka (Czech Rep.).

22 January: Croats say yes to EU membership

Croats voted their approval to join the European Union in a referendum held on 22 January.

Membership negotiations began six years ago and an EU accession treaty was signed in December 2010. Croatia should become a full member by July 2013, once all of the 27 existing members of the union have ratified the deal.
27 January: Commission answers to EP question on 2014 as the European Year of Mental Health and the Brain

On 27 January, Commissioner Geoghegan-Quinn, EU Commissioner for Research, responded to a question from the co-chairs of the Mental Health Interest Group in the European Parliament about the designation of 2014 as the European Year of Mental Health and the Brain.

Ms Geoghegan-Quinn said that the Commission was fully aware of the high burden caused by brain disorders in Europe and that brain research is a priority for the Commission. She pointed out that this has been continuously addressed in the EU Framework Programmes (FP) for research (FP7 and the Joint Programming Initiative on Neurodegenerative Diseases, in particular Alzheimer’s). These efforts are also in line with the European Pact for Mental Health and Well-Being.

Commissioner Geoghegan-Quinn recognises that the designation of 2014 as European Year of the Brain could help to increase the profile of all brain diseases across the EU and also contribute to the development of plans for addressing this important societal challenge. However, no decision has been taken yet.

Regardless of this decision, the Commission will organise a large awareness event about the brain that will take the form of a European “month of the brain” during the first half of 2013.

The original question originated from the four co-chairs of the EP Mental Health Interest Group: Nessa Childers (Ireland), Marian Harkin (Ireland), Jean Lambert (UK) and Antoniya Parvanova (Bulgaria).

30 January: Commission presents findings on the European Research Area

On 30 January, Research Commissioner Geoghegan-Quinn presented the findings of the Commission’s public consultation on the European Research Area (ERA). The presentation took place during the ERA conference 2012 in Brussels, which was entitled “Fostering Efficiency, Excellence and Growth”.

The consultation ended on 30 November 2011 with the following main recommendations:

- to make Europe more attractive to top scientists and globally-mobile private R&D investment
- to increase transnationally-coordinated research and achieve higher scientific excellence
- to freely move, work and cooperate across borders while tackling global challenges.

The Commission will now decide which issues should be prioritised when finalising the ERA Framework, which will be tabled in June 2012 with a view to completing ERA by 2014.

31 January: The Ambient Assisted Living Association will soon call for proposals

The Ambient Assisted Living Association (AAL) will soon announce the 5th call for proposals of the AAL Joint Programme (AAL JP): “ICT-based Solutions for (Self) Management of Daily Life Activities of Older Adults at Home”.

This call aims to attract proposals for ICT-based solutions which enable and sustain older adults to continue managing their daily activities in their own homes. The call will also accept ICT-based solutions which support informal carers looking after elderly people.

The call will likely be launched at the end of February 2012, with a submission deadline in May. An “Info Day” will be organised on 13 March in Brussels. All interested parties should register by sending an e-mail to Jacqueline.Teller@aal-europe.eu before 24 February.

The AAL JP also offers a “Partner Search Facility”. This service provides two alternatives for finding partners for AAL projects:

- The publication of an activity profile of an organisation, which describe the capabilities of the organisation to contribute to the scope of the launched call for proposals. All profiles can be browsed by any user of this tool.
- The submission of a short project idea in order to find additional project partners. The uploaded information should specify the rough project idea, as well as the current and missing expertise required to form a convincing consortium.

Policy Watch

13 January: Archbishop of York deplores benefit cuts to elderly

The Archbishop of York, Dr. John Sentamu, stated that "the [UK] nation’s humanity is at stake" unless the elderly are protected from Government cuts. He referred to some 800,000 people who need special care as “old and afraid of tomorrow” after running out of savings, even though they contributed to the building of the welfare state through their taxes.

Archbishop Sentamu said that society will be judged by how it treats growing numbers of vulnerable pensioners. He also pointed out that the requirement to look after older generations goes back to the Ten Commandments.

18 January: Germany improves long-term care insurance

On 18 January, German Health Minister Daniel Bahr announced new provisions for federal health insurance. These provisions will mainly benefit people with dementia who live at home and are cared for by relatives.

The German Alzheimer Association welcomes the planned improvements. Bärbel Schönhof, co-chair of the association, said “the German Alzheimer Association has always supported reform for long-term care. We welcome the improvements announced by the Federal Minister of Health for the large number of people with dementia who are cared for at home”.

18 January: US updates postmortem diagnosis and pathology guidelines

The US has adopted new guidelines for post mortem assessment of Alzheimer's disease: individuals who were...
cognitively normal at the time of death can now be diagnosed with Alzheimer’s disease based on autopsy findings alone.

The new guidelines replace criteria issued in 1997 and call on pathologists to base diagnoses on an "ABC" risk score that combines assessments of beta-amyloid plaques, neurofibrillary tangles, and neuritic plaques.

Also new to the guidelines are specific protocols for evaluating other pathologies related to cognitive impairment and dementia, including Lewy body disease, vascular brain injury, and hippocampal sclerosis.

The effort to update the guidelines was led by the National Institute on Aging (the lead NIH institute on Alzheimer’s research) and the US Alzheimer’s Association.

23 January: Ireland lags in diagnosis and care of dementia

A new report concludes that dementia continues to be underfunded and underprioritised in Ireland. This report will lay the foundation for Ireland's first national strategy for dementia, which the government has promised to develop by 2013.

According to co-author Prof Suzanne Cahill of Trinity College, Ireland is behind many other European countries when it comes to diagnosing and treating those affected by dementia.

There are some 41,000 Irish people with dementia, of which 26,000 live at home; most of these have probably never been formally diagnosed. The same applies to long-stay facilities, where as many as two in three people have dementia, but very few have diagnoses.

The total annual cost of dementia is estimated at EUR 1.7 billion per year, almost half of which can be attributed to informal care provided by family and friends. Over 40% can be attributed to residential long-stay care, while the average cost per person with dementia is an estimated EUR 40,000.

The report notes that additional public spending is needed in this area and points out that Irish GPs who become ill and their carers that they are not alone.” The hotline will continue to serve Germany, which has more than 290,000 new cases of dementia every year.

"Dementia is a subject that affects us all," says Ms Schneider-Schelte. "We must always reassure the people who become ill and their carers that they are not alone." The hotline will continue to serve Germany, which has more than 290,000 new cases of dementia every year.

18 January: Dementia Dog project aims to improve the lives of people with dementia

Dementia Dog is a research project that aims to discover the impact a pet dog can have on a person with dementia. The research team is looking for stories, experiences and examples on how pet dogs help people with dementia.

This project is a collaboration between Alzheimer Scotland, the Glasgow School of Art and Dogs for the Disabled, with expert advice from Guide Dogs UK. It has received funding from the Design Council and the Scottish Government.

21 January: Jersey researches effects of dementia on relatives and carers

A new research project in Jersey is investigating the effects of dementia on relatives and carers of people with dementia.

"Dementia: The Living Experience of Relatives" is led by Sian Wareing-Jones, an MA post-graduate student, teacher and counselor. She said, "I saw that relatives were really distressed. I was seeing that in those visits relatives almost didn’t know what to do, they didn’t know how to be with that person with dementia, maybe someone they had been married to for 50 years.”

Ms Wareing-Jones wants to identify the main difficulties that are faced by relatives and to inform service providers about what could be done to support them. She will look for gender and age specific themes and themes specific to relatives with early, moderate or advanced stages of
dementia. She will also be looking at care at home or in care-homes, nursing homes or hospitals.

The research project will last until the end of June 2011. Results will be available to, and consulted by the States of Jersey, who are in the process of designing new dementia care services.

This project is supported by the Jersey Alzheimer’s Association and the research methodology has been granted ethical approval from the University of East Anglia Ethics Committee.

24 January: German Alzheimer Association publishes new brochure for relatives and carers

The German Alzheimer Association has released a new brochure entitled “Be Active Together” which aims to improve the life of people with dementia who live at home - some 800,000 people - and their carers.

The brochure gives suggestions for planning and carrying out recreational activities such as travelling, making new games and re-discovering old hobbies, in order to reduce boredom and restlessness. The suggestions come from family members, volunteers and professionals with extensive experience in caring for people with dementia.

The new brochure is available for sale from the German Alzheimer Association.

25 January: Swiss website is re-launched with a fresh look

Alzheimer Switzerland has re-launched their website to make it more user-friendly and to facilitate publication downloads. The German-language version is already online and will shortly be joined by French and Italian versions.

www.alz.ch

25 January: Ombudsman takes the side of Bulgarians with Alzheimer’s disease

Alzheimer Bulgaria is proceeding successfully in its judicial effort to uphold the rights of people with Alzheimer’s disease. These people have been denied free drugs for their condition, despite having paid their dues for health insurance. In some cases, the cost of these medicines is higher than the minimum pension in the country.

The association has taken the Bulgarian Ministry of Health to court three times over this issue - and has won at each level. However, the Ministry has not conformed to the courts’ decision.

On 25 January, the association secured the support of Bulgaria’s ombudsman, who has recommended to the Ministry that it follow the decision of the courts.

There are more than 90,000 people with dementia in Bulgaria, more than half of whom are diagnosed with Alzheimer’s disease.

31 January: Alzheimer Italy Uniti organises museum visit for people with dementia

On 31 January, the Italian Uniti association organised a visit to the City Museum of the Fondazione Roma with a group of 14 people with dementia and seven carers. The group was led by an experienced guide who encouraged discussion about the various exhibits.

Two days later, the same guide visited the same group at the Alzheimer Day Centre. He brought along slides of the exhibits the group had seen and continued the discussions they had had at the museum.

This activity, called Memoria del Bello, is part of a wider therapy programme. In this case, the aim was to recall memories through emotions stimulated by beauty.

Science Watch

4 January: Probiodrug receives more funding for QC inhibitor research

German drug firm Probiodrug has secured EUR 15 million for further development of its glutaminyl cyclase inhibitor programme. The lead compound in this programme is the PQ912 molecule. PQ912 blocks the activity of QC, an enzyme that participates in the formation of amyloid beta.


10 January: MIT team finds a gene that controls memory storage

A research team from MIT (Massachusetts Institute of Technology) has identified a gene that seems to control the whole process of storing human memories. The brain encodes memories by altering the connections between neurons. This requires a complex process of turning on many genes in those neurons. One of these genes is Npas4, which turns itself on immediately.

The researchers found that Npas4 also acts as a traffic controller, directing a series of other genes that modify the brain’s internal wiring by adjusting the strength of the neuron connections. The science team has already
identified a few of the genes regulated by Npas4 and suspects that there could be hundreds more.

Npas4 is particularly active in the hippocampus, which is critical in forming long-term memories. The MIT team will now investigate whether the neurons that turn on Npas4 when memories are formed are the same neurons that turn it on when memories are retrieved. This could help pinpoint the exact neurons that are storing particular memories.

The research team was led by Dr. Yingxi Lin, assistant professor in the Department of Brain and Cognitive Sciences at MIT.

12 January: Disruption of circadian rhythms may cause neurodegeneration

Researchers at Oregon State University (OSU) have shown that disruption of circadian rhythms - our biological clocks - can cause accelerated neurodegeneration, loss of motor function and premature death. Prior to this study, it was not known whether the disruption of biological clock mechanisms was the cause or the result of neurodegeneration.

"In these experiments we showed through both environmental and genetic approaches that disrupting the biological clock accelerated these health problems", said OSU graduate fellow Kuntol Rakshit.

The decline and loss of clock function may be just the beginning of a damaging vicious circle, said Jadwiga Giebultowicz, Professor of Zoology. "When the biological clock begins to fail, rhythms that regulate cell function and health get disrupted, and we now know that this predisposes the brain to neurodegeneration. But that neurodegeneration, in turn, may cause more damage to the clock function."

"A healthy biological clock helps protect against this damage," she said. "When the clock fails, the damage processes speed up."

13 January: Blue-green light may improve global functioning

A recent study from Wayne State University (Detroit, USA) shows that people with Alzheimer’s disease who are treated with blue-green light were perceived by their caregivers as having improved global functioning.

Caregivers said that people receiving the treatment seemed more awake and alert, were more verbally competent and showed improved recognition, recollection and motor coordination. They also seemed to recapture their personalities, were more engaged with their environment and their moods were described as improved.

The preliminary study was headed by Dr. LuAnn Nowak Etcher, assistant professor of nursing. It involved 20 elderly women with Alzheimer’s dementia from nursing homes in southeast Michigan. Dr. Etcher’s aim was to address disagreement among researchers on the effect of therapeutic light in regulating rest-activity patterns in people with Alzheimer’s disease.

"Some of the rest-activity pattern disruptions that we see associated with Alzheimer’s dementia may not necessarily be circadian based,” Etcher said. "They may be due to unmet needs, pain or other phenomena, and therefore would not respond to an intervention aimed at regulation of the circadian system."

Dr. Etcher now wishes to replicate this study with a larger sample and different demographics, with a long-term goal of developing interventions to improve overall function of people with Alzheimer’s disease.
23 January: New protein biomarkers are found for familial AD

A study conducted by Dr. John Ringman at the University of California shows that dozens of proteins – other than tau and Aβ – rise and fall in the cerebral spinal fluid (CSF) of familial Alzheimer’s disease carriers. These variations may occur up to a decade before onset of the disease.

Some of these proteins have previously been associated with sporadic AD, but most are new to the list of potential AD biomarkers. Such molecules could eventually aid in Alzheimer’s disease diagnosis, patient stratification, and drug development.

"It was completely unknown that this large number of proteins was changed in early familial AD" said Henrik Zetterberg, professor of neurochemistry at the University of Gothenburg (Sweden), who was not involved in the study.

"Many of the markers fall within protein networks already suspected to play a role in Alzheimer’s, so the type of hits did not come as a complete surprise. They fit well with the current thinking regarding Alzheimer’s pathogenesis."

24 January: Baxter will conduct a new phase 3 trial of Gammagard

Baxter International has announced that it will conduct a new phase 3 trial of the drug Gammagard Liquid 10% to expand on these early findings. In light of the recent European ban on patents using human embryonic stem cells, it may prove important to increase our use of technology using these non-embryonic stem cells.

25 January: Alzheimer’s disease neurons are created from stem cells

Scientists at the University of California (UC) have successfully reprogrammed stem cells into Alzheimer’s disease neurons.

The original cells were taken from four people with Alzheimer’s disease and two healthy controls. The resulting neurons from the Alzheimer cells contained higher-than-normal levels of both amyloid beta and tau proteins. The use of stem cells from Alzheimer’s patients may allow researchers to overcome the problem of obtaining brain cells.

The research team was led by Dr Lawrence Goldstein, professor of cellular and molecular medicine and director of UC’s San Diego Stem Cell Programme. He said “the differences between a healthy neuron and an Alzheimer’s neuron are subtle. It basically comes down to low-level mischief accumulating over a very long time, with catastrophic results.”

Dr Simon Ridley, head of research at Alzheimer’s Research UK, said: “The authors have shown these cells can reveal vital clues about the biological changes taking place during Alzheimer’s and we hope further studies can expand on these early findings.

“In light of the recent European ban on patents using human embryonic stem cells, it may prove important to increase our use of technology using these non-embryonic stem cells.”

25 January: Infrared light may help to detect amyloid beta in blood

Spanish researchers have discovered that remnants of amyloid beta are detectable in blood. Using a method called two-dimensional infrared spectroscopy, they measured the wavelength of light emitted by white blood cells from 50 people known to have different stages of Alzheimer’s disease and 20 healthy controls.

The researchers, led by Pedro Carmona of the Instituto de Estructura de la Materia in Madrid, found a strong link between the type of light emitted by the cells and the severity of Alzheimer’s disease. This was due to the different stages of formation of the amyloid beta remnants.

Mr Carmona specified that “our measurements seem to be more sensitive for earlier stages of Alzheimer’s disease, namely mild and moderate.”

26 January: Men may be more likely to develop MCI

A new study from the Mayo Clinic (Minnesota, USA) shows that men may be at higher risk of developing mild cognitive impairment (MCI) than women. MCI is often a precursor to Alzheimer’s disease.

The study involved 1,450 people between the ages of 70 and 89 who did not have dementia. They underwent memory testing every 15 months for an average of three years.
Dementia in society

16 January: Ten European projects win the 2012 “Living Well with Dementia” EFID awards

On 16 January, ten projects led by community-based organisations received the 2012 “Living Well with Dementia” awards from the European Foundations’ initiative on Dementia (EFID). The awards recognise and encourage the dissemination of good practices that help people with dementia and their families to live well and participate actively in their local communities. The winners are:

The Bistrots Mémoire, first set up in Rennes in 2004, provide “normal”, pleasant locations where those with dementia, their carers, professionals and volunteers can meet. They are now active in 41 communities in France.

The Enger Alzheimer’s Counselling Centre, in Germany, successfully involves local communities in providing opportunities for those with dementia to meet other inhabitants of all ages in a wide range of activities.

Alzak House, in Lamezia Terme, Italy, is an intergenerational community day centre for those with dementia and their families. It encourages participation of people in all age groups and the natural networks in society, so as to improve integration in the community while also narrowing the generation gap.

Together for a dementia-friendly Brussels!, in Belgium, is a long-term awareness-building programme which involves the whole community. It aims to fight the stigmatization associated with dementia by encouraging respect and tolerance for those with the condition.

Better together than alone!, in Lübeck, Germany, provides support for early-stage dementia through bi-weekly support groups, sports and other activities with specially-trained volunteers.

Campaign Dementia, in Vorarlberg, Austria, mobilizes communities to fight the stigmatization related to dementia by involving all actors of civil society to develop original and effective programmes.

Service for People with Young Onset Dementia & their Families, UK, provides specific, individual support and empowers the local community to take initiatives to provide better integration of people aged 30 to 65 with early onset dementia.

The Twinning Programme of Alzheimer’s Disease International, in Bulgaria, has facilitated the transfer of expertise between Bulgaria and elsewhere to fight prejudice and exclusion experienced by those with dementia, via a robust awareness-building programme among the general public.

The Missing Persons project in HEKLA, in 5 Belgian communities, is the result of collaboration between the local police and the local community to rapidly locate missing persons with dementia. This network-based approach is so successful that it has been adopted by 8 other local police forces.

Oficinas Terapêuticas, in Lisbon, Portugal, helps those with dementia to regain their self-esteem through the development of old and new capabilities. It is also changing the public image of dementia, in collaboration with community institutions such as museums.

The EFID Awards, each worth up to EUR 10,000, were presented at a ceremony in the presence of HRH Princess Mathilde of Belgium. EFID consists of four European foundations which have joined forces to improve the perceptions of dementia and stimulate solidarity at local level: Atlantic Philanthropies, Fondation Médéric Alzheimer, King Baudouin Foundation and Robert Bosch Stiftung.

23 January: Elderly couple goes to court to go on holiday

An elderly couple was forced to take a council to court after social services claimed it was too risky for them to go on holiday together.

Norman Davies and Peggy Ross were looking forward to embarking on their annual cruise trip when Cardiff Council used mental health laws to stop her leaving her care home. Just days before they were due to depart, the local authority asked the Court of Protection to agree that it was not in the “best interests” of Mrs Ross, who has dementia, to board the ship.

However, a judge refused to write the order and the couple enjoyed a 16-day cruise around the Mediterranean. Mr Davies said that they “thoroughly enjoyed it”, particularly as Mrs Ross was more mentally

26 January: FKBP52 protein inhibits activity of phosphorylated tau

French scientists from INSERM have discovered a link between phosphorylated tau and the FKBP52 protein.

The team led by Prof Etienne-Emile Baulieu demonstrated in vitro that the FKBP52 protein suppressed activity of the Tau protein, and hence prevented its role in the assembly of microtubules. These are known for their role in transporting nutrient and information-bearing molecules into the cell. The team observed that a high concentration of phosphorylated tau and the FKBP52 protein.

The study also found that people who had less education or were not married had higher rates of MCI.

Men were also more likely to develop aMCI than women.

The FKBP52 protein belongs to the family of immunophilins, which are intracellular receptors of immunosuppressor compounds. This protein family is active in many neurological disorders.


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However, a judge refused to write the order and the couple enjoyed a 16-day cruise around the Mediterranean. Mr Davies said that they “thoroughly enjoyed it”, particularly as Mrs Ross was more mentally
active than she would have been in if she had stayed in her care home.

Judge Crispin Masterman said that even if others believed Mrs Ross’s decision to go on the holiday was “unwise”, that does not show she was unable to make it. He conceded that the care home had her safety in mind, but were more concerned with “trying to find reasons why Mrs Ross should not go on this holiday rather than finding reasons why she should”.

Lawyers say the case illustrates how authorities are trying to use the Court of Protection, which has far-reaching powers over the financial affairs and welfare of people deemed to lack mental capacity, to control every aspect of people’s private lives. A Court of Protection newsletter says that this case “provides another example of a tendency among local authorities to focus on risk prevention at the expense of emotional wellbeing”.

24 January: New Swiss housing project will host seniors with dementia

A Swiss company will build a 1950s style village near Bern that will exclusively host elderly people with dementia. The EUR 20 million housing project will provide accommodation and care for 150 elderly dementia patients in 23 purpose-built houses. These homes will be designed to recreate the atmosphere of the 1950s.

According to a company spokesperson, there will be no closed doors and residents will be free to move about. To reinforce an atmosphere of normality, the carers will dress as gardeners, hairdressers and shop assistants. However, residents will not be able to leave the village.

There has been some criticism of this project: Michael Schmieder, director of a Swiss dementia home with 150 residents, is opposed to the idea of creating an illusory atmosphere. He said "the very notion is an attempt to fake the normality that people with dementia don’t have. Our patients are living in the here and now, not back then."

The Swiss Alzheimer’s Association supports the project. Executive Director Birgitta Martensson denied that it was creating a ghetto for the mentally ill. “Different types of care programmes are needed because the illness has different stages,” she said. “A dementia village is a good solution for people in advanced stages of the disease.”

26 January: Alzheimer’s Challenge 2012 seeks simple tools to detect and manage dementia

Alzheimer’s Challenge 2012 is a competition to solicit creative ideas from people both within Alzheimer’s research and outside the field about how to detect the disease at its earliest stages and track its progression over time.

The Challenge, which will award cash prizes, seeks the development of simple, cost-effective, consistent tools that could be easily used to assess memory, mood, thinking and activity level over time to help improve diagnosis and monitoring of people with Alzheimer’s disease.

This competition is co-sponsored by Geoffrey Beene Gives Back Alzheimer’s Initiative, the Alzheimer’s Immunotherapy Program of Janssen Alzheimer Immunotherapy and Pfizer Inc.

www.alzheimerschallenge2012.com

New publications & resources

6 January: New resource pack offers advice and tips for carers

The South West Dementia Partnership in the UK has released a “resource pack” of cards for health workers, volunteers and carers of people with dementia.

The resource pack is made up of 18 cards, each aimed at giving specific information, advice and top tips on a range of topics. The objective is to support people with dementia to get involved in activities while recognising their current abilities and limitations.

The resource cards have been written by people living with dementia, individuals, carers, volunteers and Partnership staff.

The South West Dementia Partnership, which brings together organisations from health and social care, the voluntary sector and people using dementia services to drive forward improvements in dementia care. The UK Alzheimer’s Society is an active partner.

www.southwestdementiapartnership.org.uk/system-redesign/involvement/read-pack-online/

9 January: Alzheimer Scotland releases new leaflet and DVD

Alzheimer Scotland has released a new information sheet and a new DVD. The new leaflet, “Loss and bereavement in people with dementia”, is intended to help people with dementia come to terms with the death of someone close to them. It was written by Alzheimer Scotland with the support of the University of the West of Scotland.

The new DVD is called “Essential Conversations” and discusses the various aspects of talking about death and dementia. It is intended as an “emotional resource” for staff and carers, to help them enhance their skills in supporting people with dementia and their families.

The DVD and website are part of a programme initiated by Alzheimer Scotland, managed by the National Carer Organisations and funded by the Scottish Government.

www.essentialconversations.org.uk

12 January: US task group publishes national dementia report

The US National Task Group on Intellectual Disabilities and Dementia Practices has published its final report, entitled “My Thinker’s Not Working”. This is a national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality support.

The report offers recommendations for the various stakeholders in the field of intellectual disabilities. The authors anticipate that its findings and recommendations will be considered by the Federal Advisory Council on Alzheimer’s Research, Care, and Services.

http://aadmd.org/ntg/thinker
Job opportunities

31 January: Stirling University is hiring a Dementia Research Professor

The University of Stirling in Scotland is recruiting a Professor in Dementia Research.

Working in the School of Applied Social Science and in close collaboration with the Dementia Services Development Centre, the successful applicant will play a key role in delivery of Research and Knowledge Exchange.

He/she will be an accomplished senior academic with an excellent international record in research. The applicant will work internationally and nationally to improve standards of care and support for people with dementia and those who care for them.

http://www.stir.ac.uk/about/jobs/details.php?id=QUUFK026203F3VBQB7V79

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Alzheimer Europe Board
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Honorary Secretary: Sigurd Spar (Norway)
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AE Calendar 2012

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tr>
<td>3 February</td>
<td>Debriefing meeting with representatives of PricewaterhouseCoopers (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>6-7 February</td>
<td>Launch of JPND Research Agenda (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>7 February</td>
<td>Visit of a clinical trial center and guided tour/explanation organised by MSD (Aalst, Belgium)</td>
<td>Dianne and Annette</td>
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<tr>
<td>15-16 February</td>
<td>NILVAD first project meeting (Dublin, Ireland)</td>
<td>Alex</td>
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<tr>
<td>22-25 February</td>
<td>National Romanian conference organised by the Romanian Alzheimer Society (Bucharest, Romania)</td>
<td>Annette</td>
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<tr>
<td>27-29 February</td>
<td>Alzheimer Europe Board, Company Round Table, European Parliament lunch debate on Innovative Medicines Initiative and PharmaCog project and AE Members’ meeting (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
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<tr>
<td>1-2 March</td>
<td>2nd DECIDE Annual Review (Brussels, Belgium)</td>
<td>Alex</td>
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<tr>
<td>22-23 March</td>
<td>EMA workshop on medicines for older people (London, UK)</td>
<td>Alex</td>
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Future Conferences

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<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>14 February 2012</td>
<td>International Symposium on Promoting the Well-being of People with Dementia through Creative Arts “Kunststücke Demenz”, <a href="http://www.ibk-kultur.de">www.ibk-kultur.de</a></td>
<td>Bonn, Germany</td>
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<tr>
<td>22-23 February 2012</td>
<td>8th Annual Update Symposium on Clinical Neurology and Neurophysiology, <a href="http://www.neurophysiology-symposium.com">www.neurophysiology-symposium.com</a></td>
<td>Tel Aviv, Israel</td>
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<tr>
<td>7-10 March 2012</td>
<td>27th ADI Conference “Science Fact Fiction”, <a href="http://www.adi2012.org/">www.adi2012.org/</a></td>
<td>London, UK</td>
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<tr>
<td>8 March 2012</td>
<td>CompanionAble Consortium, AAL Companion Robotics Institute Workshop Series</td>
<td>Brussels, Belgium</td>
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<tr>
<td>8-11 March 2012</td>
<td>6th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtecmed.com">www.comtecmed.com</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>12-13 March 2012</td>
<td>European Conference on clinical Neuroimaging, <a href="http://www.neuroimage.fr">www.neuroimage.fr</a></td>
<td>Lille, France</td>
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<tr>
<td>16-17 April 2012</td>
<td>First meeting of the European Working Group for People with Dementia</td>
<td>Glasgow, Scotland</td>
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<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>12-13 July 2012</td>
<td>International Academy on Nutrition and Aging (IANA), <a href="http://www.ian.org">www.ian.org</a></td>
<td>Albuquerque, New Mexico</td>
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<tr>
<td>8-11 September 2012</td>
<td>16th Congress of the European Federation of Neurological Societies (EFNS), <a href="mailto:efns2012@kenes.com">efns2012@kenes.com</a></td>
<td>Stockholm, Sweden</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.