Editorial

This month, we cover news from the three EU funded projects that Alzheimer Europe is actively involved in:

1. The DECIDE project passed an important milestone as the second interim review took place in Brussels and Alzheimer Europe’s survey on the data protection laws in different European countries was greatly appreciated.

2. After the successful launch meeting of the NILVAD project in February, the project website has now been set up. This will be a valuable resource for people interested in the progress and results of the five year clinical trial of nilvadipine.

3. We report on the latest staff changes in the PharmaCog team as we bid goodbye to Alexandra Auffret, the coordinator of the project. She will be replaced by Régis Bordet as of 1 April 2012.

Our campaign of making dementia a European and national priority also continues to gather pace with some important developments last month.

• In the United Kingdom, Prime Minister Cameron announced increased funding for dementia research and gave the government’s support for greater public awareness, early diagnosis and the development of dementia-friendly communities.

• The Swiss Council of States supports call of States for development of dementia strategy

• The Scottish Government guarantees one year of post-diagnostic support

• Prime Minister Cameron launches dementia campaign

• Cristian Busoi, MEP (Romania) became the 60th member of our European Alzheimer’s Alliance.

None of these achievements would have been possible without the tireless campaigning and advocacy of our national member organisations.

The French association is taking advantage of the upcoming presidential elections and has asked each of the candidates for their views on some of the priorities of France Alzheimer. The website which they set up with all the candidates’ responses makes for very interesting reading. It is particularly encouraging to see that eight of the nine candidates support France Alzheimer’s call for the development of a fourth Alzheimer’s Plan.

Notwithstanding these promising initiatives, it is equally important to highlight existing shortcomings of our current approaches to the care and treatment of people with Alzheimer’s disease. In this newsletter, we cover Terry Pratchett’s criticism that people with dementia are being made to feel like “malingers” or “a nuisance” and a report of the Care Quality Commission in the UK which concluded that staff in care homes routinely ignore patients’ human rights.

Alzheimer Europe was busy in March with the continued preparations of the 22nd Alzheimer Europe Conference in Vienna and we have been able to ensure the participation of some key researchers and stakeholders in the plenary programme. Please do not forget the deadline of 30 April for the submission of abstracts.

We are also in the process of updating our website and we will inform you about the many changes and additions in our next newsletter.

Jean Georges
Executive Director
Alzheimer Europe

22 March: EMA holds workshop for safe geriatric medicines

On 22-23 March, Alex Teligadas (Communications Officer, Alzheimer Europe) attended a European Medicines Agency (EMA) workshop entitled “Ensuring safe and effective medicines for an ageing population” in London. Action in the geriatric field is an EMA priority, as people aged 80 and over constitute the fastest-growing segment of the total population.

The workshop attracted more than 130 delegates and had four main objectives:

- present and discuss the EMA geriatric medicines strategy and related activities
- identify gaps in the strategy and establish priorities for action
- provide an opportunity to highlight synergy areas between stakeholders
- offer a sounding board for the actions undertaken by and expected from EMA and its committees by stakeholders.

There were numerous presentations which dealt with the challenges of designing, prescribing and evaluating medicines for elderly people. These challenges include:

- the current paucity of clinical trials involving elderly people
- the additional resources needed to enrol and retain older people in clinical trials
- comorbidity and frailty
- medication formulation and packaging

Participants included experts and stakeholders in the regulatory field, EU public bodies, academic researchers, patient representatives, health care professionals and pharmaceutical industry representatives.

Presentations are available at: http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2011/10/event_detail_000542.jsp&mid=WC0b01ac058004d5c3&jsenabled=true

Alzheimer Europe Networking

On 6 March 2012 (Brussels, Belgium), Annette participated in the meeting of the WeDo project.

On 7 March 2012 (London, United Kingdom), Heike attended the Elected Board Meeting of Alzheimer’s Disease International (ADI).

On 8 March 2012 (London, United Kingdom), Heike attended the ADI Council Meeting.

On 8 March 2012 (London, UK), Dianne attended the Interdem meeting.

On 8 March 2012 (Brussels, Belgium), Annette represented AE in the EPFIA Think Tank.

From 8 to 10 March (London, United Kingdom), Heike and Dianne attended the 27th ADI Conference.

On 9 March 2012 (Brussels, Belgium), Annette met Lisa Junglas, France Alzheimer Vaucluse (France).

On 22-23 March 2012 (London, United Kingdom), Alex attended the EMA workshop “Medicines for Older People”.

On 26 March 2012 (Brussels, Belgium), Annette met Angelika Werthmann, MEP, Germany.

On 27 March 2012 (Brussels, Belgium), Annette attended the joint Carers Interest Group / Age Intergroup meeting in the EP 2012, European Year of Active Ageing.

EU Projects

2 March: DECIDE project holds interim review in Brussels

On 2 March, the DECIDE project team concluded a successful interim review at the European Commission in Brussels. The review was chaired by Ms Athina Zampara, the new DECIDE Project Officer, along with Dr. Kamen Beronov and Ms Juliane Jarke.

The participants discussed all of the financial, technical, scientific and legal aspects of completed work, including demonstrations of the GridSPM, GridANN and GridEEG services. The attendees also looked at the remaining work items, which include implementation of the training programme, introduction of a new MRI application and completion of the business model.

The reviewers were satisfied with the progress achieved since the last review (September 2011) and provided many constructive comments and suggestions for the work items that are still underway. It was agreed that the project will be extended by six months and will end in March 2013.

31 March: Régis Bordet is the new Academic Coordinator for PharmaCog

Prof Régis Bordet has been named the new Academic Coordinator for the PharmaCog project as of 1 April 2012.
EU Developments

1 March: Commission proposes revision to Transparency Directive

On 1 March, the European Commission published a proposal for a revised Transparency Directive. This aims to improve Member States’ procedural framework for pricing and reimbursement of medicines, to accelerate patient access to innovation.

In particular, the proposal aims to streamline and reduce the duration of national decisions on pricing and reimbursement of medicines. In the future, such decisions should be taken within 120 days for innovative medicines, and 30 for generic medicinal products, instead of the current 180 days. The proposal also includes strong enforcement measures in case decisions do not comply with the time limits.

European Commission Vice President Antonio Tajani said: “We need faster decisions leading to pricing and reimbursement to maintain a dynamic pharmaceutical market and to offer citizens better access to pharmaceuticals. Our proposal will lead to substantial savings for public health budgets, for example by allowing earlier market entry of generic products. It also creates a more predictable environment with greater transparency for pharmaceutical companies, thus improving their competitiveness.”

http://ec.europa.eu/enterprise/sectors/healthcare/files/docs/transpadir_fina
lprop01032012_en.pdf

European Alzheimer’s Alliance

1 March: Alliance Member Liz Lynne leaves the European Parliament

Liz Lynne, MEP (UK) has resigned from the European Parliament where she will be replaced by Rebecca Taylor.

Alzheimer Europe would like to thank Ms Lynne for her support as a long standing member of the European Alzheimer’s Alliance and wishes her all the best for her future activities.

31 March: Cristian Busoi joins the European Alzheimer’s Alliance

On 31 March, Mr Cristian Busoi, MEP (Romania) joined the European Alzheimer’s Alliance. He is a member of the Alliance of Liberals and Democrats for Europe (ALDE).

Mr Busoi sits on the Internal Market and Consumer Protection Committee and is a substitute on the Legal Affairs Committee and the Environment, Public Health and Food Safety Committee.


NewsLetter: March 2012

Prof Bordet is a neurologist and medical pharmacologist at the University of Lille, France. He has been involved in PharmaCog since the beginning of the project and currently leads Work Package 3. He will be assisted by a full-time project manager who has yet to be named. In the meantime, GSK Project Managers Karen Philpott and Graham Somers have agreed to provide support on a temporary basis. The managing entity responsibility remains with Aix Marseille University in France.

Prof Bordet replaces Dr. Alexandra Auffret.

31 March: NILVAD project website is launched

The NILVAD project website is now up and running. Visitors can read about the scope of the project, catch up on the latest news and contact the partners.

Alzheimer Europe is involved in the Dissemination and Communication Work Package of the project and Mr Maurice O’Connell, CEO of The Alzheimer Society of Ireland and Board Member of Alzheimer Europe, sits on the Scientific Advisory Board.

NILVAD is funded by the European Commission within the 7th Framework Programme.

www.nilvad.eu

Currently, the total number of MEPs in the Alliance stands at 60, 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:

9 March: European Competitiveness Council adopts conclusions on Active and Healthy Ageing Partnership

On 9 March, the Competitiveness Council adopted conclusions on the preparatory work for the pilot European Innovation Partnership on Active and Healthy Ageing (EIP AHA) project.

The Council highlighted the need for simple and transparent procedures that respect the voluntary nature - as well as the essential role - of Joint Programming.

The Council agreed to the establishment of a Steering Group: Member States should be involved and contribute to the Steering Group through representatives at Ministerial level. The Council particularly welcomes the proposed participation of representatives from Belgium, Hungary, Poland and Spain in the work of the Steering Group.

The Council asked to be kept informed about the work of the Steering Group and repeated its call for an evaluation of the pilot EIP AHA in due time.

Finally, the Council highlighted the need for simple and transparent procedures that respect the voluntary nature of coordination of Member States' activities.


14 March: European Commission launches public consultation on chronic diseases

On 14 March, the European Commission launched a public consultation to respond to the growing challenge of chronic diseases.

Tackling chronic diseases has been a European priority since 2010 - following the Council’s conclusions on "Innovative approaches for chronic diseases in public health and healthcare systems".

Patient organisations and other stakeholders are invited to share their views and answer the Commission’s questions by 15 April.


29 March: European Parliament votes to extend deadline for transposition of the Directive on Electromagnetic Fields

On 29 March, the European Parliament (EP) voted to extend the deadline for the transposition of the directive on the protection of workers exposed to electromagnetic fields by 18 months - instead of the 24 months proposed by the European Commission. This will leave time for the EP to possibly find an agreement on the Commission’s proposal which is currently on the table.

The Rapporteur is Elisabeth Morin-Chartier, MEP (France) and member of the European Alzheimer’s Alliance.

Background: The deadline for the transposition of the Electromagnetic Fields Directive adopted in 2004 is set for 30 April 2012.

However, the medical community raised concerns about the exposure limit values laid down in the Directive: these values would place disproportionate limitations on the use and development of medical magnetic resonance (MRI) applications. These applications are currently considered to be vital tools for the diagnosis and treatment of a number of diseases.

The European Commission has proposed a new Regulation which is currently on the table. In order to give EU legislators enough time to draft the new legislation, the Commission proposed to extend the deadline for the transposition of the 2004 Directive to two years. The European Parliament decided on an 18 month deadline.

31 March: European Patients’ Forum invites members’ feedback on IAPO patient-centred health care report

The International Association of Patients’ Organizations (IAPO) has launched a consultation on its publication "Patient-Centred Healthcare Indicators Review". The objective is to identify and assess current initiatives and indicators which measure the patient-centeredness of healthcare providers and health systems. IAPO is the sister organisation of EPF (European Patients’ Forum) at the global level.

EPF has developed a short questionnaire to guide members through IAPO’s discussion paper and to ask further questions about the assessment of patient-centred health care. EPF members can obtain the questionnaire by sending an email to kaisa.immonen.charalambous@eu-patient.eu

http://www.patientsorganizations.org/showarticle.pl?id=1453

Members’ News

1 March: Romanian Alzheimer Society holds second Annual Conference

Societatea Alzheimer Romana held its second Annual Conference on 23-25 February in Bucharest. The Conference theme, “Alzheimer Dementia – a major public health priority in Romania”, attracted some 400 participants including people with dementia, carers, local and national policy makers, representatives of regional branches and health care professionals.

Ms Catalina Tudose, President of the Society, opened the conference by highlighting the importance of making Alzheimer’s disease and other forms of dementia a national public health priority.

Throughout the conference, delegates attended a wide range of parallel sessions, with topics such as risk factors, prevention, preclinical dementia, diagnosis, drug development, future treatment strategies, pharmacological treatment and disease management.

There were two special workshops dedicated to people with dementia and their carers: “How to live with Alzheimer” and “Alzheimer’s disease - a major family problem”. These workshops covered the needs of family members, the stress of carers and the relationship between GPs and patients and their carers.
The conference was highly appreciated by attendees, who cited a very interesting programme, comprehensive presentations and stimulating workshops.

1 March: Alzheimer Austria launches a new name and logo

The Austrian association has renamed itself “Alzheimer Austria” and has launched a new logo as well. The text on the logo translates as “Support for family caregivers and people with dementia”.

The new logo intends to show that the group addresses not only relatives, but also people with dementia themselves. Alzheimer Austria is working to build up a patient group and hopes that the new logo will help to attract people with dementia.

2 March: Alzheimer Uniti Italy hosts a book launch and publishes a new caregiver guide

On 2 March, Alzheimer Uniti Italy (AU) organised an event around the publication of a new book on the subject of ageing, entitled La Longevita Attiva, or An Active Long Life: The Pleasure of Knowing How to Age. Written by geriatrician Enrico Paciaroni, the book gives a positive look at ageing and reminds readers about the pleasures of ageing and about the value of living an active, enjoyable life.

Also in March, AU published a caregiver guide entitled: Dementia – 50 Questions and Answers. This co-authored by a geriatrician and a psychologist. The booklet starts with a list of the five most commonly asked questions at a first encounter with the disease, such as “Is the disease hereditary?” and “Is there a cure?” and then proceeds with questions frequently asked as the disease progresses.

21 March: France Alzheimer compares positions of French presidential candidates

France Alzheimer has launched a website showing the positions of the presidential candidates on the challenges faced by people with dementia and their families. The candidates’ comments are in the form of replies to ten questions - prepared by the French association which cover the following points:

- support for the launch of the fourth national Alzheimer plan
- development of institutions specialising in dementia
- legal recognition for caregivers
- reimbursement for caregiver training programmes and for non-pharmacological intervention.

The French presidential election will take place on 22 April and the third national Alzheimer plan will expire at the end of 2012.

12 March: Swiss parliament votes to create a national dementia plan

On 12 March, the Swiss Council of States (upper house of the federal Parliament) approved a series of proposals which effectively call upon the government to prepare a national dementia plan.

The next step will be to establish priorities and assign action items to regional authorities and associations. The Swiss Alzheimer Association is an active supporter for a national dementia plan and has proposed that the following be included:

- funding for professional training to improve diagnosis
- support for family caregivers, including funding for day/night care centres
- campaigns to raise awareness and reduce the stigma associated with dementia

There are currently more than 100,000 people with dementia in Switzerland. This will increase to 150,000 in ten years and to some 300,000 people by 2040.

19 March: Scottish Government guarantees one year of post-diagnostic support

Nicola Sturgeon, Deputy First Minister and Cabinet Secretary for Health, Wellbeing & Cities, has confirmed the Scottish Government’s guarantee of one year’s post-diagnostic support. The guarantee means that everyone receiving a diagnosis of dementia in Scotland will have access to a year of support from a trained caregiver.

As part of this commitment, the government is supporting Test Sites in various Scottish cities until the end of 2012. These sites will provide more information on the workforce and resource implications for local services to deliver this guarantee.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: “We believe that this is a world leading commitment and we commend the Scottish Government for making it. This is a significant milestone in dementia care and we expect it to be life changing for the 7,000 people diagnosed with dementia each year and their families. The challenge now is to deliver it. This will require a major shift in both practice and culture.”

An interview with Ms Sturgeon can be seen in Dementia in Scotland magazine:


26 March: Prime Minister Cameron makes dementia a national priority

On 26 March, UK Prime Minister Cameron announced a new campaign to tackle the “national crisis” caused by dementia. He set out a series of measures to be rolled out in the coming years:

- increased funding for dementia research, from EUR 32.3 million in 2010 to EUR 80 million in 2015
- creation of 20 “dementia-friendly communities” where individuals, businesses and the state will work together to support people with dementia
financial incentives for hospitals to improve and increase formal diagnoses of dementia

a public awareness campaign in autumn 2012.

Mr Cameron said: "We have got to treat [demential] like the national crisis that is already is. We did it with cancer in the 70s. With HIV in the 80s and 90s. We fought the stigma, stepped up to the challenge and made massive in-roads into fighting these killers. Now we've got to do the same with dementia."

Jeremy Hughes, chief executive of Alzheimer’s Society, said: "Today’s announcement by the prime minister marks an unprecedented step towards making the UK a world leader in dementia. Doubling funding for research, tackling diagnosis and calling for a radical shift in the way we talk, think and act on dementia will help to transform lives."

Dementia affects some 670,000 people in the UK and the cost to society is estimated at EUR 28 billion. Over the next 10 years, the number of people with dementia is expected to each one million.

Science Watch

1 March: New drug may boost muscle strength in people with ALS

Researchers at biotech firm Cytokinetics have developed a drug called CK-357 that can potentially boost muscle strength in people with Amyotrophic Lateral Sclerosis (ALS). CK-357 sensitizes muscle cells to the calcium that activates contraction, making them flex even if the incoming signals from neurons are weak. Cytokinetics is currently testing the drug in Phase 2 trials for ALS and myasthenia gravis, an autoimmune neuromuscular disease.

In the first phase of the trial, researchers provided the drug once a day over a two-week period to 24 people with ALS. CK-357 was well tolerated, and a side effect of dizziness tended to wear off during the trial period. While the study was underpowered to detect clinical benefits, some people seemed to improve in their ability to perform daily functions and in their breathing ability. Now, Cytokinetics is testing CK-357’s effects when given concurrently with the ALS drug riluzole in another 24 people.

"If you can make the muscles a little bit stronger, it would make a big difference for people with ALS," said Dr. Robert Miller, director of the Forbes Norris MDA/ALS Research Center, who was not involved in the study. The drug boosts strength by 15-25 percent in healthy people, noted Miller. For a person with ALS, that kind of increase could mean the ability to get around as well as to eat, bathe, and dress independently, he said.

The study was led by Li-Huei Tsai, Ph.D., director of MIT’s Picower Institute for Learning and Memory. Her team found that a protein called histone deacetylase 2 (HDAC2) accumulates in the brain early in the course of Alzheimer’s disease, both in mouse models and in people with the disease.

HDAC2 is known to tighten up spools of DNA, effectively locking down the genes within and reducing their activity. In the mice, the increase in HDAC2 appears to produce a blockade of genes involved in learning and memory.

Gene therapy to reduce the levels of HDAC2 prevented the blockade of gene activity. The treatment also prevented learning and memory impairments in the mice. It did not prevent neuronal death, but it did enhance neurolipoplasticity - the ability of neurons to form new connections.

Dr. Tsai also examined HDAC2 levels in autopsied brain tissue from 19 people with Alzheimer’s at different stages of the disease and from seven healthy controls. Even in its earliest stages, the disease was associated with higher HDAC2 levels in the learning and memory regions of the brain.

"We think that the blockade of gene expression plays a very important role in the cognitive decline associated with Alzheimer’s disease," said Dr. Tsai. "The good news is that the blockade is potentially reversible."

Dr. Tsai theorizes that HDAC2 is brought into play by beta-amyloid. She and her team found that exposing mouse neurons to beta-amyloid caused them to produce more HDAC2.

"We think beta-amyloid triggers a cascade of damaging reactions. Once of these is to activate HDAC2, which in turn blocks the expression of genes needed for brain plasticity. Once this blockade is in place, it may have a more systemic, chronic effect on the brain," she said.

http://www.nature.com/nature/journal/v483/n7388/full/nature10849.html

7 March: Antibodies can protect synapses from beta amyloid attack

Researchers at University College London (UCL) have found that the amyloid beta protein stimulates production of another protein called Dkk1, which is known to destroy synapses in the hippocampus. The research team also showed that they could neutralise Dkk1 with an antibody in mouse models.

Dr. Patricia Salinas, Professor of Cellular Neurobiology, said: "These novel findings raise the possibility that targeting this secreted Dkk1 protein could offer an effective treatment to protect synapses against the toxic effect of Amyloid-β."

http://www.jneurosci.org/content/32/10/3492.abstract?sid=85196406-7163-421a-a033-125f8be95a91

9 March : New tool differentiates frontotemporal dementia from depression

A French research team from the Institut de la Mémoire et de la Maladie d’Alzheimer in Paris has developed a tool called SEA (Social Cognition and Emotional Assessment) to differentiate frontotemporal dementia from depression.

Behavioural variant of frontotemporal dementia (bvFTD) causes changes to behaviour and social interaction that get worse over time. It is often misdiagnosed as...
One of the difficulties of treating brain conditions is the blood brain barrier, or BBB. This is a roadblock of cells that prevents both harmful toxins and helpful medicines from getting to the brain. The current method of getting past the BBB is by sucking the water out of the cells that form the barrier. This causes the gaps between them to get bigger so that medicine can pass. However, this opens large areas of the barrier, leaving the brain exposed to toxins.

The technique used at Sunnybrook involves injecting microbubbles, made up of lipids and gas, into the bloodstream. When focused ultrasound is applied, the bubbles expand and contract. It is thought that the force of the movement in the bubbles causes the BBB cells to temporarily separate, allowing drugs to push past the barrier and reach the brain. In the meantime, MRI scans are used to ensure that the barrier opens and to monitor how long it takes to close.

According to Meaghan O'Reilly, Research Engineer at Sunnybrook and author of the paper: “The ability of focused ultrasound combined with microbubbles to disrupt the blood brain barrier has been known for over a decade. However, because the actual technique can be challenging - there are critical steps involved - the video article fills a gap in the literature that is a major hindrance to people getting into the field.”

She added, “It’s getting close to the point where this could be done safely in humans.”

14 March: Microbubbles and ultrasound push drugs past the blood-brain barrier

A research team at the Sunnybrook Research Institute in Toronto has produced a video article that demonstrates a technique to regulate the opening of the blood brain barrier in a rat model.

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15 March: European Medicines Agency sees no need to update Alzheimer's disease guideline

The European Medicines Agency (EMA) has determined that there is no need to update the current "Guideline on Medicinal Products for the Treatment of Alzheimer’s Disease and Other Dementias".

This recommendation was delivered by the EMA’s Committee for Medicinal Products for Human Use (CHMP): “CHMP is well aware of the ongoing clinical trials and validation studies of new diagnostic criteria and potential biomarkers. However, it seems premature to update now the current [Guideline]. As soon as new validated data on diagnostic criteria and potential biomarkers will be available these scientific developments and current experience in SAWP procedures will be taken into consideration for an update of the [Guideline]. Therefore postponement of the update is recommended by CNSWP.”

An update of the Guideline may take place in 2013.

15 March: Novartis withdraws application for extension of rivastigmine patches to people with Parkinson’s disease

On 15 March, Novartis Europharm withdrew its European Medicines Agency (EMA) application for an extension of the indications of rivastigmine transdermal patches to include treatment of symptomatic treatment of mild to moderately severe dementia in patients with idiopathic Parkinson’s disease.
The two patches are currently indicated for the symptomatic treatment of mild to moderately severe Alzheimer’s disease. The extension application was originally submitted on 30 March 2011 and was under review by EMA’s Committee for Medicinal Products for Human Use (CHMP).

Novartis decided to withdraw the application after the CHMP indicated that it needed additional data in order to conclude a favourable approval. However, this data could not be generated within the timeframe allowed.

The Novartis rivastigmine transdermal patches are marketed as Exelon and Prometax.


19 March: Flow cytometry allows tracking and recovery of protein clusters

Researchers at the University of Melbourne have developed a method to rapidly identify and track proteins which form clusters inside cells.

The research team, led by Dr. Danny Hatters, used a flow cytometer to track protein clusters in cells. They were also able to recover cells containing clustered proteins. Flow cytometry works by suspending particles in a stream of fluid and passing them by an electronic detection apparatus.

Dr. Hatters said: "Being able to identify locations of diseased proteins in cells enables drugs to be developed to target different stages of disease development."

"Now we can see how the proteins form clusters inside a cell and can examine which cell functions are being damaged at different steps of the clustering process."

www.nature.com/nmeth/journal/vaop/ncurrent/full/nmeth.1930.html

21 March: FKBP52 protein may prevent tau hyperphosphorylation

Researchers at France’s INSERM have found that the FKBP52 protein may prevent hyperphosphorylation of the tau protein, i.e. it may prevent tau from turning pathogenic.

The team, led by Prof Etienne Baulieu, found a direct correlation between high levels of hyperphosphorylated tau protein and reduced levels of FKBP52 in the brain cells of people who died with Alzheimer’s disease.

This suggests that FKBP52 could control the production of pathogenic tau: when FKBP52 was reduced in Alzheimer neurons, pathogenic tau accumulated and contributed to the neurons’ degeneration.

Prof Baulieu said: "Research on tau has been very limited, and until recently, I was among the few scientists focusing on tau pathology. The discovery of the FKBP52 protein is the only ‘anti-Tau’ perspective so far. Its reduced production in the brains of Alzheimer’s patients marks a turning point in understanding this complex disease."

http://iospress.metapress.com/content/55sp2343ab473e6u?ip=48cfc6cd160f4bb&aid=0

27 March: Brain insulin resistance contributes to cognitive decline

A new study from the University of Pennsylvania shows that insulin resistance in the brain precedes and contributes to cognitive decline, to a greater extent than other known causes of Alzheimer’s disease.

Insulin plays a role in many bodily functions, including the health of brain cells. The team identified extensive abnormalities in the activity of two major signaling pathways for insulin and insulin-like growth factor in non-diabetic people with Alzheimer’s disease.

The investigators used samples of postmortem brain tissue from non-diabetics who had died with Alzheimer’s disease, stimulated the tissue with insulin, and measured how much the insulin activated various proteins in the insulin-signalling pathways.

There was less insulin activation in Alzheimer’s cases than in tissue from people who had died without brain disease. Other proteins linked to insulin action in the brain were abnormal in Alzheimer’s disease samples. These abnormalities were highly correlated with episodic memory and other cognitive disabilities in the people with Alzheimer’s disease.

Dr. Steven Arnold, Professor of Psychiatry and Neurology, said: "Our research clearly shows that the brain’s ability to respond to insulin, which is important for normal brain function, is going offline at some point. Insulin in the brain not only modulates glucose uptake, but also promotes the health of brain cells - their growth, survival, remodeling, and normal functioning. We believe that brain insulin resistance may be an important contributor to the cognitive decline associated with Alzheimer’s disease."

http://www.jci.org/articles/view/59803?search%5Barticle_text%5D=&search%5Bauthors_text%5D=steven+arnold

30 March: MRI imaging technique shows "simple" brain wiring structure

An international team of scientists have created new visuals of human and primate brains that show a deceptively simple wiring pattern. These visuals reveal two-dimensional sheets of parallel fibres crisscrossing other sheets at right angles in a grid-like structure.

The new visuals were made by using diffusion spectrum magnetic resonance imaging. This traced the movement of water molecules along the intersections of brain fibres and to track the orientation of each fibre at each crossing.

The team scanned four types of primate brains from deceased animals, enabling them to image the brains for up to 48 hours. They also scanned brains from living humans using a new scanner that can achieve ten times the resolution of conventional MRI machines. Using special software, the researchers then reconstructed three-dimensional images of the brain-fibre pathways.

"The surface of the brain contains about 40 billion nerve cells, each making about 1,000 connections in a pattern that brain researchers have yet to decipher", said Dr. Marsel Mesulam, director of the Cognitive Neurology and Alzheimer’s Disease Center at Northwestern University, who was not involved in the study.

He added: "There can be no more fundamental question in philosophy, in psychology. The human brain is the single most complex device in the known universe, and it..."
works by nerve cells talking to each other. If we can’t figure out how they decide who to talk to and what they tell each other, we just don’t understand how the brain functions.”

Researchers from the following institutions participated in this study: Boston University, Harvard Medical School, Massachusetts General Hospital, National Taiwan University College of Medicine, University Hospital Center -University of Lausanne and Vanderbilt University.

http://www.sciencemag.org/content/335/6076/1628.abstract?sid=fa0d21f8-f4ab-4c0a-9d90-cc6b0b4963

30 March: Pin1 enzyme can prevent formation of pathogenic tau

A scientific team at Harvard Medical School (HMS) has developed a method to provides a clear distinction between two types of tau protein, one healthy and one pathogenic. The pathogenic variant is found in Alzheimer’s disease. The team showed that an antibody called Pin1 can prevent the formation of the pathogenic tau variant in animal models.

Dr. Kun Ping Lu, Professor of Medicine at HMS, said: “The major challenge to halt memory loss is to identify the initial period when the tau protein is transformed from ‘good guy’ to ‘bad guy’. By developing an innovative approach to making antibodies, we have uncovered a new strategy to specifically remove disease-causing tau, while leaving healthy tau intact to carry out its important responsibilities.”

www.cell.com/abstract/S0092-8674(12)00216-4

Dementia in Society

1 March: ADI seeks opinions on stigma

Alzheimer’s Disease International (ADI) is conducting a survey that will focus on the stigma surrounding dementia worldwide. The association is looking for people with dementia and their carers to share their thoughts and experiences. Interested parties should send an email to info@alz.co.uk

7 March: President Sarkozy wins award for French Alzheimer Plan

On 7 March, French President Sarkozy received an award from Alzheimer’s Disease International (ADI) for launching and supporting the "plan Alzheimer" throughout his tenure. This plan was launched in February 2008 - nine months after Mr Sarkozy took office - and will expire at the end of 2012.

In a letter of thanks to ADI, the president pointed out that more than EUR 165 million has been committed to dementia research in France, including funding for 143 research projects, 150 new researchers and training for 600 doctors. Mr Sarkozy noted that research into neurodegenerative diseases has also increased in many other European countries and is well-funded in various EU projects.

The President also noted that the perception of Alzheimer’s disease has considerably improved since 2007. Public awareness is much higher and this is helping the disease to shed its taboo image. Most importantly, this has proved beneficial for people with Alzheimer’s disease, their families and their caregivers.

9 March: Terry Pratchett criticises government

Author Sir Terry Pratchett claims that people with dementia are being penalised because government ministers regard the illness as just a social care problem.

"We are made to feel like malingerers", said Pratchett, himself diagnosed with Alzheimer’s disease in 2007. "Alzheimer’s patients are discriminated against by being seen as needing social care", he continued. "What they’ve got is a problem rather than a disease." The condition is seen as a “nuisance thing” whereas “a patient with cancer is a human being”.

The author also said it was unfair that many families were paying for dementia care themselves, while treatment for other conditions is covered by the NHS. Currently, UK residents with assets worth more than EUR 28,000 - including their house - have to pay their own dementia care bills. These can reach EUR 120,000 a year for patients in a nursing home.

Mr Pratchett argues that all patients pay for the NHS through their taxes, so they should all be treated the same.

22 March: Paul Allen donates millions for brain research

Paul Allen, a co-founder of Microsoft, announced that he would commit USD 300 million over the next ten years to turn the Allen Institute for Brain Science into a centre for basic neuroscience investigation.

The Allen Institute is a non-profit organisation which began operating in 2003 as a resource for researchers. They have created brain “atlases” of the mouse and adult human brains and electronic maps that show which genes are switched on in neurons. The institute will focus on:

- counting and classifying the different types of neurons
- illuminating the molecular machinery within cells
- studying how cells process information in networks.

Mr Allen said: “As someone who has been touched by the impact of a neurodegenerative disease - my mother has Alzheimer’s - there’s both a fascination in basic research and the hope that we can move things forward.”

http://www.alleninstitute.org/

23 March: Tommy is still on Tour in Scotland

In November 2011, we reported on campaigner Thomas Whitelaw’s year-long trek through Scotland to raise awareness of dementia. “Tommy on Tour” spoke to thousands of caregivers and collected a stack of letters and e-mails. He personally delivered these to Nicola Sturgeon, Scotland’s Deputy Prime Minister and we cited this as a successful ending to a very impressive campaign. Apparently we were wrong...

In 2012, Tommy Whitelaw continues to be very active. Apart from caring for his mother Joan, who lives with vascular dementia, he is still meeting caregivers around
Scotland. His blog already has 170+ posts in 2012. He has been mentioned in the papers, has given radio interviews and has appeared on TV. He is due to appear in a short film and next month he’ll meet with Ms Sturgeon again.

Tommy is always keen to hear from caregivers and is particularly interested in the life experiences of those who care for people with dementia. He can be contacted through his website, which contains many interesting links and articles.

http://tommy-on-tour-2011.blogspot.com

28 March: CQC report shows routine abuse of human rights

A report from the UK’s Care Quality Commission (CQC) concluded that staff in care homes and hospitals are routinely flouting official guidelines and ignoring patients' human rights by failing to seek permission before using restraint techniques. For example, elderly patients with dementia are being illegally locked in their rooms and confined to their beds with high rails. Other methods cited by the report include physical restraint, sedation, preventing patients from seeing family and friends and placing them under high levels of supervision.

According to the report, staff members believe they are acting in the best interests of the residents and many are unaware that they have to get permission to restrain elderly people.

The CQC report was released three years after new rules were introduced to limit the use of such restrictive methods. In particular, the Deprivation of Liberty Safeguards (DOLS) require care homes and hospitals to apply to their council or health authority if they want to restrict a resident’s normal freedoms.

However, the number of applications has been far lower than expected. The CQC found a considerable number of care homes where staff have still not been trained in the use of DOLS. In up to a third of care homes, no staff had been trained at all. Many NHS hospitals “gave no specific figures or proportions” of staff who had been trained.

Cynthia Bower, chief executive of the CQC, said: “Care homes and hospitals have had to train their staff.” She added that the CQC is currently developing an enforcement policy for those who break the rules.

http://www.telegraph.co.uk

New Publications & Resources

20 March: Stirling University launches Virtual Care Home

On 20 March, the Dementia Services Development Centre at Stirling University (Scotland) launched Virtual Care Home. This interactive home is an example of how a dementia-friendly environment would look. It contains seven rooms with information panels to highlight features of good practice in dementia-friendly design.

http://dementia.stir.ac.uk/virtualhome

20 March: Cognitive Dynamics brings art to life

Cognitive Dynamics, an American non-profit organisation, specialises in art therapy for people with dementia. The organisation offers training programmes to teach health care professionals, volunteers, students and family members how to successfully communicate with people who are living with dementia.

Cognitive Dynamics was founded by Dr. Daniel Potts, a neurologist who watched his father’s decline after he developed Alzheimer’s disease. During the process, Dr. Potts noticed that his father’s quality of life improved dramatically when he participated in an art therapy programme. The association aims to raise awareness for these kinds of programmes and to ensure they are available to all people who could benefit from them.

www.cognitivedynamics.org/home

30 March: New biobank offers anonymous medical data of 500,000 people

An enormous online database of medical and lifestyle records from half a million middle-aged British volunteers went live on 30 March. The volunteers, aged 40 to 69 years old, include 26,000 diabetics, 41,000 people who do not drink alcohol and 11,000 heart attack patients who attended recruitment centres throughout the UK between 2006 and 2010. The database includes 100,000 high-resolution eye scans and doctors hope to add MRI scans in the future. The volunteers’ medical records are linked to the database, so information on their health is regularly updated.

Doctors recorded their height, weight, body fat, hand grip strength, bone density, lung function, blood pressure and memory function. They also obtained information about their diet, early life experiences and psychological factors, such as how often they saw friends and family. The database includes 100,000 high-resolution eye scans and doctors hope to add MRI scans in the future.

To use the UK Biobank, scientists must register and submit plans for their research, which will then be reviewed before approval. Scientists who use the system must publish their findings and add their results to the database so other public health experts can use them.

www.ukbiobank.ac.uk

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**AE Calendar**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tbody>
<tr>
<td>3 April</td>
<td>European Commission’s conference on “European Innovation Partnership on Active and Healthy Ageing: From Plan to Action” (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>11-12 April</td>
<td>Meeting with ALCOVE (Paris, France)</td>
<td>Heike and Jean</td>
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<tr>
<td>13 April</td>
<td>GSK Health Advisory Board (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>15-17 April</td>
<td>First meeting of the European Working Group for People with Dementia, (Glasgow, Scotland)</td>
<td>Dianne, Henry and Jean</td>
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<tr>
<td>18 April</td>
<td>European Patients’ Forum General Assembly Meeting (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>19 April</td>
<td>European Patients’ Forum annual seminar (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>23-25 April</td>
<td>Global Forum on Incontinence (Copenhagen, Denmark)</td>
<td>Jean</td>
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<tr>
<td>26-27 April</td>
<td>Workshop “Finding the right balance between autonomy and protection of the person with dementia: advance directives and competence assessment” (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>11 May</td>
<td>PharmaCog interim review (Brussels, Belgium)</td>
<td>Alex</td>
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<tr>
<td>22 May</td>
<td>Symposium AMPA Ethique et Recherche Toulouse organised by the Association Monégasque pour la Recherche sur la Maladie d’Alzheimer (Toulouse, France)</td>
<td>Dianne</td>
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<tr>
<td>6 June</td>
<td>Annual IMPACT Consortium Meeting (Trondheim, Norway)</td>
<td>Dianne</td>
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<tr>
<td>19-20 June</td>
<td>Symposium “Biobanks and biomedical collections – an ethical framework for future research” organised by the Council of Europe (Strasbourg, France)</td>
<td>Dianne</td>
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**Future Conferences**

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>16-17 April</td>
<td>First meeting of the European Working Group for People with Dementia</td>
<td>Glasgow, Scotland</td>
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<tr>
<td>16-19 May</td>
<td>7th World Congress for Neuro-rehabilitation 2012 (WCRN 2012), <a href="http://www.dcconferences.net.au/wcnc2012">www.dcconferences.net.au/wcnc2012</a></td>
<td>Melbourne, Australia</td>
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<tr>
<td>21-23 May</td>
<td>The 10th HealthGrid Conference, <a href="http://amsterdam2012.healthgrid.org/">http://amsterdam2012.healthgrid.org/</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>28 May-1 June</td>
<td>IFA 11th Global Conference on ageing, <a href="http://www.birdproject.eu">www.birdproject.eu</a></td>
<td>Prague, Czech Republic</td>
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<tr>
<td>14-15 June</td>
<td>4th Biannual NUBIN Symposium on Biomarkers in Neurodegenerative Disease, <a href="http://www.vumc.nl/afdelingen/NUBIN">http://www.vumc.nl/afdelingen/NUBIN</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>12-13 July</td>
<td>International Academy on Nutrition and Aging (IANA), <a href="http://www.iagg.info">www.iagg.info</a></td>
<td>Albuquerque, New Mexico</td>
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<tr>
<td>8-11 September</td>
<td>16th Congress of the European Federation of Neurological Societies (EFNS), <a href="mailto:efhs2012@kenes.com">efhs2012@kenes.com</a></td>
<td>Stockholm, Sweden</td>
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<td>4-6 October</td>
<td>21st Alzheimer Europe Conference “Changing perceptions, practice and policy”, <a href="http://www.alzheimer-europe.org/EN/Conferences">www.alzheimer-europe.org/EN/Conferences</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>29-31 October</td>
<td>5th Clinical Trials Conference on Alzheimer Disease (CTAD), <a href="http://www.ctad.fr">www.ctad.fr</a></td>
<td>Monte Carlo, Monaco</td>
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<tr>
<td>8-11 November</td>
<td>International Conference on Clinical Practice in Alzheimer Disease (CTAD), <a href="http://www.paragon-conventions.com">www.paragon-conventions.com</a></td>
<td>Budapest, Hungary</td>
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<tr>
<td>4-10 March</td>
<td>11th International Conference on Alzheimer’s and Parkinson’s Diseases, <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a></td>
<td>Florence, Italy</td>
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<tr>
<td>20-23 March</td>
<td>58. Jahrestagung der Deutschen Gesellschaft für Klinische Neurophysiologie und Funktionelle Bildgebung (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Berlin, Germany</td>
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