Editorial

On 27 November 2009, José Manuel Barroso, President of the European Commission, announced the proposed line-up of the European Commission. We would like to wish all Commissioners well in their new roles and look forward to continuing with the high level cooperation we have enjoyed with the outgoing Commission and, in particular, the Health Commissioner Androulla Vassiliou. We hope that the European Alzheimer's Initiative will remain a priority for John Dalli from Malta, the Health Commissioner designate.

The European Parliament's adoption of a Resolution to coordinate research across Europe on degenerative diseases such as Alzheimer's disease and Parkinson's disease on 12 November signals the Parliament's continued vital support of our cause.

Support also continues for the European Alzheimer's Alliance and we are delighted to announce that Dagmar Roth-Behrendt, MEP (Germany) has agreed to be Vice Chair, alongside Frieda Brepoels (Belgium) and Brian Crowley (Ireland). Françoise Grossetête (France) continues as Chairperson of the Alliance and we are truly grateful to all of the Alliance members for such strong support.

It is with particular pleasure to report that Alliance members Françoise Grossetête and Frieda Brepoels have been awarded “MEP of the year” – for the work in the areas of health and trade respectively. The whole team at Alzheimer Europe is especially proud to report that Annette Dumas, Alzheimer Europe's EU Public Affairs Officer, has received the “Consultant of the Year” award.

You will see that our members have been busy this month and I am very happy to bring news of the collaboration between our associations in Germany and Switzerland, which has resulted in the Alzheimer Europe report “End of life care for people with dementia” being published in German.

As part of the ongoing development of our new website, we have now included an area for information on national dementia plans around Europe as well as a section on personal experiences of people living with dementia.

We sincerely hope that you find the website enjoyable and informative to use.

Jean Georges
Executive Director
European Alzheimer’s Alliance

3 November 2009: European Alzheimer’s Alliance Chair and Vice-Chair are elected MEP of the year

Françoise Grossetête, Chair of the European Alzheimer’s Alliance, has been elected MEP of the year 2009 for the work she has done in the area of health. This distinction rewards her continued commitment on health issues and in particular for making Alzheimer’s disease a European public health priority.

Frieda Brepoels, Vice-Chair of the Alliance, was elected MEP of the year for the work she has done for trade.

These prestigious awards are given by the Parliament Magazine, a well-recognised publication within the EU institutions. Only Members of the European Parliament are invited to select the MEP of the year from a shortlist of candidates.

18 November 2009: Dagmar Roth-Behrendt accepts to be Vice-Chairperson of the European Alzheimer’s Alliance

Dagmar Roth-Behrendt, MEP, Germany, Group of the Progressive Alliance of Socialists & Democrats in the European Parliament, has accepted to be the third European Alzheimer’s Alliance Vice-Chair.

Ms Roth-Behrendt is Vice-President of the European Parliament a member of the Bureau sits on the Committee on the Environment, Public Health and Food Safety and is a Substitute on the Committee on Legal Affairs.

The European Alzheimer’s Alliance is chaired by Françoise Grossetête, France, EPP. The other two Vice-Chairs are Frieda Brepoels, Belgium, Greens/EFA and Brian Crowley, Ireland, ALDE.

The European Alzheimer’s Alliance is a non-exclusive, multinational and cross-party group who brings together Members of the European Parliament committed to support Alzheimer Europe and its members to make dementia a public health priority in Europe.

Alzheimer Europe

12 November 2009: Annette Dumas, Alzheimer Europe Public Affairs Officer, wins award

The annual European Public Affairs Awards recognise the success of individuals and organisations throughout the European public affairs community and encourage best practices. This year, Alzheimer Europe is delighted to report that Annette Dumas, Public Affairs Officer of Alzheimer Europe, has been awarded the “Consultant of the Year” award.

Other categories which were awarded this year were the campaign of the year, consultancy of the year, Corporate Public Affairs Professional of the year, NGO of the year, outstanding contribution of the year, Think Tank of the year, trade association/professional body of the year and web 2.0 campaign of the year.

The awards are organised by Dods (the political information, public affairs and policy communication specialist in the EU).

26 November 2009: New areas added to Alzheimer Europe website

As part of the ongoing development programme of Alzheimer Europe’s website, two new sections have been added during November:

- The current status of national dementia plans around Europe can now be found on the Alzheimer Europe website under the Policy in practice section of the website (www.alzheimer-europe.org/Policy-in-Practice/National-Dementia-Plans)
- A section on people’s personal experience of living with dementia is now included in the Living with dementia section (www.alzheimer-europe.org/Living-with-dementia/Personal-Experiences-of-living-with-dementia).
Visit the completely revised AE website on:
www.alzheimer-europe.org
Alzheimer Europe Networking

On 27 October (Luxembourg, Luxembourg) Gwladys attended meetings to discuss the requirements for hotel accommodation for the 20th Alzheimer Europe conference in Luxembourg.

On 3 November (Brussels, Belgium), Annette attended the EFPIA/Parliament Magazine meeting in the European Parliament on the theme "Towards a healthier Europe".

On 10 November (Brussels, Belgium), Jean attended a meeting on European collaboration in dementia research organised by the Danish Permanent Representation.

On 17 November (Luxembourg, Luxembourg) Jean and Julie met with Binsfeld to discuss the 2009 Yearbook and 4th issue of the Dementia in Europe magazine.

On 18 November (London, UK), Jean met with representatives of GSK to present the organisation’s Work Plan for 2010.

On 19 November (London, UK), Jean attended a meeting of the Recognition Programme supported by Eisai and Pfizer.

On 19 November (Brussels, Belgium), Annette attended the EFPIA Think Tank meeting.

On 20 November (Luxembourg, Luxembourg) Jean and Julie met with Binsfeld to discuss the 2009 Yearbook and 4th issue of the Dementia in Europe magazine.

On 27 November (Brussels, Belgium), Annette met Europabio intern to discuss her assignment: ‘Bridging the healthcare information gap between EuropaBio and policy makers’.

On 30 November (Luxembourg, Luxembourg), representatives of Novartis visited the AE offices for an exchange of views and a discussion on the 2010 sponsorship opportunities which AE provides to companies.

European developments

14 October 2009: ECOSOC meeting on the European Commission’s Communication on a European initiative on Alzheimer’s disease and other dementias

The European Economic and Social Committee (ECOSOC) is preparing a report on the Commission’s Communication on a European initiative on Alzheimer’s disease and other dementias.

The drafting group invited a representative of Alzheimer Europe (Annette Dumas), DG Sanco (Antoni Montserrat) and DG Research (Manuel Hallen) to discuss their draft report and share information.

The final report will be available on the SOC Section’s website, under the link “Public health”, after the December plenary session.

27 November 2009: European Commission’s President unveils the names of the Commissioners designate

José Manuel Barroso, President of the European Commission, presented the portfolios responsibilities for the next Commission which term of office will run until 2014.

The new College will have 7 Vice-Presidents, including Vice-President Baroness Catherine Ashton who will, at the same time, be the High Representative of the Union for Foreign Affairs and Security Policy.

President Barroso has announced a number of new portfolios: Climate Action; Home Affairs; Justice, Fundamental Rights and Citizenship. He has reconfigured a number of other portfolios: Education, Culture, Multilingualism and Youth; Health and Consumer Policy; Industry and Entrepreneurship; Research and Innovation; International Cooperation, Humanitarian Aid and Crisis Response. There will be a new emphasis on inclusion in the Employment, Social Affairs and Inclusion portfolio, and a renewed focus with the Digital Agenda portfolio.

Before it takes office, the new Commission must gain approval from the European Parliament. The Commissioner designates will appear in individual hearings before Parliamentary committees from 11-19 January. The vote of consent on the new Commission as a whole is foreseen to take place on 26 January.

The new Commission will work along the political guidelines for the next Commission presented by President Barroso in the European Parliament last September:
restoring economic growth today and ensuring long-term sustainability and competitiveness for the future,

• fighting unemployment and reinforcing our social cohesion,

• turning the challenge of a sustainable Europe to our competitive advantage,

• ensuring the security of Europeans,

• Reining EU citizenship and participation.

Priorities for tackling these challenges will be set in a ten year framework to deliver a vision for the EU in 2020, reinvigorating the inclusive social market economy that is the hallmark of the European way of life.

Responsibilities of the Commissioners-designate

• Joaquin ALMUNIA: Competition. Vice-President of the Commission (Spain).

• László ANDOR: Employment, Social Affairs and Inclusion (Hungary).

• Baroness Catherine ASHTON: High Representative of the Union for Foreign Affairs and Security and Vice-President of the Commission (UK).

• Michel BARNIER: Internal Market and Services (France).

• Dacian CIOLOS: Agriculture and Rural Development (Romania).

• John DALLI: Health and Consumer Policy (Malta).

• Maria DAMANAKI: Maritime Affairs and Fisheries (Greece).

• Karel DE GUCHT: Trade (Belgium).

• Štefan FÜLE: Enlargement and European Neighbourhood Policy (Czech Republic).

• Johannes HAHN: Regional Policy (Austria).

• Connie HEDEGAARD: Climate Action (Denmark).

• Máire GEGHEGAN-QUINN: Research and Innovation (Ireland).

• Rumiana JELEVA: International Cooperation, Humanitarian Aid and Crisis Response (Bulgaria).

• Siim KALLAS: Transport. Vice-President of the Commission (Estonia).

• Neelie KROES: Digital Agenda. Vice-President of the Commission (The Netherlands).

• Janusz LEWANDOWSKI: Budget and Financial Programming (Poland).

• Cecilia MALMSTRÖM: Home Affairs (Sweden).

• Günther OETTINGER: Energy (Germany).

• Andris PIEBALGS: Development (Latvia).

• Janez POTOČNIK: Environment (Slovenia).

• Viviane REDING: Justice, Fundamental Rights and Citizenship. Vice-President of the Commission (Luxembourg).

• Olli REHN: Economic and Monetary Affairs (Finland).

• Maroš ŠEFČÍKOVÍČ: Vice-President of the Commission for Inter-Institutional Relations and Administration (Slovakia).

• Algirdas ŠEMETA: Taxation and Customs Union, Audit and Anti-Fraud (Lithuania).

• Antonio TAJANI: Industry and Entrepreneurship. Vice-President of the Commission (Italy).

• Androulla VASSILIADOU: Education, Culture, Multilingualism and Youth (Cyprus).

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on:

www.alzheimer-europe.org

12 November 2009: European Parliament calls for joint EU action on Alzheimer’s disease

The European Parliament adopted on 12 November a Resolution on plans to coordinate research across Europe on degenerative diseases such as Alzheimer’s disease and Parkinson’s disease.

The Resolution urges the Member States to develop a common research agenda in the field of neurodegenerative diseases and improve epidemiological data on Alzheimer’s disease. The aim is to pool skills, knowledge and resources to maximise the work carried out in the various EU countries.

The Resolution mentions early diagnosis and research into risk factors, treatment, prevention and social research, standard diagnostic tools and the creation on broad-based databases.

The MEPs urged the Commission to include dementia in all EU disease prevention measures. A European Year of the Brain should be launched to raise awareness of brain-related diseases associated with ageing.

MEPs stressed that all future initiatives on joint research should be adopted under the EU’s legal competency for research.

This Resolution, led by Françoise Grossetête, Chair of the European Alzheimer’s Alliance,
and supported by all political groups, received a warm response from the MEPs.

**Policy Watch**

3 November 2009: Researchers examine packages of dementia care in low and middle income countries

A report has been published on the “packages of care for dementia in low-and middle-income countries” in the journal PLoS Medicine. The researchers report that:

- Two-thirds of people with dementia live in low and middle income countries (LMICs), where there are few services available and levels of awareness and help-seeking are low.
- After early diagnosis, the principal goals for management of dementia are optimising physical health, cognition, activity and wellbeing; detecting and treating behaviour and psychological symptoms (BPSD) and providing information and long-term support to carers.
- Routine packages of continuing care should comprise diagnosis coupled with information, regular needs assessments, physical health checks, and carer support, and, where necessary, carer training, respite care and assessment and treatment of BPSD.
- Care can be delivered by trained primary care teams working in a collaborative care framework. Continuing care with practice-based care coordination, and community outreach are essential components of this model.
- Efficient care delivery in LMICs involves integrating dementia care with that of other chronic diseases and community-support programmes for the elderly and disabled.

The report is part of a “series of articles highlighting the delivery of ‘packages of care’ for mental health disorders in low- and middle-income countries” and researchers were led by Martin J Prince, King’s College, London, UK.

10 November 2009: Consultation period in Scotland opens on proposed legislation to protect vulnerable adults

In 2010 the Scottish Government will introduce a new membership scheme, “The Protecting Vulnerable Groups Scheme” (PVG), which is a system whereby all people who work with children and vulnerable adults can be placed on a register which would confirm there is no known reason why an individual should not work with these client groups. The PVG will:

- Help to ensure that those people who have regular contact with children and protected adults through paid and unpaid work do not have a known history of harmful behaviour
- Be quick and easy to use, reducing the need for PVG Scheme members to complete a detailed application form every time a disclosure check is required
- Strike a balance between proportionate protection and robust regulation and make it easier for employers to determine who they should check to protect their client group.

Following on from commitments given by the previous Scottish Parliament to consult on related draft legislation, the Scottish Government has opened a consultation period on seven draft Scottish Statutory Instruments (SSIs), a partial Regulatory Impact Assessment (RIA) and the draft guidance. The closing date is 2 February 2010.

10 November 2009: UK-Report published on the use of antipsychotic medication for people with dementia

“The use of antipsychotic medication for people with dementia – Time for action” is a report written for the Minister of State for Care Services by Professor Sube Banerjee, Professor of Mental Health and Ageing, the Institute of Psychiatry, King’s College, London. Although the report recognises that antipsychotic medications may have value in particular situations, Professor Banerjee concludes that antipsychotics “appear to have only a limited positive effect in treating symptoms, but can cause significant harm to people with dementia.” 11 recommendations are made:

1. The creation of a clinical governance priority across the National Health Service (NHS) to reduce the use of antipsychotic drugs for people with dementia and provide an assurance of when they are needed
2. National leadership for reducing the level of prescription of antipsychotic medications for people with dementia
3. The development of an audit to generate data on the use of antipsychotic medication for people with dementia
4. The setting of clear, realistic and ambitious goals for the reduction of
the use of antipsychotic drugs for people with dementia

5. A call for further research to be carried out

6. The development of a curriculum which will equip GPs and others working in care homes with the necessary skills to manage those residing in care homes

7. The creation of a curriculum for the development of skills for care home staff in the non-pharmacological treatment of behavioural disorders in dementia

8. The commission of an in-reach service that supports primary care in its work in care homes

9. The use of data to serve as markers of the quality of care provided by care homes

10. That information and support be available to carers

11. Meetings be set up between specialist older people’s mental health services and GPs in order that they plant how to address the issue of people with dementia in their own homes who are on antipsychotic medication.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

18 November 2009: UK: Personal Care Bill announced

During the Queen’s speech at the opening of the UK Parliamentary session, a personal care bill was announced “to enable the wider provision of free personal care to those in highest care need.”

The Government lists the benefits of the Bill as:

- Guarantee free personal care for the 280,000 people – including those with serious dementia or Parkinson’s disease – with the highest needs.
- Protect the savings of the 166,000 people who currently get free care from future charges.
- Help around 130,000 people who need home care for the first time to regain their independence.
- Where home adaptations or technology can increase a person’s independence and reduce care needs, these would be offered.
- It would allow GBP 130 million to be invested in re-ablement and prevention to help people to maintain their dignity and rebuild their confidence so that they can live at home for longer.
- This would put prevention at the heart of the system, improving quality, empowering people, and saving the NHS and social care money.

Gordon Brown, Prime Minister, said that the older generation were owed a “debt of dignity”. The cost of implementing the Bill is estimated to be GBP 670 million.

12 November 2009: UK government announces action plan to tackle the over-prescription of antipsychotic drugs to people with dementia

The Care Services Minister, Phil Hope, has announced an action plan to address the over-prescription of antipsychotic drugs to people with dementia. This follows the publication of the findings of an independent review which were published in a report entitled “The use of antipsychotic medication for people with dementia – Time for action”, having been carried out by Professor Sube Banerjee and commissioned by the Department of Health.

The new action plans will include:

- a new National Clinical Director for dementia
- measures to ensure people with dementia and their carers have access to psychological therapies to tackle the root of agitation and aggression
- an audit to establish definitive prescribing figures
- clear local targets to cut antipsychotics use as a result of the audit
- better regulation
- collaboration with the General Medical Council (GMC) and Royal Colleges to ensure all health and social care staff have specialist training in dementia
- Joint Department and Alzheimer’s Society guidance on what to do if a family member is given antipsychotics.

Phil Hope explained: “It is unacceptable that antipsychotic drugs are routinely prescribed to people with dementia. More than half of people with dementia will experience agitation or aggression at some point, but NICE guidance
is clear – antipsychotics should only be given when this is really necessary.”

Neil Hunt, Chief Executive of the Alzheimer Society, said “The scandalous over-prescription of antipsychotic drugs leads to an estimated 1,800 deaths a year, it must end.”

26 November 2009: UK Government investment in dementia research falls

In response to a question on dementia research from Paul Burstow, MP, the Health Minister, Gillian Merron, revealed that the combined Medical Research Council and Department of Health (National Institute for Health Research) investment in dementia research amounted to GBP 29.9 million in 2008-09. This figure is a reduction from the previous year’s investment of GBP 32.2 million.

Phil Hope, Health Minister, said the fall was due to the fact that fewer dementia research proposals had met the quality standards required. However, Paul Burstow said that “These figures reveal the huge gulf between the scale of the dementia challenge and the Government’s commitment to invest in research. Ministerial Task forces add nothing in if they don’t change the bottom line of the balance sheet. What is required is more research funding.”

Further, Rebecca Wood, Chief Executive of the Alzheimer’s Research Trust, said “After years of talking up its commitment to dementia research, it is appalling that government investment has actually fallen. The government has published promising strategies, held summits, and the heard the concerns of scientists, but all this is futile without proper financial support. If we do not significantly increase investment in dementia research in order to develop new treatments, we are headed for an unmitigated social and economic disaster.”

November 2009: Belgian Alzheimer association participates in discussions to incorporate “Milieuthérapie” in Liège hospital

Milieuthérapie is the idea that a person who has dementia should live and be taken care of within an environment (milieu) which is adapted to his/her condition. The environment includes such elements as carers and care, materials, architecture, behaviour and communication and medial attendants. Following a symposium on Milieuthérapie in September, a meeting was held in Belgium to discuss how to run a Milieuthérapie trial in the hospital Le Péri (Liège). Amongst others, Sabine Henry, Chairperson of La Ligue Alzheimer and La Ligue Nationale Alzheimer Liga (LINAL), attended the meeting along with Dr Schuerch, Head of the Psycho-geriatrics department. The aim of the trial would be to improve people with dementia’s lives and would be supported by families and professional carers. If successful, the trial could be used as an example for other hospitals and residential homes.

The Alzheimer cafés are an example of how the concept of Milieuthérapie has been incorporated. These cafés offer convivial meeting point for people with dementia, their families, carers and anyone who has an interest in Alzheimer’s disease by offering the opportunity to chat in informal surroundings about the disease and about living with the disease. Currently there are more than 20 cafés held each month throughout the French-speaking community of Belgium.

Members’ News

Autumn 2009: Alzheimer Sweden commences education programme for nurses and raises awareness of Alzheimer’s disease

The Swedish Alzheimer Association, Alzheimerföräningarna, has begun to run their education programme (which is of university level) for nurses who work in the field of dementia in Sweden. The three-day course, which accommodates up to 25 nurses, is conducted at the associations “Alzheimer house” in Lund and lectures are offered by some of Sweden’s most respected scientists (for example, PhD associate Professor Elisabet Londos and PhD associate professor Lennart Minthon). The course also covers topics such as ethics and treatments. During spring 2010, the course will be offered five more times. The education programme continues after the summer season.

The Association has also been busy raising awareness of Alzheimer’s disease by holding information evenings on different topics at various locations around Sweden. So far this year, the Association has held 30 evenings, and between 300 to 600 people have attended each meeting. On an average the association meets about 10,000 people every year by carrying out gatherings like these.

Members’ News
6 November 2009: Alzheimer Scotland launches dementia advisor network

Lord Sutherland of Houndwood, Alzheimer Scotland’s President, launched a Dementia Advisor network which consists of 19 Dementia Advisors operating in 18 local authorities throughout Scotland. The role of a Dementia Advisor is to support people with dementia, their families and friends throughout by providing ongoing support, information and connecting people with services and peer groups.

Henry Simmons, Chief Executive of Alzheimer Scotland said “We’ve recruited versatile, innovative and dedicated people to fill these posts. People who will work in partnership with local community services to make sure that no-one feels they have to go through dementia on their own. Our long term plan is to have a Dementia Advisor in every local authority an ultimately every town in Scotland.”

12 November 2009: The German Alzheimer Society co-host conference on Frontotemporal dementia

The German Alzheimer Society (Deutsche Alzheimer Gesellschaft e.V), in collaboration with Dialogue and Transfer Centre, University of Witten/Herdecke and the Dementia Service Centre, North Rhine-Westphalia, Cologne, hosted the conference “Challenge Frontotemporal dementia”.

All participants (250 people including members, nurses and doctors) agreed that there is a need for research on support for family members and the training of professionals in all aspects of frontotemporal dementia (FTD), with 33,000 people being diagnosed with this disease in Germany. The audience heard how the disease is difficult to diagnose and Dr Janine Diehl-Schmidt explained “frontotemporal dementia is often not detected and, instead, for example, diagnosed as depression”. Some of the problems which arise with FTD were also raised, such as the fact that people who are diagnosed with FTD tend to be relatively young, in employment and may have children in education and these are added concerns when a person becomes unwell. Indeed, one participant said: “My husband is not even 40 years old and is suffering from FTD. He can no longer work and we have five small children. I’m at my limit, but nowhere can I find help.”

17 November 2009: Alzheimer Society reports on the quality of dementia care in hospitals

Although there was a general awareness of unacceptable variations in the quality of dementia care provided in general wards in hospitals across England, Wales and Northern Ireland, the Alzheimer’s Society investigated the reality of this situation. They did so by collecting quantitative and qualitative evidence from people with dementia, their carers, nursing staff and nurse/ward managers via questionnaires, the responses of which were collated and can be found in the Alzheimer Society’s report: “Counting the cost – caring for people with dementia on hospital wards.” The report contains the Society’s findings on:

1. People with dementia in hospital
2. The outcomes of being in hospital
3. What is going wrong? Evidence from people with dementia, their carers and nurses.

Recommendations include:

1. That the National Health Service (NHS) as a whole and individual hospitals need to recognise that dementia is a significant, growing and costly problem
2. A call for a reduction in the number of people with dementia being cared for in hospitals
3. That hospitals identify a senior clinician to take the lead for quality improvement in dementia
4. A call to commission specialist liaison older people’s mental health teams to facilitate the management and care of people with dementia in hospitals
5. The need for an informed and effective acute care workforce in hospitals for people with dementia
6. A call for the reduction in the use of antipsychotic drugs to treat people with dementia on a general ward
7. The involvement of people with dementia, carers, family and friends in the care of people with dementia to improve person-centred care
8. That people with dementia have enough to eat and drink
9. A change in the approach to care for people with dementia to one of dignity and respect.

Neil Hunt, Chief Executive of the Alzheimer Society said: “It is shocking that people with dementia are occupying up to a quarter of hospital beds yet there are scandalous variations in quality of dementia care in hospitals. At least 80 million a year, and
probably hundreds of millions, could be saved if people with dementia are enabled to leave hospital one week earlier. Hospitals must commit to reducing the length of stay if we are to stop people with dementia deteriorating in the hospital."

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

18 November 2009: Alzheimer Portugal launches its Christmas sale

Alzheimer Portugal launched its annual Christmas Sale on the 18th of November.

Every year a group of volunteers help to run this sale, which is held in Lisbon. Decorative items with the Christmas theme can be found including various products at reduced prices from Portuguese companies. Products made by people with dementia from our Day Care Center (as part of the occupational therapy activities) are also available - The pumpkin jam is always a great success with the visitors! As in previous years, there are also several serigraphies, offered by the artist Júlio Pomar.

All revenue generated by the Christmas Sale is entirely dedicated to a project organised by the Social Service Department of the Association. This initiative aims to provide people with Alzheimer’s disease technical help and support to help improve their quality of life and of their caregivers.

The Christmas Sale is open until December 22.

23 November 2009: The Alzheimer Society of Finland elects Chairman of the Annual General Meeting

Muistiliitto ry, the Alzheimer Society of Finland, has elected Mr Pekka Laine to the post of Chairman of the Annual General Meeting. Mr Laine will follow the activity of the Board by attending the Board meetings of the Alzheimer Society throughout the year.

24 November 2009: The Alzheimer Society in Cyprus launches Christmas diaries

Paintings made by children from three primary schools in Cyprus to celebrate World Alzheimer’s day are to feature in a Christmas diary, which is being prepared by the Pancyprian Alzheimer’s Society. The paintings were displayed during the inauguration of day care centres in Nicosia and Lythrodontas. Support has been given for the Christmas diary initiative by Mr Alecos Kouratos of the Ministry of Education and Civilisation. The Christmas diaries will be sold for EUR 5.

World Alzheimer’s Day

Following our coverage of World Alzheimer’s day in October’s newsletter, we are delighted to be able to include coverage of additional members’ activities:

Belgium: celebrates World Alzheimer’s Day

The Belgium Alzheimer association, La Ligue Nationale Alzheimer Liga (LINAL), organised an “Alzheimer Café Day” in Brussels, on 9 September. Attended by some 300 people, the event included an invitation to visit the Cafés, continuous animations throughout the day, a sketch by a young artist and presentations of the various activities available (such as memory games). There was also a music therapy session, which was particularly successful both in terms of attention it received and the participation by attendees. The association was delighted by the turnout as the day helped to promote a point of contact (the free helpline 0800/15 225) and the event also enabled people with dementia’s point of view to be put forward, contributing to make the disease and its consequences sound less alarming than it is usually perceived to be.

In addition, the association presented the Santkin award to Doctors Stéphane Adam, Kristel Sleegers and Marc Cruts. The Santkin award was created by LINAL as a tribute to Minister Jacques Santkin. Since 2005, the prize has awarded research papers related to the psychosocial and/or fundamental aspects of Alzheimer’s Disease. LINAL recognises and makes known the latest scientific breakthroughs in this specific field of research by awarding deserving researchers and their teams a EUR 8,000 grant.
Greece: The Athens Alzheimer’s Association celebrates World Alzheimer Day

The Athens Alzheimer’s Association (Greece) managed to secure more than 12,000 signatures for the Greek Alzheimer’s Initiative. On 21 September, the signatures were presented, by people with dementia, to Dimitris Avramopoulos, the Greek Minister of Health in a special ceremony held in the Public Gardens in Athens. This followed a Memory Walk, in which 1,500 carers, people with dementia and supporters (including the Mayor of Athens and members of the National Parliament), took part. The event was covered by television and received publicity from the press.

Ireland: Mini-marathon participants raise money for the Alzheimer Society and company restores day-care centre garden

Runners and walkers in the Cork mini-marathon were sponsored in aid of the Alzheimer’s Society of Ireland. Staff (Jo Calnan, Ann Marie Brosnan, Noreen Maloney and Mary O’Regan) from the Brandon Day Care Centre took part, all of whom the Alzheimer Society extended their gratitude to. An especially big thank you was given to the Regional Secretary, Ailsa Thompson, who registered runners on the Society’s behalf.

In addition, a team from Deloitte and Touche, donated their community day to doing up the garden, fences and garden furniture at Bessboro Day Care Centre, Cork on World Alzheimer’s Day, for which the Alzheimer’s Society thanked Sancha and her team.

Sweden: Alzheimer Sweden organises concert on World Alzheimer’s Day

In support of World Alzheimer’s Day, Queen Silvia of Sweden sent a personal letter to the Swedish Alzheimer Association, Alzheimerforeningen. A three-hour celebration took place in the concert hall of Gothenburg, where 1,250 people listened to information on science, treatments and also music. Famous artists and musicians performed alongside well-known international scientists (Professors Kaj Blennow, Lars Lannfelt, Agneta Nordberg, Barbro Beck Friis and Associate Professor Lennart Minthon).

Science Watch

27 October 2009: Relationship between blood levels of amino acid and Alzheimer’s disease examined

A study of middle-aged women, in which high levels of homocysteine, an amino acid associated with the body’s metabolism, suggests that these levels were associated with later onset dementia. The thesis, from the Sahlgrenska Academy at the University of Gothenburg, Sweden, is based on the Prospective Population study of Women in Gothenburg which was started in the 1960s when nearly 1,500 women aged between 38 and 60 were examined and had blood samples taken. The information and samples were compared with information on those people who later developed Alzheimer’s disease and dementia.

27 October 2009: Study examines the heritability of frontotemporal lobar degeneration

Researchers collected blood samples of 225 people with a diagnosis of frontotemporal lobar degeneration (FTLD) and examined the heritability of FTLD by ascertaining family history and the existence of mutations of the disease-causing genes. They found that FTLD is a “highly heritable disorder by heritability varies between different syndromes” with specific “gene mutations (MAPT and GRN) accounting for a substantial proportion of familial cases”.

For further information please contact Professor Martin N. Rosser, Dementia Research Centre, Institute of Neurology, London or see the article “The heritability and genetics of frontotemporal lobar degeneration” in the journal Neurology (2009:73: 1451-1456).

1 November 2009: Study suggests that simple tests could help predict cognitive impairment

Over a 20 year period, researchers monitored learning and memory abilities, as well as use of language, of over 240 elderly individuals who were healthy at the start of the study. They found that “the results of the Cambridge Cognitive Examination could reliably predict when a health person was likely to develop mild cognitive impairment, a frequent precursor to dementia.”

The research was carried out by Oxford University researchers within the context of the
Oxford Project to Investigate Memory and Ageing (OPTIMA) and published in the journal Neurology.

**2 November 2009: Study identifies early risk factors for Alzheimer’s disease**

A study which aimed to identify heritable trains in middle age that contribute to Alzheimer’s disease found that “hypertension and the expression of an innate pro-inflammatory cytokine profile in middle age are early risk factors for Alzheimer’s disease in old age.”

The study was conducted in the Netherlands on 200 offspring of families with a parental history of late-onset Alzheimer’s disease and 200 offspring of families without a parental history of Alzheimer’s disease. Led by Eric Van Exel, VU University Medical Centre, Amsterdam, the study was published in the journal Archives of General Psychiatry.

We provide full references to articles on our website. Please visit the completely revised Alzheimer Europe website on: www.alzheimer-europe.org

**3 November 2009: Pharmaceutical companies announce phase three trials of drug for people with Alzheimer’s disease**

Pfizer and Medivation announced the initiation of two Phase 3 trials (CONTACT and CONSTELLATION) of the investigational drug dimebon in people with moderate to severe Alzheimer’s disease.

The CONTACT study will assess as primary endpoints the potential benefits of adding dimebon to ongoing treatment with donepezil HCl tablets, the leading AD medication worldwide, on neuropsychiatric symptoms and activities of daily living. The CONSTELLATION study will evaluate as primary endpoints the effects of adding dimebon to memantine HCl, another standard of care, on cognition, memory and activities of daily living.

**4 November 2009: Phase 2 trial to commence with gene therapy product aimed at the treatment of Alzheimer’s disease**

Following the phase 1 study of the gene therapy product CERE 110 (designed to deliver nerve growth factor (NGF) for the treatment of Alzheimer’s disease), which indicated that a single administration of the therapy was well-tolerated, a Phase 2 trial will commence in 2010. Fifty people with mild to moderate Alzheimer’s disease will be enrolled for the trial.

**9 November 2009: Study examines dual-tasking abilities of people with Alzheimer’s disease**

A study found that people with Alzheimer’s disease were less able to carry out “dual-tasking” than people with chronic depression or healthy elderly individuals. Researchers believe this may assist with diagnosis of Alzheimer’s disease, symptoms of which can be mistaken for depression.

The research team was led by Professor Sergio Della Sala, University of Edinburgh and published in the Journal of Neurology.

**9 November 2009: Study examines the relationship between muscle strength and Alzheimer’s disease**

A study which monitored cognitive function tests, neurological exams and measurements of muscle strength on 970 older adults who did not have dementia at their initial evaluation found an association between impaired muscle strength and risk of Alzheimer’s disease, mild cognitive impairment and/or cognitive decline. The researchers believe that muscle strength may offer an early clinical marker of Alzheimer’s disease but also said that “decreased strength may not be a true risk factor. Rather, loss of muscle strength may be the result of an underlying disease process that also leads to cognitive decline and clinical symptoms of Alzheimer’s disease.”

The study was led by Patricia Boyle PhD, Rush Alzheimer’s Disease Center and published in the journal Archives of Neurology.

**10 November 2009: Study examines the pathology of dementia and the risks for dementia**

A study on over 400 brains showed that the main pathological contributors to dementia were plaques and neurofibrillary tangles, with other factors contributing to the risk of dementia being age, markers of reduced brain size and atrophy of the hippocampus. Researchers concluded that dementia is often associated with mixed pathological changes.

The study was published in the PLoS medicine journal and led by Paul Ince, University of Sheffield.

**11 November 2009: Study identifies mouse gene which reduces the accumulation of proteins associated with Alzheimer’s disease**

Researchers, who searched for genes which regulate amyloid beta generation, have
identified a mouse gene (Rps23r1) that reduces the accumulation of amyloid beta and tau proteins, which play a role in Alzheimer’s disease.

The study was carried out by researchers from Burnham Institute for Medical Research, USA, and published in the journal Neuron.

13 November 2009: Study examines the relationship between cognitive impairment and gum disease

Researchers, who analysed a survey on more than 2,000 people who had been tested for periodontitis and had completed memory tests, found that people with high levels of Porphyromonas gingivalis (a gum disease-causing pathogen) were more likely to find verbal memory tasks difficult.

Carried out by Dr James Noble and colleagues from the Columbia College of Physicians and Surgeons, New York, the study “Mouths and brains. Could oral infection be a risk factor for dementia?” was published in the Journal of Neurology, Neurosurgery and Psychiatry.

17 November 2009: Study examines the relationship of dietary intake and Alzheimer’s disease symptoms in worms

As part of a study which examined how dietary restriction and a high-caloric diet influence biochemical responses, researchers controlled the dietary intake of C.elegans (a species of roundworm) which had been genetically modified to develop Alzheimer’s disease-like symptoms. They found that when the dietary restriction continued through the worms’ adulthood that lifespan increased and the Alzheimer’s disease-related paralysis decreased.

The study was led by Charles Mobbs of the Mount Sinai School of Medicine, New York, USA and published in the journal PLoS Biology.

18 November 2009: Study examines the relationship between adiposity indicators and dementia

Researchers who monitored longitudinal body weight, body mass index (BMI), waist circumference and waist to hip ratio (WHR) over a 32-year period, found that, among survivors to age 70, high midlife waist to hip ratio may increase the risk of dementia. The study commenced with over 1,400 women.

The study, led by Dr Deborah Gustafson, institute for Neuroscience and Physiology, Wallingsgan, Sweden, was published in the journal Neurology.

19 November 2009: Study examines genetic resistance to disease

In the mid 20th century there was a major epidemic of the disease ‘kuru’, a prion disease similar to CJD in humans. The disease was largely transmitted by cannibalism. Researchers who assessed more than 3,000 survivors of the epidemic found that people from the Purosa valley region of the Eastern Highlands who had a gene variation known as G127V, had high, or complete, resistance to the disease. The researchers believe that natural selection has ensured that people who have this genetic mutation were protected from kuru and “their proportion in society increased massively.”

However Professor John Hardy, University College London, Institute of Neurology, said that “in Papua New Guinea kuru became the major cause of death, so there was a clear survival advantage and the selection pressure was enormous. Here in Britain the numbers of CJD are very small and so the selection pressures will be less.”

20 November 2009: Study identifies the role of a protein in BSE

Researchers from Leeds Faculty of Biological Sciences have found that the protein Glypican-1 causes the number of abnormal prion proteins to rise, playing a key role in the development of bovine spongiform encephalopathy (BSE) (the human form of which is Creutzfeldt Jakob disease (CJD)). The symptoms of CJD include dementia.

The research is published in PLoS Pathogens and funded through the Welcome Trust and the Medical Research Council.

30 November 2009: Phase III trial commences of potential diagnostic tool for Alzheimer disease

Bayer has started to enrol participants for their phase III trial which will evaluate the efficacy and safety of florebetaben. This follows their Phase II trial in which it seemed possible to diagnose Alzheimer’s disease by injecting florebetaben which in turn highlighted the presence of beta-amyloid plaques in people’s brains under a positron emission tomography (PET) scan.

Approximately 400 people are expected to be enrolled for the Phase worldwide III trial. Whilst the primary completion of the study is anticipated for 2011, Bayer explained, that due
to histopathology examinations, the study is not anticipated to be completed before 2014.

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Dementia in Society

1 November 2009: Singer writes tribute to his mother who died with Alzheimer’s disease

“Missing Person” is a song written by Rick Guard about his late mother, Doreen, who died from Alzheimer’s disease. He explained the impact he felt of his mother’s disease, saying: “There is a huge stigma to having dementia. People don’t know how to cope with it, so you are left feeling isolated at a time when you need help the most… Although mum didn’t recognise me, Mum loved singing and amazingly remembered words to songs and she had a smile on her face when she watched my music videos. But sitting next to her, it was as if she couldn’t see me.”

Missing Person is sung by Rick Guard on YouTube.

9 November 2009: Documentary about Alzheimer’s disease wins award

“Living with Alzheimer’s” a two-part programme which documented a year in the life of author, Terry Pratchett, who has posterior cortical atrophy, has won a Scottish British Academy of Film and Television Arts (BAFTA) award for best factual series.

New resources and publications


“Alzheimer mode d’emploi – Le livre des aidants” (Caregiver’s instruction book on Alzheimer’s disease) by Dr Jean-Pierre Polydor, is published in French and includes information about Alzheimer’s disease on:

- Risk factors
- Facts about the disease
- Symptoms
- Diagnosis
- Treatment
- Communication issues
- Adaption of the environment
- Practical tips on the organisation of leisure time and carer’s schedule
- Stimulation of the brain
- Care with dignity
- End of life issues
- Retirement homes
- Legal issues
- Care associations


5 November 2009: German Alzheimer Society publishes booklet on Frontotemporal dementia

Responding to numerous requests, the German Alzheimer Society (Deutsche Alzheimer Gesellschaft e.V), has published a booklet on Frontotemporal dementia (FTD), entitled “Tragedy at midlife”. Unlike other forms of dementia, FTD often occurs under the age of 60 and people diagnosed with FTD are often still working, have young families and have many financial commitments.

Heike von Lützau Hohlbein, the first Chairperson of the German Alzheimer Society said, “We know from many reports of relatives, that FTD has a dramatic effect on the lives of those affected. Since many doctors do not know the symptoms, the disease is not diagnosed early or properly treated. Appropriate outpatient services, day care centers or homes for these people with FTD are difficult to find. Therefore, we organise an annual conference for members and now publish a brochure about FTD. We want to inform members as well as professionals, in order that people with FTD receive and take advantage of the available support.”

The brochure “Frontotemporal Dementia” was written by the physician Dr. Janine Diehl-Schmid (Center for Cognitive disorders of the TU Munich) and the lawyer Bärbel Schönhof. It contains information about FTD on a number of topics including:

- Symptoms
- Diagnosis
- Pharmacological and non-drug treatments
- Dealing with difficult behaviour
- Legal issues (including dismissal, retirement, debt capacity, power of attorney, living will and parental rights).
The booklet (Frontotemporal dementia, illness, legal issues, and support for families) can be ordered from the German Alzheimer Society for EUR 3 (from 1.1.2010 EUR 4).

23 November 2009: Report on end-of-life care for people with dementia now available in German

Alzheimer Europe’s Report “End of life care for people with dementia” has been translated into German by the German and the Swiss Alzheimer Societies. The report contains concise, practical recommendations on topics such as:

- The nursing care of people with dementia in the last phase of life
- The support for the carers
- Keeping family members informed and involved throughout
- The management of pain with special attention given to recognising signs of pain in people with dementia
- Infections and incontinence
- Swallowing problems, (artificial) nutrition and sedation
- Respecting religious and cultural beliefs
- Ethical issues such as the dignity and autonomy of people with dementia
- Living wills

Sabine Jansen, Executive Director, Deutsche Alzheimer Gesellschaft e.V, who participated in the working group, said: “People who have dementia, need to have end of life care and support tailored to their needs and disease. This is particularly important because they may not be able to express themselves verbally. In this regard, there is still much to do, for example we need to provide appropriate care at the end of life, both in the home and in care homes.”

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Marc Schaefer (Luxembourg)
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AE Calendar

The following meetings will be attended by representatives of Alzheimer Europe:

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tbody>
<tr>
<td>2 December</td>
<td>20th Anniversary Meeting of the German Alzheimer's Association (Berlin, Germany)</td>
<td>Jean</td>
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<tr>
<td>2 December</td>
<td>Meeting with representative of Bayer Healthcare (Berlin, Germany)</td>
<td>Jean</td>
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<tr>
<td>4 December</td>
<td>Meeting with Binsfeld (Luxembourg, Luxembourg)</td>
<td>Jean and Julie</td>
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<tr>
<td>7 December</td>
<td>Alzheimer Europe Board Meeting (Brussels, Belgium)</td>
<td>AE Board and Staff</td>
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<tr>
<td>9 December</td>
<td>Preparatory Meeting for Belgian Presidency Conference on AD (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>10 December</td>
<td>Symposium on “Living by proxy” (Reims, France)</td>
<td>Jean</td>
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<tr>
<td>14 December</td>
<td>Meeting with representative of Bayer Healthcare (Berlin, Germany)</td>
<td>Jean</td>
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<tr>
<td>16 December</td>
<td>France Alzheimer Meeting (Toulouse, France)</td>
<td>Jean</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>28-29 January 2010</td>
<td>Brains in dialogue on genetic testing, <a href="http://www.neuromedia.eu">www.neuromedia.eu</a></td>
<td>Trieste, Italy</td>
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<tr>
<td>27 February-2 March 2010</td>
<td>18th European congress of psychiatry, <a href="http://www.kenes.com/epa">www.kenes.com/epa</a></td>
<td>Munich, Germany</td>
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<tr>
<td>26 April 2010</td>
<td>25ème Colloque Médecine et recherche sur la maladie d'Alzheimer de la Fondation Ipsen</td>
<td>Paris, France</td>
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<tr>
<td>12-14 May 2010</td>
<td>7th Biennial Conference Barcelona/Pittsburgh, <a href="http://www.fundaciocae.com">www.fundaciocae.com</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>21-23 October 2010</td>
<td>10th Congress of European Society for Clinical Neuropharmacology, <a href="mailto:ivan.rektor@fnusa.cz">ivan.rektor@fnusa.cz</a></td>
<td>Zagreb, Croatia</td>
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