



NEWSLETTER

February 2011

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Editorial



This month marked the anniversary of the 3rd French Alzheimer Plan and we report on the considerable achievements since its implementation. President Sarkozy has reaffirmed the need to follow the 3rd Plan with a subsequent one in order that the continuing challenges are met. I am happy to report that the Welsh Government has also acknowledged the challenges dementia presents as it launched its roadmap "Dementia Vision for Wales". This important document aims to transform the care of people with dementia and their carers.

Collaboration is key in the fight against Alzheimer's disease and is a central feature of the Joint Programming of Neurodegenerative Diseases research (JPND). This month, to support the implementation of the JPND, a web-based survey has been launched to map the current research and resources supporting research into neurodegenerative diseases across 23 Member States. Once completed, the survey should prove to be invaluable when planning future research into neurodegenerative diseases.

Alzheimer Europe members have been continuing their work to raise awareness of dementia. Two national conferences on dementia took place (Greece and Romania) in February and we also report on some innovative ways in which national organisations raised the understanding of dementia. I would like to highlight two: In Germany the audience at a rock show were invited to think about how it feels to have dementia

and in the UK, the national association has launched its first iPhone application, Brain Map. Both of these initiatives are included in the Members' news section in the newsletter.

This edition has the regular science watch section, offering a snapshot of some of the research reported on during February.

Preparations are underway for Alzheimer Europe's 21st Annual Conference which will be held in Warsaw and also for the forthcoming lunch debate in the European Parliament on 15 March. Issue 7 of the Dementia in Europe magazine has been finalised, in time for its launch at the lunch debate. You will see that the Alzheimer Europe team has also been busy attending various meetings.

A play, "Dementia Diaries" and a documentary, "Bicicleta, cullera, poma" were launched this month. We report on both, which are great examples of how the wider dementia community can raise awareness of the disease.

Various reports were published this month, including one on a survey from the US and one on a separate survey in the UK: both surveys report that people fear dementia. At the same time, a report on dementia research in Europe has been published which concludes there is 'widespread disparity in the diagnosis, treatment and care of people with dementia in Europe'. I believe we can play a small part in addressing some of the fears expressed in these surveys by working together and continuing to raise awareness and understanding of the disease.

Jean Georges
Executive Director

European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at 50, representing 17 Member States of the European Union and all of the 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.

Belgium: Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Sterckx Dirk (ALDE), **Bulgaria:** Parvanova Antoanija (ALDE), Cyprus: Triantaphylides Kyriacos (GUE/NGL), **Czech Republic:** Cabnoch Milan (ECR), Kohlcek Jaromir (GUE/NGL), Roithova Zuzana (EPP), **Denmark:** Schaldemose Christel (S&D), **Finland:** Jaakonsaari Liisa (S&D), Jäättänenmäki

Anneli (ALDE), Pietikäinen Sirpa (EPP), **France:** Audi Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Morin-Chartier Elisabeth (EPP), **Germany:** Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP), **Greece:** Chountis Nikolaos (GUE/NGL), Koppa Maria Eleni (S&D), Kratsa-Tsagaropoulou Rodi (EPP), **Ireland:** Aylward Liam (ALDE), Childers Nessa (S&D); Crowley Brian (ALDE), McGuiness Mairead (EPP), Mitchell Gay (EPP), **Italy:** Panzeri Pier Antonio (S&D), Toia Patrizia (S&D), **Luxembourg:** Lulling Astrid (EPP), **Netherlands:** De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP), **Portugal:** Coelho Carlos (EPP), Matias Marisa (GUE/NGL), **Romania:** Antonescu Elena Oana (EPP), **Slovakia:** Mikolasik Miroslav (EPP), Zaborska Anna (EPP), **United Kingdom:** Hall Fiona (ALDE), Lynne Liz (ALDE), McAvan Linda (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

Alzheimer Europe Networking

On 1 February 2011, (Warsaw, Poland) Jean met with the Polish Alzheimer's Association for the organisation of the 2011 AE Conference in Warsaw.
On 2 February 2011 (Brussels, Belgium) Annette attended the breakfast meeting organised by MEP Antoina Parvanova (ELDE, Bulgaria) on the active and healthy ageing innovation partnership.
On 2 February 2011 (Brussels, Belgium) Annette met Antoni Gelonch (Sanofi-Aventis) to discuss funding.
On 3-4 February 2011 (London, UK) Jean attended the International Pharmaco-economic Conference on AD and presentation of the findings of the EuroCoDe project.
On 7 February 2011 (Luxembourg, Luxembourg) Gwladys and Jean met with Binsfeld to discuss the organisation of the 21st Alzheimer Europe conference in Warsaw.
On 10 February 2011 (Brussels, Belgium) Annette attended the EFPIA Think Tank meeting.
On 18 and 19 February 2011 (Bucharest, Romania) Annette and Dianne attended the National Alzheimer Conference and made a presentation.
On 18 and 28 February 2011 (Luxembourg, Luxembourg) Julie met with Binsfeld publishers to discuss the publication of the next Dementia in Europe magazine.
On 18 February 2011 (Basel, Switzerland) Jean had a meeting with Bruno Indelli from Novartis.

European developments

Here we report on developments from the European institutions which may impact people with dementia and/or their carers.

9 February 2011: European-wide neurodegenerative research mapping goes live

The JUMPAHEAD project has launched a web-based survey to map the current research and resources supporting research into neuro-degeneration across 23 Member States.

The information gathered with the survey will be used to support neuro-degeneration research as part of the future European Strategic Research Agenda. The database should facilitate connections between researchers, enable more collaboration and improve the exploitation of existing resources.

The survey will also capture data on the policy landscape.

JUMPAHEAD is funded by the Seventh Framework Programme [FP7 (2007-2013)] and started on 1 September 2010. This 3-year project is a coordination action in support of the implementation of the new collaborative approach to European health

research: the Joint programming of neurodegenerative diseases research (JPND). JPND is a completely new collaborative approach to European health research.

16 February 2011: European Parliament adopts its Resolution on European pensions

At its plenary sitting of 16 February 2011, the European Parliament adopted Ria Oomen Ruijten's, MEP (EPP – The Netherlands) Resolution 'Towards adequate, sustainable and safe pension systems in Europe' by 535 votes in favour, 85 against and 57 abstentions.

Member States are now called upon to ensure pension schemes can sustainably deliver an adequate income to the EU pensioners, despite the economic crisis.

Pension portability must be facilitated for Europeans who work for several employers and/or in different EU countries.

To narrow the gap between the statutory pension age and the actual age when people stop working, better adapted work places and conditions must be provided to older workers. Improved protection against dismissals is also covered by the report.

Greater emphasis must be put on gender equality to redress the labour market.

This own-initiative report seeks to improve the European Commission Green Paper on pensions of July 2010.

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

16 February 2011: Adoption of the European Parliament report on counterfeit medicines

At its plenary sitting of 16 February 2011, the European Parliament adopted Marisa Matias', MEP (GUE/NLG – Portugal) report on the Directive on the fight against fake medicines by 569 votes in favour, 12 against and 7 abstentions. This new law will aim to prevent fake medicines from entering the legal supply chain.

The internet is a key route by which the fake medicines enter the EU market and internet sales will now be covered by the law. In the Member States where the internet pharmacies are allowed to operate, these pharmacies will need to be authorised to supply pharmaceuticals to the public. Internet pharmacies will have to display a common logo, recognisable throughout the EU. All internet pharmacies will be linked to an EU website. Citizens will have to be informed about the risks of buying medicines via the internet.

The new law also introduces new safety and traceability measures that will be placed on each pack to guarantee their authenticity and enable pharmacists to check whether the package has been tampered with.

In the future, medicinal product brokers will have to register as such, and may be removed from the register if they fail to comply with the new rules. The new Directive calls for sanctions to be imposed on those who infringe it.

This law still needs to be formally approved by the Council of Ministers. Once it is signed into law, the Member States will have 18 months to make any necessary changes to their national legislation. The Commission will, in parallel, work on several measures to implement and supplement the legislation to ensure all objectives are met.

16 February 2011: Green light to the Citizens' Initiative



At the European Parliament (EP) plenary sitting of 16 February 2011, an official ceremony was organised to launch the Citizens' Initiative after it received the green light of the Council of the European Union and the EP. Hungarian foreign Minister János Martonyi, and EP President Jerzy Buzek solemnly signed the regulation, one of the significant innovations of the Lisbon Treaty that authorises any person to propose an EU law after 2012.

A set of rules has been identified:

1. At least one million EU citizens may take the initiative of inviting the European Commission, within the framework of its powers, to submit a proposal on matters where citizens consider that a legal act of the Union is required for the purpose of implementing the Treaties. The initiative can cover a wide range of topics except matters within national competence (e.g. tax or national rules on social allowances).
2. At least a quarter of member states (7 different countries) must be involved. To secure proportionality, the regulation determines the minimum number of signatories from the same member state. Collections of signatures may only be initiated by a "citizens' committee". This group must register the initiative with the Commission, and collect one million supporting signatures within 12 months.

The regulation is the result of a compromise between the Council, the Commission, and the EP. On 14 December 2010, the General Affairs Council had adopted the law and the EP adopted it at its plenary sitting of 15 December 2010.

Member States now have to adjust their national regulations so the first European collection of signatures can begin in March 2012 at the earliest.

17 February 2011: European Parliament adopts Resolution on the 2011 EU guidelines for employment policies

At its plenary sitting of 17 February 2011, the European Parliament (EP) adopted Pervenche Berès', MEP (S&D, France) Resolution on the 2011 EU guidelines for the employment policies of the Member States, by 551 votes to 59 with 8 abstentions. The Resolution calls for the employment policy guidelines to be better implemented in future, with an emphasis on the development of a skilled workforce, more and better jobs for European workers.

Other European organisations

26 January 2011: Seminar takes place to discuss how e-Science can help to address societal problems such as Alzheimer's disease

A seminar on the EU funded neuGRID project took place on 26 January 2011 in the European Parliament. neuGRID is "a user-friendly online network that was created to dramatically accelerate the rate of research into Alzheimer's and other neurodegenerative diseases, facilitating the development of markers of disease progression."

Discussions at the seminar were focused on:

- Building a global virtual imaging laboratory
- Call for support from EU policy-makers
- Barriers to harmonisation

- Facilitation of pan-European research on degenerative brain diseases
- Promotion of the exchange of technical information
- Increase awareness of the potential impact research infrastructures have on drug development.

10 February 2011: Consultation launched for opinion on Alzheimer's disease biomarkers



The European Medicines Agency (EMA) has launched a consultation on the question 'whether two cerebral spinal fluid (CSF) related biomarkers (A β 1-42 and total tau) are qualified in selecting subjects for trials in early Alzheimer's Disease (AD).

The document "Qualification Opinion of Alzheimer's Disease Novel Methodologies/biomarkers for BMS-708163 is available on the EMA website and the closing date for consultation is 25 March 2011.

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

www.alzheimer-europe.org

Policy Watch

This section of the newsletter carries news of national policy initiatives on dementia.

16 February 2011: Dementia vision for Wales launched by Welsh Government

The document 'Dementia Vision for Wales' outlines a roadmap to transform the care of thousands of people with dementia and carers in Wales. GBP 1.5 million annually has been allocated to the training of the dementia care workforce, to the creation of patient information packs and new roles in dementia within local health boards. The document was launched by the Welsh Assembly Government in partnership with Alzheimer's Society.

Launching the partnership, Ian Thomas, Director of Services for Alzheimer's Society said, "There is so much to do. Only a third of people with dementia get a formal diagnosis, denying them vital support. It is essential the strong leadership from the Welsh Assembly Government continues so that these plans become a reality. Change won't happen overnight, but Alzheimer's Society will be working tirelessly to bring dementia out of the shadows."

22 February 2011: 3rd anniversary of the French Alzheimer Plan

On the occasion of the 3rd anniversary of the French Alzheimer Plan, a roundtable was organised in Bordeaux (France) on 22 February 2011. French President, Nicolas Sarkozy, Valérie Pécresse (Minister for



Higher Education and Research), Nora Bera (Secretary of State, Work, Employment and Health Ministry) and Roselyne Bachelot (Minister for Solidarities and Social Cohesion) alongside professionals on the field were invited to report on the Plan progress.

On the research priority of the Plan, Valérie Pécresse mentioned that France's strongest research activities were on neurophysiology and epidemiology. Under the plan, in 2010 twenty international publications have reported advances in animal experimentation. Two genes showing a predictability to develop the disease were discovered in 2009 and another two in 2010. The French Alzheimer research team (set up within the framework of the plan) has recruited 96 new researchers, 509 practitioners have been trained in clinical epidemiology and 104 fundamental research projects in therapeutics and human and social sciences have been launched. An international consortium gathering all existing projects on genotype has been set up and France is leading the Joint programming of neuro-degenerative diseases (JPND) research.

Nora Bera presented the progress made in the priority dealing with the improvement of the quality of life of the person with dementia. Early diagnosis has been improved through the new 65 memory clinics that have been set up since the beginning of the Plan. This measure will be reinforced with 507 new diagnostic centres. To optimise early diagnosis, Professor Joël Ménard is now in charge of proposing solutions to improve the existing system and create links with different actors by the second semester of 2011. The reduction in the use of anti-psychotic drugs as a priority of the Plan has borne fruit : in 2007, 16.9% of people with dementia received an anti-psychotic whereas in 2009, 15.7% of them did. Behavioural and cognitive units designed to answer the specificities of people with dementia will be implemented to help stabilise the disease and maintain the person's remaining cognitive abilities.

Roselyne Bachelot presented the medico-social solutions offered by the Plan. On respite care, the Plan's website now offers a database of the respite care available across the French territory. The number of respite care facilities has not increased as planned. In 2011, a mapping of how the respite care facilities are used will be carried to support further action in this domain. Support platforms for the people with dementia and their carers will be expanded with the creation of 75 new platforms in 2011 and 75 new platforms in 2012. Innovative respite care projects will be implemented.

The professionals who were invited to express their views recognised the Plan had yielded tangible and important results, more so in the field of research. Some professionals regretted that implementation on the ground was not optimal in that coordination between all different actors was not always obvious.

All participants agreed that this plan should be followed by another plan which would be just as ambitious, in order to maintain the momentum and capitalise on the advances of the current Plan. President Nicolas Sarkozy also agreed and reminded the audience that the issues around an ageing population, Alzheimer's disease and the dependency of elderly people were not going to fade away in the

future and that a subsequent plan would be necessary. In the meantime, President Sarkozy has announced that measures regarding dependency will be put in place before the end of 2011.

Members' News

In this section we report on our members' latest initiatives and work.

6 February 2011: Belgium - Ligue Alzheimer attends Voluntary Fair



Ligue Nationale Alzheimer LINA (LINA)
ASBL/vzw/ViG

Volunteers from the French-speaking part of the Belgian Ligue Alzheimer attended the annual three-day 'Voluntary Fair' in Liège on 4 to 6 February. 2011 being the European Year of Voluntary Activities, the fair was a huge success. The event's main objective was to promote the volunteers' work. However, according to one volunteer, people were more interested in gathering information than in applying for a voluntary job. Volunteers said: 'People wanted to receive information on the disease as such. Some of them were students, who were looking for references within the framework of a school paper. Others merely wanted to be listened to. But the fair was a great opportunity to promote the associations' activities. There were so many people!'

Several conferences were also given during the fair. Sabine Henry, chairperson of la Ligue Alzheimer, gave a presentation entitled 'Why be involved?' in which she addressed the reasons which lead someone to get involved in an association (a feeling of belonging; reciprocity; the will to share and help, etc.).

16-20 February 2011: Greek Association of Alzheimer's Disease and Related Disorders co-organises Conference on Alzheimer's disease



The Pan-Hellenic Institute of Neurodegenerative Disorders in close collaboration with the Greek Association of Alzheimer's Disease and Related Disorders organised the 7th Pan-Hellenic Interdisciplinary Conference of Alzheimer's Disease and Related Disorders, in Thessaloniki, 16-20 February 2011. Over 800 delegates from academia, medical practice, the field of care and national dementia associations participated.

The conference provided a unique opportunity for the exchange of views on the latest developments in medical treatments, non-pharmacological interventions and prevention, as well as sharing best practice and advice on care.

The number of people with dementia has been rising fast the last few years. Looking ahead, the organisers expressed a strong need to further accelerate the country's development in relation to dementia services, in order to improve the quality of life of people with dementia and caregivers.



The Boards of the Pan-Hellenic Institute of Neurodegenerative Disorders and the Greek Association of Alzheimer's Disease and Related Disorders

Alzheimer's disease and Related Disorders, Professor Magda Tsolaki, President of the Greek Federation of Alzheimer's Disease and Relative Disorders and all the staff and volunteers who joined their efforts for this landmark dementia conference in Greece, would like to express once again their commitment to achieving a better quality of life for people with dementia.

18 February 2011: Romanian Alzheimer Society organizes National conference on dementia



The National Alzheimer Conference 2011 organised by Societatea Romana Alzheimer took place in Bucharest on 18/20 February 2011. The topics discussed ranged from the management of dementia (early recognition and early detection of the symptoms, diagnostic criteria) to pharmacological and non-pharmacological treatments, availability of care services and ethical and legal aspects, to name but a few.

Alongside Romanian speakers, nine international speakers participated in the conference. Annette Dumas, EU Public Affairs Officer, and Dianne Gove, Information Officer for Alzheimer Europe respectively gave a presentation: 'Alzheimer's disease: what role for the European Union?' and 'Alzheimer Europe's work on legal and ethical issues'.

The conference was a success: it received a wide media coverage and the turnout exceeded the Societatea Romana Alzheimer's expectations. The workshops designed for family carers in particular were extremely well attended and the Societatea Romana Alzheimer was asked to make the some courses a regular event.

18 February 2011: Alzheimer Scotland launches first Memory Bus



Alzheimer Scotland has launched its first-ever Memory Bus, a mobile information unit which will enable Alzheimer Scotland to reach people across Scotland in order to provide information and advice to people with dementia and their carers. Alzheimer Scotland staff, including Dementia Advisors and volunteers will operate the bus. The launch was supported by Falkirk Provost, Pat Reid (pictured left, below) and also MSP Michael Matheson.

Henry Simmons, Chief Executive of Alzheimer Scotland,(pictured right, below) said: "This launch is just the start of what will be a grand tour for Alzheimer Scotland's latest venture. We want to

make sure that no-one goes through dementia on their own, but that's easier said than done, particularly in Scotland's remote, rural communities. Even in our towns and cities, people with dementia and their families often find it difficult to access support or get information when they need it – and not everyone is connected to the Internet or feels comfortable discussing their concerns over the phone."



20 February 2011: German Alzheimer Society raises awareness of dementia with new advert



A new TV slot from the German Alzheimer Society shows, in a humorous way, dementia and its consequences. The 40 second advert starts in the backstage of a concert hall. There the entertainer Roberto Blanco is preparing for his concert. He finds it a little odd that the make-up artist uncaringly slaps a bit of gel on his head and that the refreshments are limited to a can of beer, but Roberto Blanco – being very professional – does not get irritated and makes his way to the stage. The spotlights dazzle Roberto. He thinks his band is waiting for him and he takes the stage. Then comes the shock: The zoom on the audience shows hundreds of heavy metal fans who were certainly not expecting to see Roberto Blanco. A voiceover reveals the error: "Got the place mixed up? For 1.2 million people in Germany that's everyday life. They suffer from dementia and disorientation. Let's not forget that." Even the unexpected end of the slot brings further laughter: Roberto Blanco reacts quickly and together with the band Sodom enthrals the heavy metal fans with his song "There's got to be a bit of fun".

The extraordinary thing about this was the incalculable surprising moment in its production because it was filmed during a real live concert of the band Sodom on 20 February in the rock hall in Ludwigsburg, without the public having been informed in advance. Roberto Blanco, who quickly agreed to participate, was particularly concerned about the topic of Alzheimer's. He stated, "Alzheimer's is far too little discussed in public, but everyone should be talking about it. I myself have lost friends to this disease and think it's very important to draw attention to this topic." Even Tom Angelripper, front man of the band Sodom, stated, "Alzheimer's is a disease that we must not forget and the slot reminds us of this in a very funny way." The surprise metal version of "there's got to be a bit of fun" went down really well.

"We have chosen this spot idea, because we believe that we can increase awareness of the problem of dementia through humour rather than consternation," said Swen Staack, Board Member of the German Alzheimer Society. "This advert for dementia is guaranteed to be remembered and with it the information that in Germany there is a very large number of people with dementia and family members who are grateful for any kind of commitment that you make."

22 February 2011: UK - Alzheimer Society releases iPhone app, 'Brain map'



The Alzheimer's Society has released its first iPhone application, Brain Map. The Society said, 'Brain Map has been developed so that everyone can learn more about the brain and dementia. You can rotate our 3D model to examine the different parts of the brain and find out what each bit does.'

The application can be downloaded for free from the Alzheimer's Society website.

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

www.alzheimer-europe.org

25 February 2011: The Alzheimer Society of Ireland launches its General Election Campaign 2011

On February 25th Ireland went to the polls to elect a new government. The Alzheimer Society of Ireland saw the national election as an excellent advocacy opportunity to continue its work in increasing political awareness of dementia. An election Manifesto was devised calling on all the candidates if elected, to pledge their support for the 44,000 people living with dementia in Ireland and their 50,000 carers in the following ways:

- A commitment to developing a National Dementia Strategy by 2013 to be included in the next Programme for Government and to ensure that there is a Minister/or Minister of State appointed with overall political responsibility for its delivery, with dedicated funding and an implementation plan
- The provision of quality driven, dementia specific services in the community.

To help achieve this and raise awareness about the issues facing people living with dementia, the Society developed and distributed election material which included:

- Voter Prompt Cards (to enable voters to know what to ask the candidates on the doorstep)
- Candidates Pledge Cards (highlighting the issues for people with dementia with the candidates and asking them to pledge their support to these) and
- an information poster.

In addition, the Society urged as many people as possible to sign up to its election campaign online. All the major cross party candidates were asked to sign up in order to pledge their support for a national dementia strategy in the next programme for government. Individual candidates' pledges were acknowledged in the national press.

The final part of the campaign took the form of awareness raising information stands that were set up across the country. Local candidates were invited to attend and meet with their constituents and Alzheimer Society supporters.



Labour and Fine Gael have given their commitment to the development of a National Dementia Strategy in their Election Manifesto. Joan Burton (Deputy Leader of the Labour Party) and Ivana Bacik (Labour Candidate)

met with Muriel Banks (Branch Chair of Dublin South Alzheimer Society).

Science Watch

This section has highlights of the most recent published research on dementia.

1 February 2011: International consortium launched to discover and map Alzheimer's disease genes

The International Genomics of Alzheimer's Project (IGAP) has been launched which will create a shared resource data base including genetic data for more than 40,000 individuals. This collaborative project combines the knowledge, staff and resources of four consortia that conduct research on Alzheimer's disease, hopefully facilitating greater knowledge about the disease. The primary goal of IGAP is to completely understand the role inheritance plays in Alzheimer's disease. The four groups are:

- The European Alzheimer's Disease Initiative (EADI) in France led by Philippe Amouyel, M.D, Ph.D, at the Institute Pasteur de Lille and Lille University.
- The Alzheimer's Disease Genetics Consortium (ADGC) from the United States led by Gerard Schellenberg, Ph.D, at the University of Pennsylvania School of Medicine.
- The Genetic and Environmental Risk in Alzheimer's Disease (GERAD) from the United Kingdom led by Julie Williams, Ph.D, at Cardiff University.
- The neurology subgroup of the Cohorts for Heart and Aging Research in Genomic Epidemiology (CHARGE) led by Sudha Seshadri, M.D, at Boston University.

Dr Philippe Amouyel, explained, "Our first efforts will be to bring together all the data from the different groups so that they can be analyzed. The next step will be to perform new analysis on subjects not yet in any genetics studies to further increase the number of people in our studies and to increase the ability to detect new genes."

The formation of IGAP is supported by the Alzheimer's Association and the Fondation Plan Alzheimer.

2 February 2011: Study examines relationship between hearing loss and dementia



Researchers conducted a study on over 600 (aged 36 to 90 years) individuals to determine whether hearing loss is associated with all-cause dementia and Alzheimer's disease. They concluded that 'hearing loss is independently associated with incident all-cause dementia. Whether hearing loss is a marker for early-stage dementia or is actually a modifiable risk factor for dementia deserves further study.'

The study was conducted by Luigi Ferrucci, Clinical Research Branch, National Institute on Aging and published in the journal Archives of Neurology.

6 February 2011: Study examines relationship between ADHD and dementia

A study on 500 people (360 with dementia and 140 healthy individuals) found "a higher risk of Lewy Bodies Dementia (DLB) in patients with preceding adult attention-deficit and hyperactivity disorder (ADHD) symptoms. To date, there is no clear explanation for the association found; however, further investigation will widen our understanding about both disorders."

Researchers from Argentina, led by Dr Golimstock, Neurology Department, Hospital Italiano Buenos Aires, Argentina; Gascon 450 C1181ACH Buenos Aires, Argentina, carried out the study which was published in the journal European Journal of Neurology.

14 February 2011: Study suggests blood test may offer new biomarker for Alzheimer's disease



A study in which serum samples from six people with dementia, six healthy people and six people with Parkinson's disease were examined found that three peptoids (synthetic molecules) could be identified which 'captured six times the IgG antibody levels in all of the Alzheimer's patients compared to the control group or the Parkinson's patients'. An additional analysis was carried out on a set of 16 control subjects and 10 people with early stage Alzheimer's disease where the researchers found 'the three candidate biomarkers identified Alzheimer's disease with 90% accuracy'. The researchers hope that this procedure may be helpful in the diagnosis of Alzheimer's disease before symptoms appear and called for further studies to be carried out.

The study was conducted by researchers from the UT Southwestern Medical Center, USA and it received funding from the National Institutes of Health.

16 February 2011: Study examines relationship of levels of brain enzyme and Alzheimer's disease progression

An animal study suggests that an increase of a brain enzyme [puromycin-sensitive aminopeptidase (PSA/NPEPPS)] may slow the accumulation of tau proteins which are associated with Alzheimer's disease. The researchers found no unwanted side effects during this study.

Published in the journal Human Molecular Genetics, the research was carried out by Stanislav L Karsten of the Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center, and colleagues.

18 February 2011: Study suggests bilingualism may delay symptoms of Alzheimer's disease

A study suggests that people with probable Alzheimer's disease who are bilingual are more likely to have delayed symptoms of Alzheimer's disease compared to those who are monolingual.

The study was presented to the American Association for the Advancement of Science in Washington, USA by Ellen Bialystok, professor of psychology at York University in Toronto, Canada.

Dementia in society

In this section we report on how dementia is portrayed by the general media (for example, on television and in films).

7 February 2011: Film launched about Alzheimer's disease "Bicicleta, cullera, poma"



The film entitled "Bicicleta, cullera, poma" was shown on 7 February 2011 during the 18th cinema festival of the Catalan-Luxembourgish Centre of Luxembourg. The film focuses on the life of Pasqual Maragall (who was Mayor of Barcelona from 1982 to 1997 and President of the Catalan government from 2003 to 2006) starting shortly after his diagnosis in 2007 up to the present day. His family explain how their lives have been affected by Alzheimer's disease and his doctors are also interviewed.

The film is a moving account of Maragall's personal experience. It is full of humanity, sincerity and humour as well as sadness. It addresses important issues such as research into a cure and prevention, autonomy and the right of the person with dementia to personal freedom. Whilst the main language spoken was Catalan, parts of the documentary were filmed in India, the United States and the Netherlands (with English sub-titles throughout). This highlights the fact that Alzheimer's disease affects people all over the world and shows how people from very different cultural and social backgrounds experience AD and try to deal with it from medical, scientific and personal perspectives.

The film was directed by Carles Bosch, lasts 106 minutes and the main language is Catalan with subtitles in English.

11 February 2011: Play opens about dementia



'Dementia Diaries' is a play which explores 'the troubled relationships within a family struggling to cope with dementia'. It is presented through the monologues of an Anglo-Polish family and their Polish carer. Maria Jastrzebska, the writer, explains 'I wrote the monologues for the five characters in Dementia

Diaries to represent the way family members can sometimes speak without listening to each other. I also wanted to explore responses to and preconceptions about dementia and its impact on families and to look at Polish immigrants of different generations – those established here and those recently arriving.'

Dementia Diaries opened in the Nuffield theatre, Southampton and during 2011 will tour the UK, starting in London.

21 February 2011: Alzheimer's Foundation of America held a teen video competition and the 2010 winners have been announced

Winner: Margaret Yan, Orlando, FL for the video "The Picture Book". Margaret said "In the video, I was trying to symbolically capture the hopelessness that a family member or a friend might feel losing their loved ones to Alzheimer's. Personally, my experiences and memories are very important to me and I would be devastated if I was losing these memories one at a time. It is like losing the pages to a picture book ; the story would never be complete.

"This year my grandmother will be 77 years old. It has been five years since she was first diagnosed. Last summer my mother and I went back to Taiwan from Florida to see her wheelchair bound and incapable of living her daily life without a caretaker. I was most moved by my mother, who was reduced to sobs and tears. My mother had not seen her own mother in seven years and now she had completely lost her to a disease. But what happens to the memories of my grandmother, scattered and lost? Even though Alzheimer's might take my grandmother from me, the people who lived, smile and cried with her will hold onto her memories."

Runner-Up: Samantha DeMaria, Carmel, IN for the video "Moments of Life" Samantha explained 'I want people to cherish the moments they've had with their loved ones. I had a revelation of sorts as I was compiling memories captured on film for this video. Looking at the happy moments I've shared with friends and family has made me realize how precious life is, and that nothing should be taken for granted."

Runner-Up: Melissa Phillips, Salisbury, NC for the video "Twilight of the Mind" Melissa explained "The message I was trying to convey was that Alzheimer's disease isn't something to be taken lightly. It makes people lose their relatives long before they physically lose them, and it can be painful. I want people to know that it's not some simple issue.

"A lot of people I know consider it 'humorous because all they know of it is that it causes slight memory lapses in some, but in reality it can cause individuals to forget entire portions of their lives, family and eventually become violent. Basically, it's no laughing matter, and that's what I'd like people to take from this."

21 February 2011: The Institute for Education and Culture (Bildung und Kultur) has put out a call for best artistic and cultural practices on the theme of dementia within the context of its project entitled "Arts and Dementia"

The Institute is looking for:

- Projects in the areas of music, theatre, dance, art, art education, literature, biography/memory work, media and similar that are geared toward people with dementia
- Artistic works as well as campaigns that aim at a change in perspective on dementia

- Advanced training for artists, art educators or caregivers who are interested in offering artistic and cultural programmes for people with dementia
- Institutions or networks engaged with the theme of dementia.

A main goal of treatment for people with dementia is to improve the quality of life of people with dementia and their loved ones and the website states: "Art and culture can play a significant role in this undertaking. Even when cognitive skills are diminished, a person living with dementia still disposes over a high degree of emotionality and creative potential that can be encouraged. For this purpose, concepts and methods derived from art or music therapy or cultural education are usually applied that have been further developed for working with this group of people. In artistic and cultural activities, people with dementia can find a renewed lease on life and fresh challenges. Engaging with art and designing and crafting their own creations gives them an opportunity to experience strong sensations and express how they feel. It opens up new possibilities for (non-verbal) communication and various forms of social participation. Moreover, art can provide the people around them with a new means of accessing the world of people with dementia, and can help reinforce understanding and acceptance while alleviating fears and prejudices. Art exhibitions and photo calendars in which those affected participate, for example, as well as public campaigns, have demonstrated impressively how effective this approach can be."

Submissions should be made to the Institut für Bildung und Kultur e.V., Kim de Groot, Flavia Nebauer Küppelstein 34, 42857 Remscheid, Germany.

New resources and publications

By reporting on recently published books, reports and information videos on dementia we hope to offer updates on the current resources available to anyone who is affected by dementia.

31 January 2011: Hungary: Book and film on Alzheimer's disease published



To mark the occasion of the 10th Anniversary of the Hungarian World Alzheimer's Day (2010) a 45 minute documentary film and book about Alzheimer disease has been published, which had the support of the Hungarian Alzheimer Society. Copies of the publications were handed over to the media at a press conference. Participants at the Alzheimer conference also had the chance to see the film which was later screened by one of the major channels of Hungarian television.

The documentary gives a glimpse into the life of a professionally very active couple (one of them a psychiatrist) who came forward to speak about the difficulty of living with Alzheimer's disease. The aim of the film, 'Anyone can be affected' is to raise

awareness of the disease and the social problems which can arise in order to combat related stigma. The film was directed by Lídia Szádvári.

The book, published in Hungarian, entitled 'Alzheimer Misery' is about a middle-aged couple who care for the husband's mother who has Alzheimer's disease. Their experience is documented in diary form. Authors, Szilveszter Horváth and Zsuzsa Petrovics said 'To sum up what lies ahead for you: laughter, tears, sympathy, surprise, astonishment and love and understanding – I hope.'

9 February 2011: UK poll published which shows that dementia is biggest fear in later life

A new UK YouGov poll which was designed to gauge public perceptions of dementia was carried out on over 2,000 people. It revealed, amongst other things:

- 31% of respondents feared dementia most, with 27% fearing cancer most and 18% fearing death most.
- Dementia fears extend to all ages. Over half (52%) of UK adults aged 30-50 fear dementia for their parents, compared to 42% fearing cancer and 33% heart attack.
- Among retirees, 34% worry about health the most, and more than other issues, such as money (33%). When asked specifically which conditions they worry about, 52% worry about dementia, 33% worry about cancer and 30% worry about strokes.

The research was commissioned by Alzheimer's Research UK.

23 February 2011: US survey published which indicates adults' fear of Alzheimer's disease

A survey carried out in the US on over 1,000 adults showed, amongst others things:

- that 41% of people fear cancer the most, followed by Alzheimer's disease at 31% (in 2006 only 20% feared Alzheimer's disease)
- 62% of people knew little or nothing about it
- 18% of people had developed a care plan, should they get the Alzheimer's disease
- 9% of people indicated they were extremely concerned about having to take care of a loved one (compared to 5% in 2006).

The survey was conducted by Harris Interactive for the MetLife Foundation and is available on the WebMD website.

24 February 2011: Report published on dementia research in Europe

The report "The European Dementia Research Agenda" has been published by the International Longevity Centre-UK (ILC-UK). The report found "there is widespread disparity in the diagnosis, treatment and care of people with dementia across

Europe" and concludes that "research needs to be afforded a greater role in tackling Alzheimer's disease and other dementias."

The ILC-UK issued a Call to Action for the European Commission, the European Parliament, EU governments, and wider civil society which includes the call:

For the European Commission to:

- Prioritise dementia research under Framework Programme 8, given the growing burden and financial, health, social and human cost of dementia across Europe.
- Develop a European Charter to increase the participation of people with dementia in clinical trials, share best practice and examine current obstacles.

For the Members of the European Parliament to:

- Support the drafting and adoption of a United Nations convention on the human rights of older people.

For Governments of the Member States to:

- Ensure parity in funding for dementia research in line with other chronic diseases and the disease burden
- Ensure the implementation and adequate resourcing of comprehensive national strategies to address all aspects of dementia
- Create national centres of excellence in dementia research.

For NGOs, clinicians, industry and academia to:

- Work with professional bodies that represent, regulate and are responsible for the training of GPs and other health care professionals to encourage more Continuing Professional Development in dementia and the exchange of best practice.

The European Dementia Research Agenda report can be found on the ILC website.

28 February 2011: Guidelines for care of people with dementia published

The Alzheimer Society of Canada has published the document, "Guidelines for Care: Person Centred Care of People with Dementia Living in Care Homes" These guidelines address the following questions:

- What does a person-centred philosophy mean?
- What does person-centred care look like in a care home?
- Ensuring family inclusiveness
- Extending a person-centred philosophy through end of life.

The Society hopes that these guidelines will "inform two pathways to change the way care is experienced by people with dementia living in long term care homes and their families":

- Advocacy to influence the policies, standards, and funding streams to integrate more person-centred practices
- Tools for long-term care home staff to support person-centred care.

The guidelines are available in French and English from the Alzheimer Society of Canada's website.

AE Calendar 2011

The following meetings will be attended by representatives of Alzheimer Europe

Date	Meeting	AE Representative
3-4 March	Steering Committee of PharmaCog project (Paris, France)	Jean
9 March	Innovative Medicines Initiative Workshop at AD/PD Conference (Barcelona, Spain)	Jean
13-14 March	AE Board (Brussels, Belgium)	AE Board and staff
14 March	AE Public Affairs Working Group (Brussels, Belgium)	AE Member representatives and staff
15 March	European Parliament lunch debate (Brussels, Belgium)	AE Board and staff
25-29 March	Alzheimer's Disease International Conference (Toronto, Canada)	Heike and Jean
1 April	Health Advisory Board of GlaxoSmithKline (London, UK)	Jean

Call for abstracts

The call for abstracts for the Alzheimer Europe Conference is now online. Abstracts can be submitted via the Alzheimer Europe website on the following topics:

- Avoiding mistakes in care
- Carers' stories
- Day care centres – Innovative solutions
- Effective communication
- Family care versus institutional care
- Fundraising – Success stories
- How to recognise and cope with psychopathological symptoms in Alzheimer's disease
- Legal systems and regulations – a review
- Occupational therapy
- People with dementia speak up
- Policy initiatives and dementia strategies
- Preventing isolation and loneliness of people with dementia and their carers
- Problems and dilemmas in end-of-life dementia
- Raising awareness – successful campaigns
- Sexuality and relationships
- Support groups for carers

Deadline: 30 April 2011.

**21st Alzheimer Europe Conference
European Solidarity
without borders**
Warsaw / 6-8 October 2011
Mark the dates!
www.alzheimer-europe.org/conferences



 

Future Conferences

Date	Meeting	Place
9-13 March 2011	The 10th International Conference on Alzheimer's & Parkinson's Diseases (AD/PD 2011), www.kenes.com/adpd	Barcelona, Spain
17-18 March 2011	Colloque Le défi de l'intervention auprès des personnes atteintes de la maladie d'Alzheimer, http://www.iugm.qc.ca/iugm/diffusion-de-l-expertise/colloques-et-symposiums	Montréal, Canada
26-29 March 2011	26th International Conference of Alzheimer's Disease International, http://www.adi2011.org/default.aspx?PageID=Home	Toronto Canada
13-14 April 2011	The 7th Annual World Health Care Congress—Europe, http://www.worldcongress.com/events/HR11015/	Brussels, Belgium
14-17 April 2011	The VII International Association of Gerontology and Geriatrics (IAGG) – European Region Congress "Healthy and Active Ageing for all Europeans II", www.iaggbologna2011.com	Bologna, Italy
9-12 May 2012	12th International Stockholm/Springfield Symposium on Advances in Alzheimer Therapy, www.ad-springfield.com	Stockholm, Sweden
20-23 October 2011	7 th International Congress on vascular dementia: Facing the challenges of dementia, http://www.cts.vresp.com/c/?KenesInternationalVA/e06f64a56d/5ba2f9d3c6/0d0ca1445f/ref5=db1	Riga, Latvia



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