Editorial

September was an especially busy month for Alzheimer Europe. Whilst the office staff were ensuring that Annual Conference was a success, our member associations were raising awareness of the disease to mark World Alzheimer’s Day.

From 30 September to 2 October, Alzheimer Europe, together with Association Alzheimer Luxembourg, organised its Annual Conference in Luxembourg. This year’s conference was particularly special as we celebrated our 20th anniversary and I am delighted that so many people were able to join us.

At the opening ceremony, we were fortunate to have the active participation of two Luxembourg ministers, Marie-Josée Jacobs (Minister for Family and Integration) and Mars di Bartolomeo (Minister for Health) who announced that their departments would be collaborating to develop a national action plan for Luxembourg. It is encouraging to see how the list of countries developing national dementia strategies is continuing to grow.

At our Annual General Meeting, we were able to present our members with a report on an impressive list of activities carried out in the past year as well as positive news regarding the financial situation of the organisation.

At this meeting, we also elected a new Board and Heike von Lützau-Hohbein was elected to take over as chairperson of Alzheimer Europe from Maurice O’Connell. My personal thanks go to the outgoing chair and his vision and leadership over the past six years and I look forward to an equally close and productive collaboration with Heike.

In September, Alzheimer Europe published issue 6 of the Dementia in Europe magazine and we dedicated a special supplement to our 20th anniversary. In this edition, we were able to include contributions from, amongst others, John Dalli, the EU Health Commissioner, Magda Aelvoet, Belgian Minister of State for Belgium, Astrid Lulling, MEP from Luxembourg and Irene Oldfather, a Member of the Scottish Parliament.

On a European level, whilst we await the details of the European Joint Action on dementia, it is encouraging that the European Commission has proposed that 2012 be the European Year of Active Ageing.

Although we cover information on a number of our members’ activities for World Alzheimer’s Days in this newsletter, I wanted to single out the outstanding report commissioned by our Swiss member organisation on the cost of dementia in their country and the celebration of France Alzheimer’s 25th Anniversary.

I hope you enjoy this issue of our newsletter.

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 Antonyia (ALDE)

**Cyprus**
Triantaphyllides Kyriacos (GUE-NGL)

**Czech Republic**
Cabrnoch Milan (ECR), Kohlicek Jaromír (GUE/NGL), Roithova Zuzana (EPP)

**Denmark**
Schaldemose Christel (S&D)

**Finland**
Jaakonsaari Liisa (S&D), Jäättteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP)

**France**
Audy 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-Tsaragopoulou Rodi (EPP)

**Ireland**
Aylward Liam (ALDE), Childers Nessa (S&D); Crowley Brian (ALDE), McGuinness Mairead (EPP), Mitchell Gay (EPP)

**Italy**
Panzeri Pier Antonio (S&D), Toia Patrizia (S&D)

**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**
Mikolask 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).

29 September 2010: European Alzheimer’s Alliance members win MEP awards

Winners of the 6th annual MEP awards, hosted by the Parliament Magazine, were announced on 29 September 2010. Three of the winners are members of the European Alzheimer’s Alliance:

- Brian Simpson, UK (S&D) for transport
- Gay Mitchell, Ireland (EPP) for development, and
- Antonyia Parvanova, Bulgaria, (ALDE) for Health.

Alzheimer Europe

30 September 2010: Alzheimer Europe holds its Annual General Meeting

The Alzheimer Europe Board met in the morning of 30 September to prepare for the Annual General Meeting which was held the same day. At the Annual General meeting:

1. The Honorary Secretary, Sigurd Sparr, reflected that the 2009 Annual Report had an unprecedented list of successful outcomes, including the:

   - ongoing campaign to make dementia a European priority (with nearly 80% of MEPs giving their support in 2009 to Written Declaration 80/2008 on the political priorities in the fight against Alzheimer’s disease),
   - membership involvement in the exchange of information regarding the European Commission’s joint programming discussions,
   - launch of Alzheimer Europe’s updated website, which integrates Alzheimer Europe’s conference website,
   - two well-attended lunch debates in the European Parliament,
   - publication of the 2009 Dementia in Europe Yearbook and two Dementia in Europe magazines,
   - launch of the Dementia Ethics Network and the,
   - continued development of our policy work and strategic partnerships.
2. The Honorary Treasurer, Heike von Lützau-Holhlbein, gave an overview of the financial report for 2009, saying that there had been a stable increase of income and that it had been necessary to adapt Alzheimer Europe’s budget to address the lack of EU funding during 2009. She extended special thanks to sponsors who had supported Alzheimer Europe through 2009.

3. The representatives of 22 Alzheimer Europe member organisations voted in the new Board, which will have its mandate for a period of two years. The 2010-2012 Board members are:

**Executive members:**
- Heike von Lützau-Holhlbein, Germany (Chairperson)
- Iva Holmerová, Czech Republic (Vice-Chairperson)
- Maria do Rosário Zincke dos Reis, Portugal (Honorary Treasurer) and
- Sigurd Sparr, Norway (Honorary Secretary).

**Ordinary members:**
- Alicja Sadowska, Poland
- Charles Scerri, Malta
- Henry Simmons, UK (Scotland)
- Liane Kadusch-Roth, Luxembourg
- Maurice O’Connell, Ireland
- Patrick Maugard, France
- Sabine Henry, Belgium and
- Sirpa Pietikäinen, Finland

The newly-elected Chairperson, Heike von Lützau-Holhlbein, thanked the outgoing Board members, in particular she thanked Maurice O’Connell, Sigurd Sparr and Sabine Henry for their contribution to the Executive Board and also Pekka Laine (Finland) who is retiring from the Board for his long service.

4. Discussed membership applications and welcomed a new provisional member from Italy, Alzheimer Uniti.

5. Reviewed the 2010 workplan, noting that by the end of this year Alzheimer Europe will publish a report on Assistive Technology, a 2010 Dementia in Europe Yearbook on proxy decision making and legal capacity as well as another Dementia in Europe magazine.

6. The Executive Director, Jean Georges, presented the members’ survey. Predominantly, the feedback received vindicated the work which Alzheimer Europe has carried out and will help guide future workplans. A draft Strategic Plan (2011-2015) was presented to the members who supported the general direction of the organisation in the future.

30 September 2010: Alzheimer Europe publishes issue 6 of the Dementia in Europe magazine together with a 20th Anniversary supplement

Alzheimer launched issue 6 of the Dementia in Europe magazine at the opening of the 20th Alzheimer Europe Conference in Luxembourg. This issue includes news on:

- How to ensure dementia is a European health priority by John Dalli, the European Commissioner for Health and Consumer Policy
- The situation in Luxembourg for people with dementia and their carers, written by Astrid Lulling MEP (Luxembourg)
- The recently launched National Dementia Plan for Scotland
- The role which Alzheimer associations play in Europe
- The debate in the European Parliament on national dementia approaches in France and England, which was hosted by Dagmar Roth-Behrendt MEP (Germany)
- The Belgian and Spanish Presidency conferences
- Legal developments in relation to guardianship in Switzerland and
- The impact the decision to stop driving has had on James McKillop, who lives with dementia.

Issue 6 also has a Alzheimer Europe 20th Anniversary supplement which looks back at the organisations achievements over the last twenty years.

Issue 6 of the Dementia in Europe magazine (48 pages) and supplement (28 pages) can be ordered via the publications section of Alzheimer Europe’s website (EUR 2.50 plus handling and postage).
Alzheimer Europe Networking

On 1 September (Brussels, Belgium) Annette attended the Parliament Magazine Presidency reception.
On 3 September (Brussels, Belgium) Annette had a meeting with AGE representatives.
On 6 September (Brussels, Belgium) members of the Alzheimer Europe Board met to analyse the results of the membership survey and to discuss the future strategic direction of the organisation.
On 7 September (Brussels, Belgium) Annette had lunch with M. Yannakoudakis (MEP) assistant.
On 13, 14, 17 and 20 September (Luxembourg, Luxembourg) Julie met Jean-Paul Reuland from Binsfeld publishers to finalise issue 6 of the Dementia in Europe magazine together with the 20th Anniversary supplement.
On 14 September (Brussels, Belgium) Annette attended the Servier annual cocktail.
On 16 September (Louvain-la-Neuve, Belgium) Annette attended the Ligue Alzheimer Annual conference (Quoi de neuf Alzheimer? L’info dans tous ses états).
On 22 September (Berlin, Germany) the working group on assistive technologies and the steering group of the European Dementia Ethics Network met to analyse the draft report on the ethical implications of assistive technologies.
On 22 September (Brussels, Belgium) Annette attended the EFPIA Think Tank meeting.
On 28 September (Brussels, Belgium) Annette attended the Carers interest group meeting.
On 28 September (Santiago de Compostela, Spain) Rosário represented Alzheimer Europe at a symposium on carers at the Conference of the International Psychogeriatrics Association.
On 30 September-2 October (Luxembourg, Luxembourg) the AE Board meeting and the Annual General Meeting took place.

European developments

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

6 September 2010: European Commission proposes 2012 to be the European Year for Active Ageing

On 6 September 2010, the European Commission proposed that 2012 be designated as the "European Year for Active Ageing".

This initiative is to be placed in the context of the challenges of the ageing of the European population and its impact on public services and finances. The initiative should help create better job opportunities and working conditions for the growing numbers of older people in Europe, help them take an active role in society and encourage healthy ageing.

The proposed European Year for Active Ageing is designed to serve as a framework for raising awareness, identifying and disseminating good practice and encouraging policymakers and stakeholders at all levels to promote active age ing. These players will be invited to commit to specific action and goals in the run-up year 2011 so that tangible achievements can be presented during the European Year itself in 2012.

Active ageing includes creating more opportunities for older people to continue working, to stay healthy longer and to continue to contribute to society in other ways.

While the EU has a role to play in areas such as employment, social protection and inclusion, public health, information society and transport, the primary role is for national, regional and local governments, as well as civil society and the social partners.

The European Parliament and Council are expected to endorse the initiative by the beginning of 2011.

7 September 2010: European Commission State of the Union address

On 7 September 2010, European Commission President, José Manuel Barroso, delivered his first State of the Union address before the European Parliament. The State of the Union address will become a regular feature when the Commission President outlines the Commission’s work for the next 12 months.

Although the European determination to recover from the economic crisis has borne fruit, Mr Barroso insisted that there still were some uncertainties and risks across the EU and that the work was far from being finished. Structural reforms are needed to create sustainable growth and the next 12 months will be used to accelerate the reform agenda. The EU must modernise its social market economy so that it can compete globally and respond to the challenge of demography.

During his address, Mr Barroso only focused on five non-exhaustive major challenges for the Union over the next year:

1. dealing with the economic crisis and governance,
2. restoring growth for jobs by accelerating the Europe 2020 reform agenda,
3. building an area of freedom, justice and security,
4. launching negotiations for a modern EU budget,
5. pulling the EU weight on the global stage.

Unsustainable budgets make the EU vulnerable. Not only do debt and deficit lead to boom and bust, they also unravel the social safety net. The money spent on servicing debt is money that cannot be spent on the social good nor address the costs of an ageing population. A debt generation makes an unsustainable nation. The Commission’s proposals will thus strengthen the Stability and Growth Pact.
through increased surveillance and enforcement. Sound public finances are a means to an end: growth for jobs. The Commission’s overarching priority is sustainable and inclusive growth.

Although most of the competences for employment policy remain with Member States, the EU can help people seize new opportunities. This should be centred on skills, jobs and investment in life-long learning. Opportunities exist: while he level of unemployment is high in the EU, there are 4 million job vacancies. The Commission will propose later this year a “European Vacancy Monitor” that will show people where the jobs are in Europe and which skills are needed. The Commission also wants to move forward with plans for a European skills passport. To tackle the problems of poverty and exclusion, a “Platform Against Poverty” will bring together European action for vulnerable groups such as old people.

7 September 2010: DG Research publishes calls for proposals under FP7: ‘A roadmap for mental health research in Europe’

On 7 September 2010, DG Research published calls for proposals under FP7.

The FP7 Health theme key features are in line with the EU 2020 strategy and will seek to improve the health of European citizens and increase the innovative capacity and competitiveness of the European health sector.

A budget of EUR 682 million for R&D will support the 2011 calls.

There will be a strong emphasis on research to tackle lifestyle-related health issues across the calls and thematic areas, such as in diabetes/obesity, cardiovascular disease, brain-related diseases and social determinants of health.

7 September 2010: EP Resolution on the role of women in an ageing society adopted in plenary

European Alzheimer’s Alliance member Sirpa Pietikäinen (MEP, EPP, Finland) Resolution on the role of women in an ageing society was adopted in plenary on 7 September (562 votes in favour, 78 against and 29 abstentions).

Innovative policies must be devised to address the challenges of an ageing population, women’s increasing longevity, age discrimination, reconciliation of work and care, health of ageing women, care and social services.

The Resolution also calls on the Commission to come up with an action plan, by the end of 2011, providing for:

• an examination of the need for more resources for scientific research on ageing,
• measures to ensure the quality of care and the quality of the working conditions of carers,
• changes to increase coherence in the area of social security, including pension schemes, care leaves and part-time working arrangements,
• a gender-sensitive concept of age-related diseases and measures for their optimum recognition and treatment,
• yearly reporting, based on the principles of the Charter of Fundamental Rights of the European Union and managed by the Fundamental Rights Agency at the institutional level and national agencies in the Member States, on the violation of older people’s rights and on measures to be taken at EU and national level to abolish direct and hidden discrimination,
• non-legislative measures to tackle age discrimination, such as awareness-raising campaigns,
• mainstreaming of the perspective of older migrants and LGBT people,
• measures to support intergenerational solidarity, such as plans to support women who care for grandchildren while the parents are absent due to employment reasons,
• measures to make use of the knowledge and professional experience of older people, for example by setting up associations of older people to provide advice for job-seekers,
• exchange of best practice.

8 September 2010: Directive on the protection of animals used for scientific purposes adopted in Parliament

On 8 September, the European Parliament adopted the compromise text of the revised Directive 86/609 on the protection of animals used for scientific purposes. This new Directive aims to minimise the number of animals used in experiment and requires alternatives to be used when possible, while ensuring a level playing field for the EU industry and enhancing the quality of the research carried out in the EU.

The Member States will have 24 months to adopt and publish national legislation which will transpose the provisions of this Directive.

The new Directive will take effect on 1 January 2013.

9 September 2010: Resolution on long term care of older people adopted in European Parliament

On 9 September, the European Parliament adopted a Motion for resolution on the long term care of older people initiated by European Alzheimer’s Alliance member, Liz Lynne (MEP, ALDE, UK), and Pervenche Berez (MEP, S&D, France). On 07 September, the Parliament had discussed an oral question put forward to the European Commission by the same MEPs on the same topic. The reason for putting the oral question and resolution on the agenda is to try to achieve an EU wide code of conduct for long term care for older people. The idea is to exchange of best practices among Member States rather than legislate.

The Resolution calls on the Commission and Member States to:
Recognise the importance of both the quality and continuity of care, improve, facilitate, and encourage specialist training, education and reinsertion measures for all those people.

Recognise the needs of informal carers and take concrete measures to support and safeguard this resource via training, respite and measures to reconcile work and family life.

Support older people in every way necessary to ensure that they can manage by themselves in their own homes.

Calls on the Member States to provide support for the establishment of home palliative care units.

Collect data and draw up a summary of the institutional, community and home care infrastructure for older people in each Member State.

Establish the number of deaths among older people in long-term care that are attributable to malnutrition or dehydration.

In particular, the Resolution calls on the Commission to:

- Produce a Green Paper on elder abuse and safeguarding older people in the community and in all care settings, including a focus on patient mobility and details of best practices already existing in the 27 Member States.
- Prepare a study which will give a clearer picture of the increasing requirements for the care of older people and an estimate of the anticipated specialist provision for the period until 2020.
- Exchange information, policy ideas and best practice through the Member States on the on the provision of long-term care for older people and, in particular, measures and minimum professional standards using the Open Method of Coordination.

Policy Watch

In this section you can find articles on various national policies and initiatives which can have an impact on issues surrounding dementia.

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

13 September 2010: Study published on the cost of dementia in Switzerland

The Swiss Alzheimer Association funded a study on the cost of dementia in Switzerland, the results of which have been published. The aims of the study were:

- To estimate the cost of dementia in Switzerland,
- To compare the average annual cost for people with dementia who live at home and those living in an institution, and
- To analyse how the average cost per person with dementia who live at home increases with the severity of dementia.

The study found that:

- The total annual cost of dementia to be CHF 6.3 billion (EUR 4.85 billion) for the year 2007 (of which institutional and informal care account for over 90% of the cost).
- The average annual cost is estimated at CHF 55,300 (EUR 42,500) per person with dementia who lives at home and at CHF 68,900 (EUR 53,000) per person who lives in an institution.
- The cost per person living with dementia at home with severe dementia is nearly five times the cost per person with mild dementia.

The study concluded that "dementia imposes a considerable economic burden on Swiss society. The cost of dementia is dominated by the costs of care. Diagnosis and treatment related costs are minor. These findings are consistent with contemporary international studies on the subject. The contribution of informal caregivers is substantial since they account for 45% of the total cost of dementia. Give demographic developments in Switzerland healthcare decision making should have an interest in securing this potential for the future."

Members’ News

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

1 September 2010: Alzheimer’s Society contributes to the consultation for Northern Ireland’s first dementia strategy

The consultation for Northern Ireland’s first dementia strategy ended at the beginning of September. As party of the consultation response, the Alzheimer’s Society asked who uses Alzheimer’s Society services about health and social care and support. Its survey found that:

- 90 per cent of people do not think people with dementia in Northern Ireland are getting enough help and support
- 13% of people with dementia and their carers said they always receive high quality care.

Other key points in the Alzheimer’s Society’s consultation response include:

- The strategy does not have to have huge funding implications but it must make efficient use of available funding and have realistic costs attached to identified priority
- There is insufficient evidence about the current standard of services or detailed time frames for when proposed changes would be implemented
- There needs to be strong leadership at a national and local level if we are to make the most of this opportunity
- More focus needs to be placed on early intervention so we can reduce or prevent the need for expensive hospital or residential care.

Deirdre Blakely, Acting Director for Northern Ireland for the Alzheimer’s Society, said:
"If it is to be a success, the voice of people with dementia should be evident throughout. We also need to see a clearer roadmap for change with an accurate picture of the inconsistent standards we have today and the ideals that we have to achieve."

19 September 2010: 4,000 people run to raise money for the Alzheimer’s Society

The 30th Bupa Great North Run took place on 19 September with some 4,000 people running for the Alzheimer’s Society, Bupa’s nominated charity for 2010. It was also Bupa’s nominated charity in 2009 when over GBP 1 million was raised for Alzheimer’s Society. An Alzheimer’s Society spokesperson said that it seems they are on track to match the 2009 figure.

Supporting the Alzheimer’s Society, model and TV presenter Nell McAndrew ran in honour of her grandfather, who died in March this year. She said, “My granddad, Sam, had Alzheimer’s disease and shortly after I’d signed up to run for Alzheimer’s Society he died unexpectedly. It has been a huge blow to me, but I know he would have been proud of me running in the Bupa Great North Run this year.”

The final 2010 part of the Bupa Great Runs will be the South Run in Portsmouth on 29 October.

21 September 2010: France Alzheimer celebrates its 25th anniversary

September marks the 25th anniversary of France Alzheimer, which was created in 1985 with the aim of finding a way for people with dementia and their families to come together to learn, share their experiences and meet with professionals. Although the organisation was small when it started, by 2001 it had over 10,000 members. Alzheimer France is now a leading organisation for the training of dementia care for carers, volunteers and professionals, contributes to research, is a source of information on dementia for the public and government as well as continuing to offer support to people with dementia and their families.

On its website, the organisation has created a special anniversary area with the history of the organisation, photographs and videos of their work as well as their hopes for the future.

22 September 2010: Alzheimer Scotland launches fundraising campaign for dementia nurses

Alzheimer Scotland’s new fundraising campaign was launched by the Duchess of Hamilton. The campaign, which will run for three years, aims to raise GBP 1.5 million in order to be able to place an Alzheimer Scotland Dementia Nurse in every health board in Scotland.

Lady Hamilton, whose late-husband had vascular dementia, called for improved dementia training for nurses and doctors, explaining, “I have memories etched, of my Angus, sitting in the hospital bed, looking distraught at what had happened to him. No person should have to remember this and no ill person should have to endure such misery. If a nurse who was experienced in care of dementia could have talked with us, understood his needs, then his stay and our experience would have been so very much easier. That is why this appeal is so very important.”

Alzheimer Scotland Dementia Nurses:

- work with NHS colleagues to increase staff understanding of dementia and improve standards of care,
- aim to reduce the inappropriate prescribing of powerful antipsychotic drugs to modify behaviour,
- seek to reduce the number of people with dementia who are compelled to go from hospital into residential care, instead of being able to go back to their pre-hospital homes.

Henry Simmons, Chief Executive of Alzheimer Scotland, said, “In an average 900 bed hospital, approximately 150 patients will have some form of dementia. The vast majority of NHS staff want to provide a better hospital experience for people with dementia, but are not equipped to do so; they need more information, increased support and better training to cope with the changing demographics of today’s hospital wards.”

“This appeal will help us to fund more specialist Dementia Nurses, who will work to promote best practice and influence the way that people with dementia experience the NHS for the better.”

World Alzheimer’s Day in Europe

21 September marks World Alzheimer’s Day. Here we bring news of Alzheimer Europe members’ events held to mark the occasion.

10 September 2010: Norway marks World Alzheimer’s Day

World Alzheimer’s Day is celebrated every year all over Norway and this year was no exception. Local dementia associations arranged meetings for the general public with information on dementia. At the same time, the Norwegian Alzheimer Association, Nasjonalforeningen Demensforbundet, collected money for Alzheimer research by getting volunteers to raise money door to door. We also gave a dementia prize in each county to a person who has made a special contribution either as a researcher, a professional carer or a volunteer.

16 September 2010: Belgian “Ligue Alzheimer” triggers discussions and debates at its annual Conference

La Ligue Alzheimer ASBL held its annual Conference on the 16th of September. This Conference was organised within the framework of World Alzheimer Day.

The morning was dedicated to oral presentations. Speakers addressed issues such as: “A pathology that may affect younger patients: FTD and similar diseases”; “The diagnosis of Alzheimer’s Disease: how to announce it?”, “Helping the carers: the short-
therapy’s contributions”; “Alzheimer’s Disease and research”.

During the afternoon, various speakers debated on a series of themes at a round-table. The main theme was “Who does what for Alzheimer’s?” Amongst the speakers was Martial Van der Linden, the translator (into French) of Peter Whitehouse’s essay “The Myth of Alzheimer’s Disease”. The discussions were lively, as everybody wanted to have a say on the subject.

At the end of the Conference, one participant said: “I spent such a good day! The presentations were truly interesting, the organisation was very good… and the sandwiches were delicious.”

16 September 2010: World Alzheimer’s Day celebrated in Spain

The Spanish Alzheimer Confederation, Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), celebrated World Alzheimer’s Day by holding two events:

1. A press roundtable with the participation of the President of CEAFA, Emilio Marmaneu, General Directorate of Elderly and Social Affairs Instituto, Purificación Casusapie, and the neurologist Rafael García. The main aim of this was to raise awareness of the petition to Government calling for a National Policy about Alzheimer’s disease.

2. CEAFA’s Award ceremony (4th Edition) where organisations receive recognition for their work in the field of Alzheimer’s disease. Awards given were:
   - Information: Contenidos e Información de Salud
   - Investigation (research): Spanish Foundation of Neurological Diseases
   - Carer: State Reference Centre of people affected by Alzheimer Disease
   - Social: Valencia’s Federation.

18 September 2010: Belgium (Flanders) Alzheimer’s association celebrates 25 years and World Alzheimer’s Day

On 18th September Alzheimer Liga Flanders marked World Alzheimer’s Day whilst also celebrating their 25th anniversary.

Testimonies were given by Marleen Daecker, a young person with dementia and also from a family member, Godelieve Vaeyens. The Mayor of Leuven, Mr Tobbac (pictured), Minister Vandeurzen and other dignatories supported the celebrations at the city hall in Leuven. Minister Vandeurzen explained his Dementia plan for Flanders (2011-2014) and the Flemish Liga expressed their appreciation to the Minister for this presentation.

A wish tree was created, which carried more than 500 wishes from family members. There was also a special academic session.

A spokesperson from Alzheimer Liga said “After 25 years Alzheimer Liga Flanders we are proud to say that we realised a lot: the Alzheimer phone is a success, we established 31 family groups and have around 111 volunteers and 1,500 members.”

19 September 2010: Alzheimer Luxembourg organises its 2010 Memory Walk

To raise awareness of dementia, the Alzheimer Luxembourg Association (ALA) organised a memory walk on Saturday, 18 September. The theme for the 2010 Luxembourg Memory Walk was “The path of memory. Esch and Luxembourg during the Second World War”. It took place in Esch-sur-Alzette, Luxembourg.

In addition, ALA organised:
   - Information stands - information provided about dementia and services offered by the Alzheimer Luxembourg Association (ALA) (from 11am to 6 pm).
   - An Alzheimer café
   - A balloon contest and entertainment for children
   - Music with “The Luxembourg Pipe Band” and “Les Gavroches”
   - Free entry due to the friendly support of the National Museum of the Resistance and the Tourist Office of Esch/Alzette.

20 September 2010: Alzheimer Uniti, Italy, organises conference

Alzheimer Uniti in Italy organised its 12th annual Alzheimer conference entitled “Alzheimer XII – Today and Tomorrow” on September 20, 2010 in Rome to coincide with World Alzheimer Day 2010. The one-day conference addressed the interests of health care and social workers and was open to carers of people with dementia as well as the general public. Similar conferences took place in Perugia on September 21st and in Crotone (Calabria) on September 25th.

21 September 2010: Italy celebrates World Alzheimer’s Day by proposing a national advice network for people with Alzheimer’s disease and their families

On the occasion of the XVI World Alzheimer Day Federazione Alzheimer Italia organised a conference which was open to the public:

“Alzheimer: It’s time for action together!”

The conference had the patronage of the President of the Republic, the Ministry of Health, the Lombard region, the Province and the Municipality of Milan, the Italian Society of Gerontology and Geriatrics, the Italian Association of Psychogeriatrics and Unamsi (National Scientific Association of the Press).

The conference was divided into two parts: In the first part Teresa Di Flandra (Ministry of Health), Amalia Cecilia Bruni (Regional Centre of Neurogenetics), Nicola Vanacore (Istituto Superiore di Sanità) brought the public up to date on the state of the services in
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Italy and in Europe. Alessandro Nobili (Mario Negri Institute for the research) illustrated the Project Mapping and Evaluation of the services and the structures for the care and the care of persons with dementia in Lombardy which Federazione Alzheimer carried out with the collaboration of Mario Negri Institute.

In the second part, Marco Tabucchi, President of the Italian Association of Psychogeriatrics, chaired a round table with the delegates of the health departments of Lombardia, Toscana, Emilia Romagna and Liguria. He proposed a collaboration between Federazione Alzheimer Italia and the regional health departments to repeat the mapping in all Italy.

The aim of the conference was to establish a national advice network in order to help the families both in the south and in the north of Italy.

21 September 2010: World Alzheimer’s Day celebrated in Ireland

The Alzheimer Society of Ireland organised a number of events to mark World Alzheimer’s Day on Tuesday 21 September including two free Alzheimer Awareness evenings which were held in Dublin and Cork on that evening. Clinicians, carers, volunteers and legal experts were present on the night to answer any queries people had.

Media coverage of the day was secured in all the Irish national papers. Irish actor Bryan Murray, whose mother is living with dementia joined Minister for Older People and Health Promotion Aine Brady T.D., Alzheimer Society CEO Maurice O’Connell and RTE Television presenter Michael O’Muireachartaigh, to discuss the landmark report entitled “Dementia: It’s time for action!” to mark World Alzheimer’s Day 21 September (above).

The report warned of increasing dementia rates worldwide and the need for dementia to become a national health priority in Ireland. It is predicted that the number of people with dementia in Ireland will shoot up from a current total of 44,000 to over 104,000 by 2036.

21 September 2010: Greece celebrates World Alzheimer’s Day

A month full of events that were open to the public and free of charge, had been organized by the Greek Association of Alzheimer’s Disease and Related Disorders GAAHDRD) in order to celebrate World Alzheimer’s Day. During September the following events took place:

- An awareness week (30/8 – 5/9/2010): GAAHDRD took part in the events “Balkan square” that were organized by the Municipality of Neapolis. These events took place from 31st of August to 5th of September (19:00 -22:30). GAAHDRD had its own stand that provided informational material to the public attending the events.

- A press conference in Athens (Tuesday 14/9/2010): Dr. Paraskevi Sakka (from the Athens Alzheimer Association) and Professor Magda Tsoiaksi (from GAAHDRD) presented to the journalists of radio and TV the new data on Alzheimer’s Disease.

- A workshop (15/9/2010): This took place at the Municipality of Eleftherio-Kordelo and was open to the public. Professor Magda Tsoiaksi gave a speech that was titled “Smart ideas for successful ageing”.


- A day course on dementia (Saturday 18/9/2010): Professor Magda Tsoiaksi was one of the speakers.

- Presentations - Chalkida (Saturday 18/9/2010). Polema Kostas Petsanis, neurologist and Professor Magda Tsoiaksi gave presentations on Alzheimer’s Disease.

- An information stand (29/9/2010 – 24/9/2010): In the heart of the city of Thessaloniki, in Aristotelous square, GAAHDRD had its own informational stand. Our trained personnel were able to provide the general public with reliable information about dementia and Alzheimer’s disease. At the same time, a short test with ten questions was distributed to older population. T-shirts and jockeys with our logo were given to the participants. On World Alzheimer’s Day, GAAHDRD, in close cooperation with the organization for social support “Agapi”, added a second informational stand in the city centre.

- Professor Tsoiaksi Magda with Mr Fitsioris Xenofon gave presentations on preventive strategies of Dementia in Edessa in the presence of President of Greek Neurological Society Mr Nicolaos Artemis and the Mayor of the City.

- Alzheimer radio spot and TV slot: (throughout September): one TV and one radio spot, specially designed for the World Alzheimer’s Day will be broadcasted from the local and national TV and radio stations.

- Memory walk: (24/9/2010) A memory walk was held in the city center, which was attended by almost five hundred people (500). The memory walk ended at the cinema "Olympion" were a short speech was given about new data on dementia. The local authorities were present and the audience had the chance to watch a dementia related short film.

21 September 2010: Slovenia World Alzheimer’s Day celebrations include making children aware of how they can help people with dementia

The Association of Western Styrian Region for Help at Dementia “Forget-me-not Šentjur” (Forget-me-not Šentjur) had a stand on the very popular square in the centre of Šentjur, Slovenia. Volunteers raised awareness of Alzheimer’s disease by handing out
brochures, our newsletter “Touch of memory” and information about the disease. They explained to passers-by how dementia develops, what the symptoms are, how important it is to obtain an early diagnosis and treatment and how can people can help people with dementia.

In addition, volunteers discussed with children how they can help grandparents who have Alzheimer’s disease and other dementias. The volunteers discussed how children can continue to have a happy relationship with grandparents in spite of their memory loss and how they can help grandparents remember things, for example, through music.

21 September 2010: Alzheimer Portugal celebrates World Alzheimer's Day

To celebrate World Alzheimer’s Day, Alzheimer Portugal raised awareness of Alzheimer's disease and its consequences. As in previous years, Alzheimer Portugal marked the day with various activities around the country which included conferences, information stands, lectures, the distribution of flowers, sessions dedicated to answering questions as well as a fundraising dinner.

Science Watch

This section has highlights of the most recent published research on dementia, including research on the prevention, diagnosis, and treatment of the disease.

1 September 2010: Study examines the relationship between activity and cognitive morbidity

A study found that “mentally stimulating activity in old age appears to compress the cognitive morbidity associated with Alzheimer’s disease by slowing cognitive decline before dementia onset and hastening it thereafter.” The study was conducted on over 1,000 participants (aged 65 and over) over a 12-year period. Assessments were carried out every three years and it was noted how often they engaged in various activities including listening to the radio or watching TV, reading a book, carrying out a crossword puzzle or jigsaw, or going to a museum.

Carried out by researchers from Rush University Medical Center, Chicago, the research was published in the journal Neurology.

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

7 September 2010: Collaboration announced between manufacturers of Alzheimer’s disease medicines

A collaboration to develop novel therapeutics aiming to slow down neuro-degeneration in people with Parkinson’s and Alzheimer’s disease was announced between the pharmaceutical companies Roche and reMYND. The focus of the collaboration will be on two of reMYND’s preclinical oral compounds which inhibit tau neurotoxicity in Alzheimer’s disease as well as alpha-synuclein neurotoxicity in Parkinson’s disease.

8 September 2010: Study examines the relationship between omega 3 fatty acids and Alzheimer’s disease

A study has found that the levels of omega-3 fatty acid are depleted in brain tissue samples from people with Alzheimer’s disease. Researchers carried out analysis on post-mortem liver tissue from people with dementia and found that the liver’s ability to make docosahexaenoic acid (DHA), which is an omega-3 fatty acid, was defective. Further, the researchers found that the “greater the amount of Alzheimer’s-related cognitive problems experienced in life by the patients, the lower were their liver DHA levels.” This led them to conclude that the low levels of omega-3 in the brain may be a result of the liver’s impaired ability to make DHA.

The study was carried out by researchers from the University of California Irvine, Institute for Memory Impairments and Neurological Disorders and the University of Kentucky’s Anders-Brown Center on Aging, USA. It was reported in the journal PLoS ONE.

9 September 2010: Study examines role of Vitamin B

Researchers have found that people who were given a combination of vitamin B (6,9 and 12) over a two-year period experienced brain shrinkage (atrophy) at a slower rate than those who were given inactive tablets. The study did not identify the individual effects of each vitamin nor did it assess the effects of the treatment on cognition and more research has been called for.

Carried out by researchers from the University of Oxford, the Oxford Radcliffe Hospitals NHS Trust and the University of Oslo, Norway and published in the journal PLoS One.

10 September 2010: Study examines the effects of non-pharmacological therapies on the quality of life for people with Alzheimer’s disease and their carers

A study which evaluated the best evidence on the effects of non-pharmacological therapies (NPTs) in Alzheimer’s disease found that NPTs “emerge as a useful, versatile and potentially cost-effective approach to improve outcomes and quality of life in people with Alzheimer’s disease and related disorders (ADRD) for both the person with dementia and the carer.”

The study was carried out by team of international researchers from Austria, Australia, Canada, China, Spain, UK and the USA and published in the journal Dementia and Geriatric Cognitive Disorders.

12 September 2010: Study examines the relationship between memory and heart dysfunction

Researchers who investigated differences in cognitive impairment associated with two types of heart dysfunction (systolic versus diastolic dysfunction) in 80 older adults found that “two-thirds
of those with systolic dysfunction had evidence of cognitive impairment, affecting both the immediate and delayed memory. In contrast only a fifth of people with diastolic heart failure had memory-related cognitive impairment.”

Carried out by Lisa Bauer of the University of California San Francisco and colleagues, the study was presented at the Heart Failure Society of America conference.

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14 September 2010: Study compares brain process in younger people and protein build up in later life

Researchers who measured the levels of aerobic glycolysis (a process in which the brain converts sugar into energy) in young adults (average age 25) found the levels to be especially high in those areas of the brain where amyloid plaques build up in people with Alzheimer’s disease (such as the medial and lateral parietal and prefrontal cortices).

These levels contrasted in other regions of the brain and led the researchers to conclude that if the variations in aerobic glycolysis could be linked to the build up of plaques associated with Alzheimer’s disease, that this may lead to early screening and intervention.

The study was conducted by Professor Mark Mintun and colleagues and published in the journal the Proceedings of the National Academy of Sciences PNAS.

15 September 2010: Study examines the relationship between brain lesions and cognitive decline

A study which aimed to assess the relationship between cognitive function and dementia-related neuro-pathologic lesions found that “mild age-related decline in cognitive function is mainly due to the neuro-pathologic lesions traditionally associated with dementia.” The study also found that memory decline was gradual until the last four to five years of life, when it speeded up and almost no gradual decline was evident where there was an absence of tangles.

The study was conducted over a 13-year period on 350 participants (nuns, priests and brothers) and was led by Robert S Wilson, Rush University Medical Center in Chicago. It was published in the journal Neurology.

17 September 2010: Review of application for Alzheimer’s drug accepted by US government agency

The pharmaceutical company Teikoku Pharma USA has announced that a review of a New Drug Application (NDA) which could be used to treat people with Alzheimer’s disease has been accepted by the US Food and Drug Administration (FDA). The Application relates to a weekly transdermal patch of Acipt, a drug used to treat people with Alzheimer’s disease.

22 September 2010: Study examines the relationship between premorbid occupations and asymmetric atrophy in people with fronto-temporal lobar degeneration (FTLD)

A study suggests that in people with fronto-temporal lobar degeneration (FTLD) there may be a relationship between occupation selection and asymmetric atrophy. Those people with FTLD “whose professions placed high demands on language and mathematics had relatively preserved left temporal relative to right temporal volumes. Also, occupation selection occurring in early adulthood is related to lateralized brain asymmetry in patients who develop FTLD decades later in the relatively deficient hemisphere”.

The research was carried out by an international team of scientists from the USA, Canada, Germany and the UK. The lead author was Brian Levine, University of Toronto, Canada and the research was published in the journal Neuropsychologia.

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.

6 September 2010: DG SANCO presents improved web tool for finding EU public health data

The European Commission has made available a new version of the ECHI (European Community Health Indicators) website.

This tool offers health indicators (sets of data providing information on health status, health determinants and care in the EU countries). These indicators enable monitoring, comparison and serve as as basis for policy making.

ECHI allows users to find and download core indicators such as dynamic graphs, maps and tables covering all EU countries and stratified by age and gender.

21 September 2010: Discussion paper published on stigma and dementia

Alzheimer’s Australia NSW has published a discussion paper entitled “Addressing the Stigma associated with Dementia”, the aim of which is to “raise public awareness about the effects of stigma...
associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action. The recommendations call on the Australian and NSW Governments to fund:

- programmes for early diagnosis and timely referral to dementia support services to avoid the impact stigma has in delaying access to diagnosis and medical support
- and support dementia-specific education and training for all personnel working in dementia care services to reduce prejudice and stereotyping amongst dementia-care workers
- develop and fund an on-going National Dementia Awareness campaign that aims to increase and understanding of dementia to decrease stigma
- amend aged care legislation to include enforceable quality dementia care standards which include staffing, ongoing training and appropriate workforce qualifications
- recognize the need to invest in further social research into the effect of stigma on the lives of people living with dementia, their carers and families.

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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<tr>
<td>30 September-2 October</td>
<td>20th Alzheimer Europe Conference “Facing Dementia together”</td>
<td>AE Members, Board and staff</td>
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<td>6-9 October</td>
<td>EU Health Forum (Healthy Ageing Workshop) (Bad Hofgastein, Austria)</td>
<td>Annette</td>
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<td>10 October</td>
<td>Ligue Alzheimer, Alzheimer Café meeting (Brussels, Belgium)</td>
<td>Annette</td>
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<td>11 October</td>
<td>European Commission Workshop on Healthy Ageing (Brussels, Belgium)</td>
<td>Annette</td>
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<tr>
<td>13 October</td>
<td>Meeting with Bristol-Myers Squibb (Brussels, Belgium)</td>
<td>Jean and Annette</td>
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<tr>
<td>13 October</td>
<td>Meeting with Alzheimer’s Society (Brussels, Belgium)</td>
<td>Jean and Annette</td>
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<tr>
<td>18 October</td>
<td>Meeting with Pfizer (Brussels, Belgium)</td>
<td>Jean</td>
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<td>20-21 October</td>
<td>9ème Congrès International francophone de gériatrie et gérontologie (Nice, France)</td>
<td>Jean</td>
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<tr>
<td>26 October</td>
<td>Meeting with Eli Lilly (Brussels, Belgium)</td>
<td>Jean</td>
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<tr>
<td>28 October</td>
<td>EP Hearing on Alzheimer’s disease (Brussels, Belgium)</td>
<td>Jean and Annette</td>
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Future Conferences

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<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tr>
<td>7-9 October 2010</td>
<td>Gemeinschaft leben, <a href="http://www.deutsche-alzheimer.de">www.deutsche-alzheimer.de</a></td>
<td>Braunschweig, Germany</td>
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<tr>
<td>19-21 October 2010</td>
<td>Coming of Age: Dementia in the 21st Century, <a href="http://www.dementia.stir.ac.uk">www.dementia.stir.ac.uk</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>21-23 October 2010</td>
<td>10th Congress of European society for clinical neuro-pharmacology, <a href="mailto:ivan.rektor@fnusa.cz">ivan.rektor@fnusa.cz</a></td>
<td>Zagreb, Croatia</td>
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<tr>
<td>28-31 October 2010</td>
<td>The 4th World Congress on Controversies in Neurology (CONy), <a href="http://www.comtcmned.com">www.comtcmned.com</a></td>
<td>Barcelona, Spain</td>
</tr>
<tr>
<td>3-5 November 2010</td>
<td>Third Conference: Clinical Trials on Alzheimer’s Disease (CTAD), <a href="http://www.ctad.fr">http://www.ctad.fr</a></td>
<td>Toulouse, France</td>
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<tr>
<td>9-13 March 2011</td>
<td>The 10th International Conference on Alzheimer’s &amp; Parkinson’s Diseases (AD/PD 2011), <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a></td>
<td>Barcelona, Spain</td>
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<tr>
<td>14-17 April 2011</td>
<td>The VII International Association of Gerontology and Geriatrics (IAGG) – European Region Congress “Healthy and Active Ageing for all Europeans II”, <a href="http://www.iaggbologna2011.com">www.iaggbologna2011.com</a></td>
<td>Bologna, Italy</td>
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