Welcome to 2013! After a pleasant break, the Alzheimer Europe staff are all back at their desks, planning the new year’s activities. This issue covers an impressive range of events and activities that happened before the break.

In December, we released our 2012 “Dementia in Europe” Yearbook, which details the status and development of national dementia plans in Europe. The yearbook was presented at a European Parliament lunch debate, where various members of the European Working Group of People with Dementia (EWGPWD) provided insights on being diagnosed and then living with dementia. We are grateful to the five MEPs - all members of the European Alzheimer’s Alliance - that hosted EWGPWD members after the debate: Linda McAvan, Nessa Childers, Alojz Peterle, Sirpa Pietikäinen and Marc Tarabella.

In European affairs, the EU Council presented the main activities for the next three presidencies, including health and long-term care programmes. There were also four calls for proposals that will receive EU funding: the EAHC called for “Health 2013” applications, IMI will fund a project on neurodegenerative disorders and the JPND also issued two separate calls.

In the scientific world, there were two announcements of new clinical trials: Merck will test its BACE inhibitor compound and Lilly will run a new solanezumab trial. In addition, a new international report has confirmed - once again - that dementia is becoming a more prevalent cause of death.

This issue also reports on some new resources: a new German song on YouTube and the Commission’s new website on the “Month of the Brain” that will take place in May. In addition, ADI is looking for nominees for a new dementia award programme.

Our first events in 2013 will be a Lunch Debate in the European Parliament and a Public Affairs meeting, both in late February. The next issue of Dementia in Europe magazine will also appear at that time. We’ll also be improving and updating our website, which had a remarkable 334,000 visitors in 2012 - more than twice the 2010 visits!

We look forward to another productive year of working together with all our member organisations and partners.

Jean Georges
Executive Director
Alzheimer Europe

1 December: Alzheimer Europe releases 2012 Yearbook

Alzheimer Europe has released its "Dementia in Europe Yearbook 2012". The yearbook focuses on the current status and development of national dementia strategies in Europe, including specific reference to provisions relating to diagnosis, treatment and research.

Wherever possible, details are also provided on how these issues are handled in countries which do not yet have a plan, or are not in the process of developing one.

The yearbook includes Alzheimer Europe's 2011 Annual Report. It will soon be available for purchase on the Alzheimer Europe website.

3 December: EWGPWD holds meeting in Brussels

The European Working Group of People with Dementia (EWGPWD) held its second official meeting on 3 December in Brussels. During the meeting, the members:

• Debated on how best to disseminate information about the group, both at national level and also via Alzheimer Europe.
• Decided to develop a brief information leaflet on the work and aims of the group.
• Proposed the development of a detailed brochure on the work and aims of the group. This could be presented at the 2013 Alzheimer Europe conference in Malta.
• Finalised presentations for the lunch debate in the European Parliament on 4 December.
• Appointed two members as representatives for Alzheimer Europe’s 2013 working groups on ethics and incontinence.

The EWGPWD, an independent group, works to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia.

4 December: Alzheimer Europe holds Board meeting

The Alzheimer Europe Board met in Brussels on 4 December. This was the first meeting of the new Board elected in October 2012 – and also the first to include the Chairperson of the European Working Group of People with Dementia (EWGPWD).

The Board members discussed various financial and operational matters and voted to adopt Alzheimer Europe’s 2013 Work Plan and Budget.

The next Board meeting will take place on 25 February 2013.

4 December: Alzheimer Europe holds lunch debate at the European Parliament

On 4 December, Alzheimer Europe held a lunch debate at the European Parliament entitled “Living with dementia: learning from the experiences of people with dementia”.

The debate was hosted by MEP Sirpa Pietikäinen (Finland) who kindly accepted to take over from MEP Heinz Becker (Austria); he was unable to honour his commitment due to a last minute change in his agenda. Sirpa, who is also on the Board of Alzheimer Europe, welcomed the participants and opened the debate.

The first speaker was Helga Rohra, Chairperson of the European Working Group of People with Dementia (EWGPWD). She introduced the new group and described its activities and aspirations. Helga was followed by EWGPWD members Nina Baláčková (Czech Republic) and Daphne Wallace (England). They both gave presentations about their experiences of being diagnosed and then living with dementia.

Heike von Lützau-Hohlbein, Chair of Alzheimer Europe, then introduced the association’s latest publication. “Dementia in Europe Yearbook 2012” focuses on national dementia strategies in Europe, with specific references to diagnosis, treatment and research.

There were more than 50 participants at the debate, including Françoise Grossetête, MEP (France) who was represented by her assistant. Other participants included representatives from the European Commission, national policy makers, Alzheimer associations and pharmaceutical companies.

4 December: EWGPWD members visit the European Parliament

Following the lunch debate, five EWGPWD members each had the opportunity to meet one of their representatives. All five of these MEPs are members of the European Alzheimer’s Alliance.

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<th>Country</th>
<th>EWGPWD</th>
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<td>Belgium</td>
<td>Jean-Pierre Frognert</td>
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<td>Finland</td>
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<td>UK</td>
<td>Daphne Wallace</td>
<td>Linda McAvan</td>
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10 December: Florence Lustman leaves French Alzheimer Plan post

On 10 December, Florence Lustman, administrator of the French Alzheimer Plan, transferred to a new government position. Florence, a General Inspector of Finances, was in charge of the French Alzheimer Plan since 2008. She also acted as Vice Chair of the Foundation for Scientific Coordination of the Alzheimer Plan.

Florence was tireless in pursuing policy to strengthen and protect the rights of people with dementia and their families and caregivers. She was a keynote speaker at two Alzheimer Europe Conferences and also contributed interviews and articles to our Dementia in Europe magazine.

We will miss Florence and wish her every success in her new position at La Banque Postale.

Impressions from the Lunch Debate & European Parliament visit

Alzheimer Europe Networking

On 3-4 December (Brussels, Belgium), AE staff attended the 2nd EWGPWD meeting, the AE Board Meeting and the lunch debate at the European Parliament on “Living with dementia”.

On 7 December (Brussels, Belgium), Annette met with Štefanija Lukič Zlobec from Alzheimer Slovenia.

On 10 December (Lille, France), Alex attended a PharmaCog Steering Committee meeting.

On 11 December (Brussels, Belgium), Annette attended the EFPIA Think Tank.

On 12 December (Luxembourg, Luxembourg), members of the Luxembourg Alzheimer’s Association and Jean met with the new chief executive of the Integrated BioBank of Luxembourg.

On 12 and 21 December (Luxembourg, Luxembourg), Julie met J.P. Reuland from Binsfeld to discuss issue 13 of Dementia in Europe magazine.

On 13-15 December (Prague, Czech Republic), Jean attended the ELTECA meeting on long-term care.

On 17 December (Brussels, Belgium), Annette met Mari Satur Torre (Vodafone Spain Foundation) at the Vodafone Accessibility Awards Ceremony.

On 9 January (Brussels, Belgium), Dianne attended a budget meeting for the proposed PACE project.
Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 66, representing 22 Member States of the European Union and all seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their continued support of the European Alzheimer’s Alliance:

Austria: Becker K. Heinz (EPP), Werthmann Angelika (Nl).
Belgium: Brepoels Frieda (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabell Marc (S&D).
Bulgaria: Parvanova Antonya (ALDE).
Cyprus: Triantaphyllides Kyriacos (GUE/NGL).
Czech Republic: Cabrnoch Milan (ECR), Kohlcek Jaromir (GUE/NGL), Roithova Zuzana (EPP).
Denmark: Christensen Ole (S&D), Rohde Jens (ALDE), Schaldemose Christel (S&D).
Finland: Jaakonsaari Liisa (S&D), Jaätteenmäki Annette (ALDE), Pietikäinen Sirpa (EPP).
France: Audy Jean-Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Juvin Philippe (EPP), Morin-Chartier Elisabeth (EPP), Pargneaux Gilles (S&D).
Germany: Niebler Angelika (EPP), Roth-Behrendt Dagmar (S&D), Ulmer Thomas (EPP), Weisgerber Anja (EPP).
Greece: Chountis Nikolaos (GUE/NGL), Koppa Maria Elieni (S&D), Kratsea-Tsaagrapoulou Rodi (EPP).
Ireland: Aylward Liam (ALDE), Childers Nessa (S&D), Crowley Brian (ALDE), McGuinness Maeve (EPP), Mitchell Gay (EPP).
Italy: Mauro Mario (EPP), Panzeri Pier Antonio (S&D), Toia Patrizia (S&D).
Lithuania: Vilija Blinkevičiute (S&D).
Luxembourg: Engel Frank (EPP), Lulling Astrid (EPP).
Netherlands: De Lange Esther (EPP), van Nistelrooij Lambert (EPP), Wortmann-Kool Corien (EPP).
Poland: Łukacijewska Elżbieta (EPP).
Portugal: Carvalho Maria da Graça (EPP), Coelho Carlos (EPP), Matias Marisa (GUE/NGL).
Romania: Antonescu Elena Oana (EPP), Busoi Cristian (ALDE), Sârbu Daciana Octavia (S&D).
Slovakia: Mikolajský Miroslav (EPP), Zaborska Anna (EPP).
Slovenia: Pletchke Alja (EPP).
Spain: Badia i Cutchet Maria (S&D).
United Kingdom: Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), Moraes Claudia (S&D), Simpson Brian (S&D).
Austria: Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

EU Developments

7 December: EU Council presents 18 month programme

On 7 December, the EU Council presented its 18 month programme, which runs from 1 January 2013 to 30 June 2014. The programme is in two parts: 1) the strategic framework for the programme that sets it in a wider context, with long-term objectives running into the subsequent three Presidencies - Irish, Lithuanian and Greek - and 2) the operational programme that sets out the issues which are expected to be addressed during the 18 month period.

In the area of social protection and inclusion, the Presidencies will continue to follow up on Commission initiatives, particularly the new “Social Investment Package” which will launch in 2013. They will also address the issues of the financing of social protection systems and adequate access to services, as well as potential responses to the ever-increasing need for long-term care.

The Presidencies will also work on the proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or beliefs, disability, age or sexual orientation. In addition, promotion of the social and economic inclusion of persons with disabilities and marginalised groups will continue.

The current economic situation and its impact on health and health systems will lead the three Presidencies to focus on measures towards enhancing public health in the EU as well as on innovation in the health sector. They will move forward the “reflection processes” on modern, responsive and sustainable health systems and chronic diseases launched under the auspices of the Working Party on Public Health.

The programme was prepared by the future Irish, Lithuanian and Greek Presidencies and the High Representative and Chair of the Foreign Affairs Council - in close cooperation with the Commission and the President of the European Council.

8 December: Commission publishes decision on 2013 health work plan

On 8 December, the Commission published its decision of 28 November concerning the adoption of the 2013 work plan of the second programme of Community action in the field of health (2008-2013). This includes the selection, award and other criteria for financial contributions to the actions of this programme.

10 December: JPND launches calls for proposals

On 10 December, the EU Joint Programme - Neurodegenerative Disease Research (JPND) launched two calls for proposals from research teams across Europe. These should aim to increase understanding of the factors that put people at risk of developing neurodegenerative diseases such as Alzheimer’s and also to evaluate health and social care strategies for people living with these debilitating illnesses. The two calls will see more than EUR 25 million made available to applicants from over 20 countries.


The JPND diseases are: Alzheimer’s disease (AD) and other dementias, Parkinson’s disease (PD) and PD-related disorders, Prion disease, Motor neurone diseases (MND), Huntington’s disease (HD), Spino-cerebellar ataxia (SCA) and Spinal muscular atrophy (SMA).
10 December: Parliament pursues healthy ageing in plenary session

On 10 December, the European Parliament voted in favour of the resolution of Roberta Angelilli, MEP (Italy) on “the prevention of age-related diseases of women” during its plenary session.

The resolution particularly points out that many disorders are often underestimated where women are concerned – and recommends that measures aimed at raising awareness among women of the risk factors are put in place. It also calls on the Member States and the Commission to adopt awareness programmes to discourage smoking and to encourage a proper diet and sufficient exercise. Further, the resolution calls for awareness programmes to better inform the public about Alzheimer’s disease - which affects about one person in 20 over age 65, one in five over 80 and one in three over 90. A holistic and gender-sensitive approach to Alzheimer’s disease and other dementias is also called for.

In addition, the Parliament calls upon the Commission to prepare the following:
- A study on the link between the economic downturn and suicide in elderly women
- More accurate information about mental health and the relationship between mental health and a healthy lifetime
- Specific training courses for mental health professionals on the prevention and treatment of neurodegenerative diseases and depressive disorders. These should focus on the challenges faced by older women.
- Specific actions in the field of memory disabling diseases, such as dementia, and an increased effort in medical and social research in order to increase the quality of life of people with dementia and that of their carers.

17 December: IMI launches 8th call for proposals

IMI – the Innovative Medicines Initiative – has launched its latest call for proposals, including a topic on neurodegenerative disorders called “Developing an aetiology-based taxonomy of human disease.” The topic aims to develop a new classification for neurodegenerative disorders, with a focus on Alzheimer’s disease and Parkinson’s disease.

This call for proposals is known as IMI-JU-8-2012. More information is available on IMI’s website.

17 December: Vodafone Foundation Smart Accessibility Awards 2012

On 17 December, the Vodafone Foundation organised a ceremony in Brussels to announce the winners of the 2012 Vodafone Foundation Smart Accessibility Awards. This is a contest to promote the development of IT applications designed to improve the lives of those with disabilities and people that are older, to help them become more actively involved in society.

The awards categories included social participation, independent living, wellbeing and mobility. A prize fund of EUR 200,000 for the best Android apps to assist those with disabilities and the elderly was shared between four winners.

The Smart Accessibility Awards are part of the Vodafone Foundation’s “Mobile for Good” programme, which supports initiatives around the world that use mobile technology to drive positive social change. They are supported and co-organised by AGE Platform Europe and by the European Disability Forum.

Commissioner Viviane Reding, Vice-President of the European Commission, responsible for Justice, Fundamental Rights and Citizenship, participated in the ceremony. In her speech, she mentioned the Commission’s recent plans to propose a European Accessibility Act, which will include measures to improve the accessibility of goods and services in Europe. The Act is expected to address issues such as improving the inclusion and participation of people with disabilities throughout Europe.

18 December: EMA Board approves 2013 work programme

On 18 December, the Management Board of the European Medicines Agency (EMA) endorsed its 2013 work programme and budget.

The agency will continue to ensure that assessment activities are conducted to the highest scientific levels, but will also increase efficiency in its activities and develop initiatives for greater transparency and communication with stakeholders. Other tasks include the continued implementation of the pharmacovigilance legislation and the new falsified medicines legislation, as well as the planned revision of the veterinary medicines legislation.

In 2013, the Agency expects a stable total number of applications for human medicines, with 100 total applications. These include some 54 applications for new medicinal products (excluding designated orphan medicines), 20 new orphan medicines and 20 generic applications (2012: 52, 13 and 39 respectively). Some 10 applications for new veterinary medicines are expected, with 3 generic applications (2012: 9 and 3 respectively).

The work programme is accompanied by a budget of EUR 231.6 million, an increase of 4.1% from 2012. This includes fee revenue of EUR 179.8 million (3.8% increase compared with 2012) and an EU contribution of EUR 39.2 million.

For more details, please consult the EMA website.
20 December: EAHC launches call for “Health – 2013” applications

On 20 December 2012, the Commission’s Executive Agency for Health and Consumers (EAHC) launched its call for “Health - 2013” applications within the framework of the second programme of Community action in the field of health (2008-2013).

This call is based on the Commission’s 2013 Work Plan of the Health Programme and consists of:

- proposals for financial contributions to specific actions of projects and conferences
- proposals for financial contributions toward the functioning of non-governmental bodies and specialised networks (operating grants)
- an invitation for Member States and participating countries to submit joint actions

The deadline for submissions is 22 March 2013.

20 December: Commission launches website for “European Month of the Brain”

On 20 December, the European Commission presented its website for the “European Month of the Brain”.

The Commission decided in 2012 to make May 2013 the European Month of the Brain with the overarching theme “A month to make a difference”. The decision was based on the fact that brain research needs a decisive and concerted effort in Europe with more investment, clearer and more innovative research and healthcare strategies.

The European Commission will organise two conferences as part of the European Month of the Brain 2013:

- Brussels (14 May), to showcase European projects in the field and outline future scientific efforts.
- Dublin (27-28 May), during the Irish EU Presidency, on European policy for brain research and healthcare.

The European Commission calls upon all stakeholders interested in the subject to organise events and activities around brain research during May 2013. These could include workshops, exhibitions, “brain days”, science cafes, lab visits, media events and awareness campaigns. The Commission may be able to support stakeholders by adding their activities to its own calendar of events.

21 December: EU Council presents conclusions on “Healthy Ageing through the Life Cycle”

On 21 December, the Council presented its conclusions on “Healthy Ageing through the Life Cycle”.

The Member States are invited to make the issue of healthy ageing across the lifecycle one of their priorities for the coming years, with a social and equity approach. To do so, they should adopt an approach that shifts the focus towards health promotion, disease prevention, early diagnosis and better condition management from the early years of life throughout the lifecycle, as a strategy to improve quality of life and reduce the burden of chronic diseases, frailty and disability.

Member States are also invited to enhance and strengthen coordination and collaboration between all relevant stakeholders and among Member States, as well as to promote intersectoral action.

Innovative approaches in health promotion and disease prevention that promote the active involvement of individuals, families and community are also called for by the Council.

The Council asks the Member States to support the European Innovation Partnership on Active and Healthy Ageing, implement the Partnership’s specific actions and engage in the delivery of robust outcomes. To do so, the Member States are invited to make effective use of the available EU funding. This includes Structural Funds, Cohesion Social Funds, FP7, Horizon 2020 and the Competition and Innovation Programme.

In particular, the Council calls upon the Member States to support cities and municipalities in their initiative to promote age-friendly and healthy environments and to develop networks to implement common guidelines.

Members’ News

3 December: Romanian society meets pensioners and plans conference

On 3 December, members of the Romanian Alzheimer Society met with members of the Association of Pensioners Rights. The purpose of this meeting was to share opinions and experiences related to two themes: “Cognitive function and changes occurring with age” and “Continuity and change for our seniors”.

The Society also hosted a delegation from the TUNA foundation on 22 December. This joint Romanian-Turkish friendship group brought Christmas gifts to Romanian Alzheimer Society’s members, consisting of clothes and food. Members of the two associations chatted and drank tea around the Christmas tree, laying the foundations for future collaborations.

Finally, the Romanian Alzheimer Society launched the official website for its National Alzheimer Conference, which will take place from 27 February to 2 March 2013 in Bucharest.

www.abcongres.ro
10 December: “Meeting without Frontiers” team releases press book

Last June, we reported on a project called "Meeting without Frontiers" that was organised by the Munich chapter of the German Alzheimer Society and the Vaucluse chapter of France Alzheimer. In May 2012, seven people with dementia, accompanied by their carers, travelled from Munich to Provence where they were hosted by friends from the French association.

The aim was to demonstrate the possibility of people with dementia to travel abroad and that the disease was not an obstacle. The travellers enjoyed many visits and activities during the trip; they realised that dementia did not hinder them from discovering new places and enjoying life away from a familiar environment.

The organisers have now released a Press Book, which contains photos, quotes and experiences from this unique trip. The book is available online in English, French and German.

www.agm-online.de/fileadmin/downloads/Frankreich-Austausch/pressbookeng_en.pdf
www.francealzheimer-vaucluse.org/content/%C2%AB-rencontre-sans-fronteres-%E2%80%93-begegnung-ohne-grenzen-%C2%BB

10 December: Alzheimer Scotland opens new centre

On 10 December, the University of the West of Scotland (UWS) launched its new Institute of Older Persons’ Health and Wellbeing at its Hamilton campus. At the same time, Alzheimer Scotland opened a new Centre for Dementia Policy and Practice, which will also be based at the UWS campus and aligned to the new institute.

The Institute of Older Persons’ Health and Wellbeing will be a centre of excellence, advancing knowledge relating to ageing, with a view to improving the health and quality of life of older people. It brings together the skills and knowledge of staff within higher education institutions, the NHS, local authorities, businesses, and not-for-profit organisations, in order to promote the development of policy and practice relating to older people.

The Alzheimer Scotland Centre for Dementia Policy and Practice aims to become a recognised centre of excellence, improving the quality of life of those with dementia by informing policy relating to the care of those affected and their families.

Henry Simmons, Chief Executive of Alzheimer Scotland, said: “We are delighted to launch this new Centre in partnership with UWS. No one should underestimate the size and scale of the problem facing us in Scotland and beyond. Across the globe, someone is diagnosed with dementia every four seconds. We have a limited number of treatments to manage some symptoms, but we are still far from arresting or curing the illness. Human intervention is one of the most effective ways that we support people with dementia to live well.”

11 December: Alzheimer Bulgaria presents seminar results

On 11 December, Alzheimer Bulgaria held a press conference to announce the results of its first International Seminar, which took place from 30 November to 2 December 2012.

The seminar attracted 52 delegates from Bulgaria, the Czech Republic and Macedonia. They concentrated on the need to prepare national plans for solving the problems of the people with Alzheimer’s disease and other forms of dementia. Various working groups focused on early diagnostics, preparation of professional caregivers, opening of day centres, self-help groups and reimbursement of Alzheimer’s medicines.

The reimbursement issue is particularly critical. Alzheimer Bulgaria, along with the government ombudsman, was instrumental in the work leading to the February 2012 ruling of the High Administrative Court. The court ordered regulatory changes to allow reimbursement for Alzheimer’s medicines. However, reimbursements had still not begun at the time of the conference.

Delegates also discussed the EU’s Written Declaration 80/2008, which calls on national governments to recognise Alzheimer’s disease as a public health priority and to develop a national dementia plan. The declaration was adopted by the European Parliament on 6 February 2009 - including signatures from 16 Bulgarian delegates - but the government has yet to act upon it.

12 December: Irish President hosts volunteers from the Alzheimer Society of Ireland

On 12 December, Michael D. Higgins, Irish President and patron to The Alzheimer Society of Ireland, hosted 100 volunteers at a special reception at the presidential residence. The reception marked the 30th anniversary of the Society and particularly acknowledged
the invaluable contributions of volunteers over the past thirty years. Special recognition was given to Dermod Slevin, a member of EWGPWD. He has worked extensively to help reduce stigma and raise awareness around living well with dementia in Ireland. The Alzheimer Society of Ireland was privileged to attend the event and the day was thoroughly enjoyed by all who attended.

14 December: Spanish author releases children’s book about dementia

A new children’s book about Alzheimer’s disease has been published in Spain. “Coloured threads” is about a woman who weaves a story about her life as a gift for her granddaughter, before her memories escape her. The book was written and illustrated by Elena Ferrandiz. She hopes that it will help children to understand their grandparents a little better and learn the importance of expressing affection.

On 14 December, a special edition of the book was released on behalf of Fundación Alzheimer España. The Spanish association will receive part of the proceeds from the sales of this edition.

14 December: Alzheimer Nederland launches awareness campaign

Alzheimer Nederland recently launched a campaign that aims to educate a large target group of people with little knowledge of dementia. The campaign aims to deliberately confuse people in an effort to demonstrate the realities of living with dementia. It includes a TV hidden camera spot and printed puzzles that have no solution. All of these carry the message that “people with Alzheimer’s have to cope with this feeling every day.”

18 December: Alzheimer Uniti Italy presents a new book

Alzheimer Uniti Italy recently presented a new book called “The Alzheimer Café: A Rich Experience”, written by Professor Marco Trabucchi, a noted expert in Alzheimer’s disease. Alzheimer Uniti Rome also contributed to the book, together with six other Alzheimer organizations in northern Italy. Loneliness and exclusion are often a heavy burden on the families of people with dementia; hence, Alzheimer cafés have become a new, safe and relaxed social setting. The book describes the process of developing and creating Alzheimer cafés throughout Italy. It also includes charts showing the positive results for the persons with dementia, such as the decrease in behavioural disturbances and reduction of caregiver stress, leading to a better quality of life.

The book presentation was attended by the author and also Carla Colicelli, a sociologist who described the current social situation in Italy. In addition, caregiver Maria Sandias spoke about her experiences: she underlined the importance for people affected by Alzheimer’s disease and their caregivers to establish a network of relationships.

The event was moderated by Luisa Bartorelli, Director of the Alzheimer Center Fondazione Roma. Following the presentations, Alzheimer Uniti hosted a reception to celebrate Christmas and the New Year.

20 December: Alzheimer Slovenia elects new executives

On 20 December, Slovenia’s Alzheimer Spominčica elected Dr. Ales Kogoj as the new President of the association and Štefanija Lukči Zlobec as Vice President. This election is part of the association’s ongoing effort to overhaul its statutes. Dr. Kogoj is a psychiatrist specialising in dementia and was one of the founders of the association in 1997. Ms Lukči Zlobec, who has been with Spominčica since 2009, is very active in representing the association internationally.

28 December: Norway promotes dementia research

The Norwegian Health Association will continue to fund dementia research in 2013, according to May-Hilde Garden, Dementia Consultant to the association. Every year, the organisation awards various research grants for research on dementia. These grants are financed entirely by private donations and are quite separate from the research funds granted by the Norwegian government. In 2012, the association awarded grants for two PhD scholarships and also funded running costs for four further studies.
“Does impairment of fast neuronal signaling expedite development or augment symptoms of dementia in neurodegenerative diseases.” University of Oslo, supervisor Farroukh Chaudry, PhD candidate Maria MastrangeloGPLoulou.

“Mapping new cases & types of dementia in people under 65 in Trøndelag county.” TrønderBrain, supervisors Sigrid Botne and Linda White, PhD candidate Marte Kvello.

“The effect of physical activities and aerobic capacity on the structure and function of the brain in older people.” Helen Palmer, NTNU.

“Progression of Alzheimer’s disease (PAD).” Ingvid Saltvedt, St. Olavs Hospital/NTNU.

“Cognitive therapy in early stage of dementia.” Ingun Ulstein, Norwegian Centre for Research, Education and Service Development.

“Impact of mitochondrial DNA damage for neurodegeneration in brain.” Magnar Bjørås, Oslo University Hospital.

In 2013, the biggest annual charitable public fundraising event in Norway will focus on dementia. This may lead to an increase of up to EUR 9.6 million in funding for dementia research. These funds will be used for a coordinated national research strategy aimed towards increasing knowledge of both the causes and treatment of dementia.

28 December: Scottish Dementia Working Group celebrates 10th birthday

2012 was a year of hard campaigning but also celebration as the Scottish Dementia Working Group (SDWG) celebrated its 10th birthday.

SDWG is a national campaigning group run by people with dementia. They represent the independent voice of people with dementia within Alzheimer Scotland. The Working Group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia. In 2012, the group participated in the following activities:

February: hosted a lunch reception at the ADI conference in London. Agnes Houston (SDWG Chair) and James McKillop (founding member) both gave speeches to an attentive and enthusiastic audience.

April: brought together people with dementia and representatives of national Alzheimer Associations in Glasgow, together with Alzheimer Europe. This led directly to the creation of EWGPWD, the European Working Group of People with Dementia.

June: held a birthday party with 100+ guests, including Nicola Sturgeon, then Cabinet Secretary for Health, Wellbeing and Cities Strategy. She praised the group members for their expertise, determination and organisational strength.

November: held an Annual General Meeting in Perth.

December: elected Committee members for 2013 and held the first committee meeting in Glasgow. The new Chairperson is Henry Rankin and the two Vice Chairs are David Mackenzie and Peter McLaughlin.

In 2013 the Scottish Dementia Working Group looks forward to continued progress in making a difference in the lives of people with dementia.

L-R: David Batchelor, Nicola Sturgeon, Agnes Houston. www.sdwg.org.uk

Policy Watch

22 November: France to expand 4th Plan Alzheimer

On 22 November, the French government tasked two experts to evaluate the 2008-2012 Plan Alzheimer: Prof Joel Ankri, Geriatrician at the Sainte Périne - Chardon Lagache - Rossini hospital in Paris and Dr. Christine van Broeckhoven, Professor of Molecular Genetics at the University of Antwerp. They will evaluate the progress made by the plan and make recommendations for improvements. They’ll also suggest ways to expand the plan beyond Alzheimer’s disease, to include all neurodegenerative diseases. Their final report is expected in May 2013.

Science Watch

3 December: Merck begins phase 2 trial of BACE inhibitor

Merck has started a phase 2 trial of its compound MK-8931 on 200 people with Alzheimer’s disease. The compound is a BACE inhibitor, i.e. it blocks the production of beta secretase - an enzyme involved in the production of beta amyloid. The trial will test whether the compound can prevent a worsening of symptoms among people in the mild-to-moderate disease stages.

Earlier this year, Merck presented findings of a multiple dose Phase 1 study which demonstrated that MK-8931 can reduce cerebral spinal fluid (CSF) beta amyloid by more than 90% in healthy volunteers, without dose limiting side effects.

3 December: Vitamin D & calcium combo does not protect against dementia

A recent study on women that combined vitamin D and calcium supplements did not show any added protection against dementia.

The researchers analysed data from 2,034 women of average age 71 that took vitamin D and calcium daily for an average of eight years. Results showed that they
developed cognitive impairments at the same rates as a control group on placebo.

However, the two elements were found to have conflicting effects. The research team, led by Dr. Rebecca Rossom, Geriatric Psychiatrist at the University of Minnesota, still believes that vitamin D alone may have beneficial effects.

Dr. JoAnn Manson, Professor of Medicine at Harvard Medical School and co-author of the study, said: "The next step is to test a higher dose of vitamin D. Higher doses will bring a study population to an achieved blood level that has been associated with reduced risk of cognitive decline in past studies."


5 December: Mentally ill people are more likely to be undertreated

A research team from the University of Leicester found that people with severe mental illness were less likely to get drugs for conditions such as high blood pressure.

The team reviewed 61 existing studies to reach their conclusions. The studies covered almost two million people, mainly living in the US.

They looked at treatment of conditions including cardiovascular disease, diabetes, cancer, arthritis, osteoporosis and HIV. It was found that people with severe mental illness received lower than expected prescriptions for essential drugs to treat high blood pressure.

Overall, it was estimated that the rate of under-treatment for medical conditions was 10% for those with severe mental illness. Dr. Alex Mitchell of the University of Leicester, who led the study, said: "People with severe mental illness appear to be receiving significantly less medication for medical disorders, particularly for cardiovascular problems.

"Mental health professionals may not feel confident in prescribing medication to treat physical problems, and hospital specialists may be worried about interactions of mental health medication. However we cannot rule out the possibility that medical conditions are being undertreated where they co-exist with mental health problems."

http://hpj.rcpsych.org/content/201/6/435

5 December: Janssen announces galantamine safety results

On 5 December, Janssen issued a press release about a long-term safety study of galantamine.

The study showed a significantly lower mortality rate in patients who were treated with galantamine for mild to moderately severe Alzheimer’s disease, versus those who received placebo. Patients treated with galantamine also had significantly lesser decline in cognitive impairment after two years, compared to patients in the placebo group.

Galantamine is marketed by Janssen as Reminyl. The full press release is available on the company’s website.

http://www.janssennmd.com/sites/default/files/pdf/GalantamineMortalityACNPRelease_2soProof.pdf#zoom=125

5 December: Brain implants may slow memory loss

On 5 December, researchers at Johns Hopkins Medicine surgically implanted a pacemaker-like device into the brain of a patient in the early stages of Alzheimer’s disease. The device provides deep brain stimulation and is already in use in thousands of people with Parkinson’s disease. It is seen as a possible means of boosting memory and reversing cognitive decline. A total of 40 people with mild Alzheimer’s disease are expected to receive similar implants over the next year.

In a preliminary safety study in 2010, the devices were implanted in six people in Canada. Results showed that people with mild forms of the disease showed sustained increases in glucose metabolism, an indicator of neuronal activity, over a 13-month period. In Alzheimer’s disease, glucose metabolism would normally decrease. Glucose acts as a “fuel” that regulates many brain functions, including learning and memory.

Dr. Paul Rosenberg, Associate Professor of Psychiatry and Behavioral Sciences at Johns Hopkins University School of Medicine, said: “Recent failures in Alzheimer’s disease trials using drugs such as those designed to reduce the buildup of beta amyloid plaques in the brain have sharpened the need for alternative strategies.

“This is a very different approach, whereby we are trying to enhance the function of the brain mechanically. It’s a whole new avenue for potential treatment for a disease becoming all the more common with the aging of the population.”

This trial is supported by the US National Institutes of Health. It is led by Dr. Constantine Lyketsos, Professor of Psychiatry and Behavioral Sciences at Johns Hopkins University School of Medicine and Dr. Andres Lozano, Chairman of the Neurology Department at the University of Pennsylvania, the University of Florida and Banner Health System in Phoenix, Arizona.

www.hopkinsmedicine.org/news/media/releases/johns_hopkins_surgeons_implant_brain_pacemaker_for_alzheimers_disease_in_united_states_as_part_of_a_clinical_trial_designed_to_slow_memory_loss

10 December: Lack of TDP-43 causes neuron death in ALS and FTD

Researchers have identified a cellular chain reaction based on the TDP-43 protein that leads to neurodegeneration in amyotrophic lateral sclerosis (ALS) and fronto-temporal dementia (FTD).

Dr. Mercedes Prudencio, lead investigator and Senior Research Fellow in Neuroscience at the Mayo Clinic in Florida, said: “We sought to investigate how TDP-43 regulates the levels of the protein progranulin, given that extreme progranulin levels at either end of the spectrum,
too low or too high, can respectively lead to neurodegeneration or cancer."

TDP-43 regulates both mRNA - a molecule that is active in protein synthesis - and the sortilin protein, which in turn regulates progranulin, also a protein.

The team found that a lack of TDP-43 disrupts the normal operation of mRNA, resulting in the generation of defective sortilin. The sortilin then binds to progranulin, but the defect causes the loss of progranulin’s ability to prevent neuron death.

11 December: Multiple tests improve prediction of Alzheimer’s disease

A recent study shows that using more than one diagnostic test could better predict which people with MCI will go on to develop Alzheimer’s disease.

Researchers at North Carolina’s Duke Medicine (DM) studied 97 people with MCI. The participants underwent typical diagnostic procedures for Alzheimer’s disease, including cognitive testing, as well as MRI, CSF and PET tests.

The study participants were followed for up to four years. It emerged that the rate of misdiagnosis was highest (41.3%) when the study participants only received the typical cognitive testing. The percentage went down with each additional test the person was given, with the lowest percentage of misdiagnosis (28.4%) occurring when all three tests were administered.

Dr. P. Murali Doraiswamy, Professor of Psychiatry & Behavioral Sciences at DM, said: "Misdiagnosis in very early stages of Alzheimer’s is a significant problem, as there are more than 100 conditions that can mimic the disease. In people with mild memory complaints, our accuracy is barely better than chance. Given that the definitive gold standard for diagnosing Alzheimer’s is autopsy, we need a better way to look into the brain."

12 December: Lilly plans new trial of solanezumab

Lilly will begin a new Phase 3 trial of solanezumab on people with mild Alzheimer’s disease in late 2013.

Earlier this year, the company reported that two Phase 3 trials of solanezumab in mild-to-moderate Alzheimer’s disease failed to meet their main goals. However, a later pooled analysis suggested that the drug slowed cognitive decline in people with a mild form of the disease.

The company decided to run a new trial rather than seek marketing authorisations based on these studies.

13 December: Mental activity in early life helps memory in old age

A research team from the UK and Australia has shown that people who were more mentally active in early life had a lower risk of developing memory problems in old age – and were also likely to live longer.

For example, the researchers calculated that a man aged 65 with a very good education, a good job and an active retirement would live for an average 81 years. This is some three years longer than one with a short education, an undemanding job and a lonely retirement period.

The study measured the effects of education, occupation, and social engagement on long-term cognitive health in people with and without severe cognitive impairment. Data came from 12,470 participants from a multi-centre cohort, mainly from the UK. Respondents were aged 65 years and over and were followed over 16 years.

The study included researchers from Cambridge University, University of Sydney, University College London and the Medical Research Council Biostatistics Unit. It also received funding from by Alzheimer’s Research UK.

14 December: Diabetes drug may prevent neuron death

A research team from the University of Alberta (UA) reported that a diabetes drug that never made it to market may be able to prevent beta amyloid from damaging neurons.

The researchers were led by Dr. Jack Jhamandas, Professor of Neurology at UA. They tested the memory of normal brain cells and those with Alzheimer’s disease - both from mouse models - with the drug AC253.

When AC253 was given to brain cells with Alzheimer’s and memory tests were redone, memory was restored to levels similar to those in normal cells.

Dr. Jhamandas said: “This is very important because it tells us that drugs like this might be able to restore memory, even after Alzheimer’s disease may have set in.”

He also noted that it is difficult for AC253 to cross the brain barrier; pharmaceutical companies would need to design a drug that can penetrate brain cells more easily.

20 December: Chronic inflammation may lead to Alzheimer’s disease

A research team from the University of Bonn and the University of Massachusetts has discovered a new signalling pathway associated with the death of neurons from chronic inflammation in mouse models.

The caspase-1 enzyme is partly responsible for activating the inflammatory reaction: the team found higher amounts of caspase-1 in the brains of people with Alzheimer’s disease compared to healthy persons. These increased levels were associated with chronic inflammatory reactions of the immune cells in the brain. The same findings were observed in Alzheimer’s mouse models.

The other influencing factor is the NLRP3 gene. This causes the creation of cryoprin proteins, which then become active in the process leading to inflammation. When scientists deactivated NLRP3 and caspase-1 in the
Alzheimer’s mice, there was neither brain inflammation nor memory loss in the animals.

Dr. Michael Heneka, lead author of the study and Head of the Clinical Neuroscience Unit at the Neurological Clinic of the University of Bonn, said: “Many years before the initial symptoms occur, so-called plaques, which consist of incorrectly folded beta-amyloid peptides, form in the brain of affected persons. In addition, there are abnormal tau protein deposits in the brain cells of the patients.

“We are still in the basic research stage and thus therapeutic success cannot be foreseen at this time point. There is still a long way to go until the first clinical studies.”

www.nature.com/nature/journal/vaop/ncurrent/full/nature11729.html

Dementia in Society

26 December: Gerry Anderson, producer of Thunderbirds

Gerry Anderson (1929-2012) the British producer of Thunderbirds, Captain Scarlet and Space: 1999, passed away on 26 December at the age of 83. He is best known for his “supermarionation” puppets that featured in various popular TV series of the 1960’s and 70’s.

Mr Anderson had been suffering from Alzheimer’s disease for almost three years. After being diagnosed, he became an avid supporter of the UK Alzheimer’s Society. Gerry Anderson is survived by his third wife Mary and four children.

www.justgiving.com/RememberingGerryAnderson

New Publications & Resources

1 December: New music video about dementia debuts on YouTube

A new German video on YouTube portrays the life of a man living with dementia. “Question mark” was recorded by the band Purple Schulz but has received only light radio airplay – commercial stations consider the topic “too heavy”.

The German Alzheimer Society kindly requests that you visit YouTube and click Like!

www.youtube.com/watch?v=MSWm9bgkidE

14 December: Dementia is becoming a more prevalent cause of death


Results show that infectious diseases and malnutrition now cause fewer deaths and less illness than they did twenty years ago. As a result, fewer children are dying every year. However, more adults are dying and suffering from disease and injury as non-communicable diseases - including dementia - become the dominant causes of death and disability worldwide. Since 1970, men and women worldwide have gained slightly more than ten years of life expectancy overall, but they spend more years living with injury and illness.

The work was led by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington, with other collaborating institutions including the University of Queensland, the Harvard School of Public Health, the Johns Hopkins Bloomberg School of Public Health, the University of Tokyo, Imperial College London and the World Health Organization.


28 December: ADI calls for award nominations

Alzheimer’s Disease International (ADI) is calling for nominations for a new award programme called “Best Dementia Care Education Projects”.

Nominations can be made by national Alzheimer associations, either on their own behalf or for other institutions in their countries. There are three awards for three regions of the world: the Asia Pacific region; Europe, Middle East and Africa; North, Central and South America. Each award includes a cheque of USD 10,000.

A high-level jury with representatives from all continents of the world will review the applications and take a decision on behalf of ADI. The deadline to submit is 22 February 2013 and the winners will be announced at the ADI conference in Taipei on 18-20 April 2013.

Interested applicants are invited to contact ADI at info@alz.co.uk
**AE Calendar**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE Representative</th>
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<tr>
<td>10-11 January 2013</td>
<td>Meeting in Malta for the 23rd Alzheimer Europe conference</td>
<td>Gwladys</td>
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<tr>
<td>27 January 2013</td>
<td>Meeting with Alzheimer’s Disease International (Luxembourg, Luxembourg)</td>
<td>Jean</td>
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<tr>
<td>21 January 2013</td>
<td>ALCONE high level expert workshop to formulate recommendations on the use of advanced directives (Brussels, Belgium)</td>
<td>Dianne</td>
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<tr>
<td>21-22 January 2013</td>
<td>Kick-off meeting of European Medical Information Framework project (Amsterdam, Netherlands)</td>
<td>Jean</td>
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<tr>
<td>25 January 2013</td>
<td>INTERDEM meeting (Prague, Czech Republic)</td>
<td>Dianne</td>
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<tr>
<td>29-30 January 2013</td>
<td>EFGCp seminar “Virtual future: the ethical dimensions of emerging technologies in clinical trials and research” (Brussels, Belgium)</td>
<td>Dianne</td>
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**Future Conferences**

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
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<tbody>
<tr>
<td>29-30 January 2013</td>
<td>EFGCp Annual Conference: Virtual future: what are the ethical dimensions of using emerging technologies in clinical trials and research?, <a href="http://www.efgcp.eu">www.efgcp.eu</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>19-20 February 2013</td>
<td>Workshop for “European Month of the Brain”, European Federation of Neurological Associations (EFNA), email contact: <a href="mailto:executivedirector@efna.net">executivedirector@efna.net</a></td>
<td>Brussels, Belgium</td>
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<tr>
<td>6-10 March 2013</td>
<td>11th International Conference on Alzheimer’s and Parkinson’s Diseases, <a href="http://www.kenes.com/adpd">www.kenes.com/adpd</a></td>
<td>Florence, Italy</td>
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<td>11-14 April 2013</td>
<td>The 7th World Congress on Controversies in Neurology (CONy), <a href="http://www.concemed.com/congs/2013/">www.concemed.com/congs/2013/</a></td>
<td>Istanbul, Turkey</td>
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<tr>
<td>4-12 May 2013</td>
<td>Neural Stem Cells in Development and for Brain Repair, <a href="http://www.rnas.it/neural-stem-cells-for-development-and-repair">www.rnas.it/neural-stem-cells-for-development-and-repair</a></td>
<td>Cortona, Italy</td>
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<tr>
<td>21-27 September 2013</td>
<td>XXI World Congress of Neurology, <a href="http://www.oegnt.at">www.oegnt.at</a></td>
<td>Vienna, Austria</td>
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<tr>
<td>5-9 October 2013</td>
<td>26th ECNP (European College of Neuropsychopharmacology), <a href="http://www.ecnp-congress.eu">www.ecnp-congress.eu</a></td>
<td>Barcelona, Spain</td>
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The Alzheimer Europe newsletter arises from the 2012 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.