Marina Yannakoudakis explores the EU’s initiatives to combat dementia

Paraskevi Sakka reports on Greece’s national dementia strategy

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Welcome

As you read this, the EU elections are over and a new group of Members of the European Parliament are taking up their posts in Brussels. We are very grateful to the 219 candidates from 26 countries who signed the European Dementia Pledge. I would like to thank all my colleagues at Alzheimer Europe for keeping the pledge website up to date and also for the continuous social media presence that was an integral part of the campaign. A great deal of credit also goes to our member associations, as they translated the Pledge into 11 languages and worked tirelessly to get their candidates’ signatures.

Over the next few months, Alzheimer Europe will relaunch the European Alzheimer Alliance. I am sure that it will emerge as an even stronger body, with a powerful voice to help all our constituents who are living with dementia along with their families and caregivers. We are already looking forward to December and our first lunch debate with the Members of the new European Parliament.

In the meantime, preparations for the Glasgow conference continue. Judging from the high volume and quality of the abstract submissions, I can safely predict another very popular event in October! In particular, the European Working Group of People with Dementia will have an expanded presence this year. The group members are avidly working on their presentations and Jean-Pierre Frognet, Vice Chairperson, offers us a preview in this issue.

Returning to our member countries, Switzerland has launched a national dementia strategy and the Greek working group is making good progress toward the same goal. For this issue, we spoke to key players in both countries and also included a feature about austerity measures in Finland. In addition, there is a profile of AMPA Monaco – our newest member association.

I am pleased to report that Alzheimer Europe is in growing demand as a partner in European projects; we are currently involved in all the IMI projects related to dementia and also projects funded directly by the EU. In this issue we interview the coordinators of the AETIONOMY project and also present AE’s new clinical trial database. Our future outlook is also very positive, as Alzheimer Europe is currently being solicited to participate in numerous Horizon 2020 projects.

The next issue of Dementia in Europe will appear at Alzheimer Europe’s 24th Annual Conference in Glasgow. Dignity and autonomy are at the heart of this year’s conference: we want to demonstrate the responsibility of policymakers, decision-makers, health and social care professionals and all of society to make positive changes for all people with dementia. I look forward to seeing you in Glasgow!
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The Innovative Medicines Initiative: improving drug discovery for Alzheimer’s disease

On 18 February 2014, Françoise Grossetête, MEP (France) and Chair of the European Alzheimer’s Alliance (EAA), hosted an Alzheimer Europe lunch debate focusing on the activities of IMI, the Innovative Medicines Initiative.

MEP Grossetête welcomed the participants and thanked Michel Goldman, IMI's Executive Director, for taking the time to present the workings of the public-private partnership. She also gave a short overview of IMI – whose funding phase has now ended – and an update on "IMI 2", for which she is the shadow rapporteur for the EPP group in the European Parliament. As rapporteur for the first IMI, she was also keen to stress that no other European or national programme had led to such comprehensive collaboration between pharmaceutical companies.

IMI is a public-private partnership between the EU and EFPIA, the European Federation of Pharmaceutical Industries and Associations. EFPIA brings together 33 European national pharmaceutical industry associations as well as 40 leading companies undertaking research, development and the manufacture in Europe of medicinal products for human use.

IMI received EUR 2 billion in financing over its 2008-2013 lifetime, evenly split between the EU and EFPIA. These monies have so far funded 46 medical research programmes, including EUR 167 million for four Alzheimer's disease projects. Alzheimer Europe (AE) is participating in all of them: AETIONOMY, EMIF and PharmaCog are already underway and EPOC-AD will begin in 2014.

In January 2014, the Industry Committee of the European Parliament approved the text for IMI 2, which will operate during 2014-2025 with a budget of over EUR 3 billion. The new initiative will fund, among other things, research on healthy ageing and speeding up the identification of new treatments. According to Ms Grossetête, dementia research will be a priority, especially the development of new diagnostic tools. [Editor's note: the IMI 2 text was approved in a plenary session of the European Parliament on 16 April.]

Ms Grossetête concluded her presentation with the hope that IMI will help lead to a cure for Alzheimer's disease by creating new synergies among public and private research bodies. Cooperation and sharing will continue to be essential in eliminating the fragmentation of research efforts.

Professor Goldman thanked MEP Grossetête for her efforts to shepherd the IMI 2 bill through the Parlia-
ment’s administrative process. He specifically noted that her work had helped the Industry Committee to see beyond the traditional funding models of previous research programmes.

**An engine for therapeutic innovation**

Prof. Goldman began his presentation by explaining that IMI is above all else a collaborative effort. To illustrate this, he quoted Dr. Elias Zerhouni, medical researcher and former Director of the U.S. National Institutes of Health: “Deciphering the complexity of human diseases and finding safe, cost-effective solutions that help people live healthier lives requires collaboration across scientific and medical communities throughout the health care ecosystem. Indeed, we must acknowledge that no single institution, company, university, country, or government has a monopoly on innovation.”

By mid-2013, IMI projects involved more than 6,000 people from 650 academic and research teams, 409 EFPIA teams, 120 SMEs, 25 patient organisations and 17 regulatory agencies. This unique blend of public and private skills has led to the development of a collective intelligence network that will inevitably grow – and continue to operate beyond the lifetime of the IMI projects. In addition, the EFPIA pharmaceutical companies are seeing improved research and development productivity. The result is a series of innovative approaches for unmet public health needs.

Prof. Goldman also showed that scientific papers published by IMI partners during 2010-2012 were consistently rated higher than non-IMI publications. This was especially true for papers about psychiatry, clinical neurology and neuroscience research. He firmly believes that better cooperation between academia and the pharmaceutical industry will always lead to better science.

**Addressing the specific challenges of dementia**

In the first IMI programme, around 10% of the total budget has been allocated to brain disorders. This is more than the funding for any single disease and a clear indication of the urgent need for therapeutic strategies. Prof. Goldman pointed out that EUR ten billion has been spent on beta amyloid research without any real results. This is partly due to the
way clinical trials are conducted today, as they do not allow to adequately establish the efficiency of a drug. The overhaul of clinical trial design is one the principal aims of IMI: Prof. Goldman referred to a January 2014 paper in Nature Medicine where drug companies are teaming up to run clinical trials in many different disease areas.

Currently, four IMI projects are addressing dementia-specific topics: the complexity of brain pathology, patient heterogeneity and the lack of validated markers for disease activity.

**PharmaCog** (2010-2015) is developing models to predict the efficacy of drug candidates by combining past and current data to define a series of biomarkers of dementia progression.

**EMIF** (2013-2018) is connecting data on 40 million individuals to decipher links between genetic background, biological abnormalities, brain imaging changes, mental symptoms and disease progression.

**AETIONOMY** (2014-2019) is identifying subgroups of dementia and Parkinson’s disease, based on the underlying genetic or molecular causes of the variants, in order to allow tailored therapies.

**EPOC-AD** will launch in 2014 with the aim to accelerate drug development by helping pharmaceutical companies share resources in the early phases of drug testing. According to Prof. Goldman, 18 companies have agreed to cooperate in this project.

He also explained that IMI supports the PROTECT project, which aims to improve the benefit-risk assessment methods used by the EMA (European Medicines Agency) to authorise the use of new drugs in Europe. Prof. Goldman’s presentation was followed by a discussion period where various issues were addressed:

**Involvement of people with dementia**: all IMI project planners are strongly encouraged to include patient groups as active partners and this is already the case for many projects. Jean Georges, Executive Director of Alzheimer Europe, explained how AE represents the interests of people with dementia in the IMI projects listed above.

**Alcoholism and dementia**: replying to Hiltrud Breyer, MEP (Germany), Prof. Goldman agreed that more research is needed to differentiate the causes of dementia, including the effects of alcoholism. He noted that the AETIONOMY project is specifically tasked to identify these underlying causes.

**Parliament Dementia Envoy**: Mr Georges suggested that the European Parliament appoint a dementia envoy to ensure that all scientific and social research efforts are coordinated. Prof. Goldman commented that the OECD and the G8 Dementia Challenge are also working to enhance research activities.

**Geographical inequity**: Prof. Goldman said that IMI projects are reaching a growing number of countries in Europe, including the eastern and southern regions. A basic tenet of IMI is to involve as many organisations in as many countries as possible. In addition, patients need to be considered as active players in drug development by all the research and government agencies involved.

**Alzheimer Europe presents 2013 reports**

The lunch debate was followed by a presentation of Alzheimer Europe’s 2013 research reports by Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

**2013 Dementia in Europe Yearbook**: the new yearbook contains the results of a survey on national policies relating to the care and support of people with dementia and their carers. The report also features dementia prevalence figures in 33 European countries.

More specifically, the yearbook details the provision of care, the training of health and social care professionals and support in the home, the community and in nursing homes. For each country, the
The report includes details of the national dementia strategy and/or any related policy provisions.

In addition, there is a section on the services and types of support provided by the national Alzheimer association. The country reports also include comparative tables that show the prevalence of dementia by sex and age group, as well as the various services offered by the associations.

2013 Ethics report: “The ethical issues linked to the perceptions and portrayal of dementia and people with dementia” look at the many different ways that people make sense of dementia. They cover perceptions associated with the experience of dementia, the cause of dementia and the possible implications of dementia on individuals and society.

There are also sections on the use of metaphor and on the portrayal of dementia in the media and in films. Each section details the reflection by the multi-disciplinary working group on the ethical implications for people with dementia of being perceived and portrayed in a particular way.

The report also considers how people with dementia feel about dementia and about the way they are perceived and portrayed within society. The report ends with a set of guidelines on things to consider when writing about or portraying dementia and people with dementia.

Following this presentation, Françoise Grossetête and Heike von Lützau-Hohibein thanked Michel Goldman and all the participants for their attendance and active participation.

Delegates at the lunch debate included MEPs Hiltrud Breyer (Germany), Sirpa Pietikäinen (Finland), Angelika Werthmann (Austria) and Marina Yannakoudakis (UK). Other participants included representatives from the European Commission, the pharmaceutical industry and representatives from 19 Alzheimer Europe member associations.

“Patients must be considered as active players in drug development by all the research and government agencies involved.”

MICHEL GOLDMAN
On 1 April 2014, Marina Yannakoudakis, MEP (UK) and Vice-Chairperson of the European Alzheimer’s Alliance, organised a meeting in the European Parliament to explore how the EU’s 2009 European initiative on Alzheimer’s disease has supported progress in the field of dementia across Europe.

Ms Yannakoudakis welcomed the delegates and opened the meeting on a positive note, saying that dementia has been a priority of the current European Parliament. She hoped this would continue in the future, as dementia remains a pressing challenge: in the UK, one third of people over 65 have dementia, which represents 800,000 people. The UK has shown leadership on the issue with the Prime Minister’s Dementia Challenge and the organisation of the G8 Dementia Summit.

MEP Yannakoudakis also highlighted her personal commitment to the cause and mentioned that she was one of the shadow rapporteurs for the EP report on dementia and then turned over the stage to her guest speakers.

Alzheimer Europe: making dementia a public health priority

Jean Georges, Executive Director of Alzheimer Europe (AE), presented highlights of the organisation’s campaign to make dementia a European public health priority:

- 2013: AE research findings showed that 8.7 million people have dementia in the European Union. This figure will double in Western Europe and treble in Eastern Europe by 2050.
- 2011: AE and Harvard School of Public Health conducted a joint survey on public perceptions on Alzheimer’s disease in five countries.
Results showed that AD was the most feared disease after cancer.

• 2008: The organisation’s EuroCoDe project estimated the cost of AD at EUR 156 billion (EUR 22,000/person/year) with 56% of the costs being borne by informal carers.

• 2007: The European Alzheimer’s Alliance was set up in the European Parliament and unites over 70 MEPs from 24 EU countries and all political group groups.

Looking beyond the implementation of the 2008 European Alzheimer’s Initiative, he suggested that the Commission appoint a dedicated EU dementia official to coordinate the various European programmes on dementia and collaborate with the WHO and G8 efforts. He also proposed the creation of a Standing Committee on Dementia which could include representatives from Member States and civil society and serve as a forum for the exchange of best practices. He closed by thanking the European Alzheimer’s Alliance members for their efforts over the past seven years. Alzheimer Europe looks forward to continuing this work in the new European Parliament.

**Alzheimer's Research UK: promoting excellence in medical research**

Matthew Norton, Head of Policy and Public Affairs, Alzheimer’s Research UK (ARUK), explained the organisation’s strategy to find treatments and cures for dementia through world-class biomedical research. He also presented ARUK’s six key priorities for the G8 Dementia Summit:

• Double dementia funding every five years until 2025.
• Double the number of researchers in neurodegenerative research by 2025.
• Invest in the development of new treatments.
• Ensure easier market access for new treatments.
• Share research results on an open and global basis.
• Establish a long-term, collaborative Global Dementia Strategy.
Alzheimer’s Society: aiming for one million Dementia Friends

Alison Cook, Director of External Affairs at the UK Alzheimer’s Society, presented “Dementia Friends”, the organisation’s campaign to raise awareness about dementia and enrol one million dementia friends. It began in 2013 and has already made 80,000 Dementia Friends in local communities, authorities and businesses all over the UK.

The campaign focuses on community engagement and social action and aims to change peoples’ behaviour toward dementia. Dementia Friends hopes to involve people in all sectors, including people and organisations providing services in the vicinity of people with dementia.

Individuals and businesses wishing to become Dementia Friends can visit a dedicated website that provides information about the campaign as well as various incentives.

European Commission: enabling international cooperation and research

Joanna Darmanin, Head of Cabinet (Health) at the European Commission, presented an overview of EU activities following the Communication on “European Initiative on Alzheimer’s Disease and other forms of dementias” in 2009:

- ALCOVE (ALzheimer COoperative Valuation in Europe) brought together 30 partners from 19 countries to evaluate information on epidemiological data and issue recommendations for the timely diagnosis of dementia, the treatment of behavioural and psychological symptoms, the rights of people with dementia and limiting the use of antipsychotic drugs.

- JPND (EU Joint Programme – Neurodegenerative Disease Research) coordinates and funds the efforts of dementia research projects that involve organisations from 27 countries.

- As part of the FP7 Research Programme, the EU allocated EUR 100 million to dementia research for the period 2011 to 2014.

Ms Darmanin also noted that the recent revision of legislation on clinical trials will undoubtedly benefit people with dementia. Finally, she mentioned two action groups of the European Innovation Partnership on Active and Healthy Ageing:

- The “Prevention of Frailty and Functional Decline” group looks at the role of new information and communication technologies in improving screening and diagnostic tools to detect early stages of dementia.

- The “Age Friendly Environments” group is developing solutions to allow people with dementia to live as independently as possible – including designs that aim to preserve the dignity, physical and mental health of people with dementia.
The final speaker was Dr Catherine Berens, Head of Sector (Neuroscience), DG Research and Innovation, European Commission. She gave an overview of the EU’s current funding programmes.

The Innovative Medicines Initiative (IMI) is a partnership between the European Commission and the pharmaceutical industry to speed up drug development. IMI’s latest call for proposals included EUR 53 million for the EPOC-AD project: the “European platform for proof of concept for prevention in Alzheimer’s disease” will promote more efficient clinical trial designs and execution to prevent AD. The second phase of the initiative (IMI 2) is about to begin and the first calls for proposals are expected in July 2014.

Horizon 2020 is the new EU research and innovation programme that intends to address society’s biggest health challenges with nearly EUR 7.5 billion in funding. The programme will support research into biomarkers, diagnostics and new medicines in a similar way to its Seventh Framework Programme (FP7) predecessor. In addition, Horizon 2020 will seek to develop ICT-based approaches for self-management of health and diseases; this includes advancing active and healthy ageing as well as integrated and sustainable citizen-centred care.

The EU also supports the Human Brain Project, launched in May 2013, with EUR 500 million. This project focuses on ICT as a means to understand the brain, develop new treatments for brain diseases and build revolutionary new computing technologies.

The presentations were followed by a lively discussion period where the following items were addressed:

In response to a question from Ms Yannakoudakis, Mr Georges further elaborated on his vision of an EU dementia official within the Commission and a Standing Committee on Dementia. He cited the French Alzheimer Plan 2008-2012 as a reference, partly for its clear guidelines and indicators but also the fact that a coordinator and several Ministers reported directly to the French President. Mr Georges believes that such a model could easily be adapted to the European Commission.

Mr Georges also referred to a recent meeting organised by the Commission where representatives from various European Health Ministries shared information about their respective activities on dementia. This meeting proved to be highly valuable for sharing information and building relationships between the countries.

Ms Tina Leonard from the Alzheimer’s Society of Ireland gave a short overview of her organisation’s activities in developing Dementia-Friendly Environments. She then asked how such activities could be integrated in European Parliament and Commission policies. More specifically, she wanted to hear how dementia will be specifically taken into account, rather than under general headings like “ageing”. Ms Berens answered that the topics were very broad; the proposals can be extremely focused and offer many opportunities to bring some projects forward.

Ms Yannakoudakis closed the meeting by thanking all the speakers and participants. She called for the next European Parliament to continue fighting dementia and join forces with all stakeholders, including patient organisations.
European Alzheimer’s Alliance: continuing our fight against dementia together

Annette Dumas, EU Public Affairs Advisor for Alzheimer Europe, describes the efforts of the European Alzheimer’s Alliance to make dementia a European priority.

In recent years, the joint efforts of Alzheimer Europe (AE), its members and the European Alzheimer’s Alliance (EAA) in the European Parliament (EP) have led to increased policy awareness about the challenges of dementia for the healthcare and social systems across Europe. We now call upon the newly elected Members of the European Parliament (MEPs) to help us keep up the momentum.

Alzheimer’s disease: a pressing challenge for all EU Member States

AE’s recent work shows that 8.7 million people have dementia in Europe. Although dementia generally affects people over the age of 65, an increasing number of younger people are affected by early onset dementia. AE’s findings also show that dementia is a costly disease: EUR 21,000 per patient per year, of which 56% for informal care. The ageing of the population, new societal patterns and economic imperatives have compelled Member States to take timely and tailored actions that will answer the needs of people with dementia and their carers – all while ensuring the sustainability of their healthcare and social services systems.

Making dementia a European priority – concrete results

Over the years, the combined efforts of the EAA members, AE and its members have led to concrete EU achievements: at European level, two Council recommendations and a Written Declaration by five EAA members led the European Commission to present in 2009 a Communication on a European initiative on AD and other dementias.

A number of EU initiatives are of particular interest to people with dementia and their carers:

- **JPND:** the Joint Programme for Neurodegenerative Diseases Research is a Member State-led initiative to coordinate national dementia research efforts.

- **IMI:** the Innovative Medicines Initiative, a public private partnership between the European Commission and the pharmaceutical industry issued several calls in the field of dementia.
Horizon 2020 and FP7: the current and previous EU research framework programmes supported dementia projects and continue to do so.

ALCOVE: Alzheimer Cooperative Valuation in Europe, the European Joint Action on dementia brought together Ministries of Health to exchange best practices and develop common recommendations.

EIP AHA: the European Innovation Partnership on Active and Healthy Ageing aims to improve older peoples’ lives and reduce pressure on health and care systems.

At national level, a growing number of countries now have a national Alzheimer plan or strategy in place while others are actively developing plans.

The European Alzheimer’s Alliance – a rewarding role for members

None of this could have happened without the support of the members of the EAA. The Alliance is a non-exclusive, multinational and cross-party group of MEPs committed to support AE and its members in making dementia a European priority and shaping the health, social and research agenda. It calls for immediate and concerted action at European and national level in the field of prevention, diagnosis and treatment of AD, research and social policies.

This group was set up in 2007 by AE to raise awareness at EU level about the challenges of dementia and stimulate political actions. Many MEPs realised the urgency to act and supported the Alliance over the years.
At European level, Alliance members have hosted numerous lunch debates in the EP, where AE could present its research and invite experts to discuss specific topics. They also organised events in the EP or meetings with their constituents to discuss dementia, contributed articles or interviews for AE’s Dementia in Europe policy magazine and sought AE’s input when working on EP reports or influencing the EU legislation.

At national level, Alliance members have supported Alzheimer associations by participating in local events or contributing to national discussions on dementia strategies.

The European Election Dementia Pledge and the way forward

Awareness raising and political action must continue. For this reason, AE and its members adopted the “EU Election Dementia Pledge” at the organisation’s Annual General Meeting in Malta in October 2013. This pledge invited all candidates at the European Parliament elections to support AE’s campaign to make dementia a European health and research priority. By signing the Pledge, the candidates also committed to join the EAA upon their election and to support the efforts of their national Alzheimer’s association.

Thanks to the support of our national member organisations we have been able to gather the support of a significant number of candidates. We are really grateful for their support and look forward to rallying more MEPs to our cause. We need to unite our forces, regardless of political affiliation and nationality. Dementia has no boundaries and calls for united action.

AE would like to thank all the Alliance members who have strived to make dementia a priority over the years and those who have already committed to continue.
Alzheimer Europe thanks all European Parliament election candidates who were members of the European Alzheimer’s Alliance and/or signed our European Election Dementia Pledge.

**Austria:** Heinz K. Becker, MEP; Angelika Werthmann, MEP.

**Belgium:** Mark Demesmaeker, MEP; Frédérique Ries, MEP; Bart Staes, MEP; Marc Tarabella, MEP; Kathleen van Brempt, MEP.

**Bulgaria:** Daniela Bozhinova, Hristo Bozov, Andrey Kovatchev, MEP; Antonyia Parvanova, MEP; Stefan Shilev.

**Croatia:** Biljana Borzan, Višnja Fortuna, Damir Hršak, Neven Mimica, Tonino Picula, MEP; Milorad Pupovac, Ruža Tomašić, Nikola Vuljanic, MEP.

**Cyprus:** Simos Angelidis, Eleoni Chrysostomou, Androurla Eleftheriou, Yiorgos Lillikas, Alexandros Michaelidis, Yiannis Panayiotou, Antigoni Papadopoulou, MEP; George Perdikis, Charis Polycarpou, Vera Polycarpou, Christos Stylianides, Eleoni Theocharous, MEP; Kyriacos Triantaphyllides, MEP.

**Czech Republic:** Zuzana Brzobohatá, Jaromír Kohlíček, MEP; Zuzana Roithová, MEP; Libor Rouček, MEP; Zdeněk Šigut, Olga Sehnalová, MEP; Pavel Svoboda, Oldřich Vlasák, MEP; Tomáš Zdechovský.

**Denmark:** Lave K. Broch, Ole Christensen, MEP; Jens Rohde, MEP; Christel Schaldemose, MEP; Britta Thomsen, MEP.

**Finland:** Pirkka Aalto, Eila Aarnos, Jari Andersson, Anne Bland, Rita Dahl, Jörn Donner, Sari Essayah, MEP; Kyuu Eturautti, Satu Immonen, Liisa Jaakonsaari, MEP; Aine Pantti, Sari Ronkainen, MEP; Anneli Jäätteenmäki, MEP; Sven Jerker, Tuuli Kouosa, MEP; Matias Kallio, Kimmo Piironen, MEP; Sakari Puisto, Mitro Repo, MEP; Jussi Saramo, Hanna Sarkkinen, Kaarin Taijale, Hannu Takkula, MEP; Juhan Tanski, Maria Tolppanen, Tiina Tuomela, Uma Uotila, Antti Vuolanne, Lena Wiksten.

**France:** Jean-Pierre Audy, MEP; Christine de Veyrac, MEP; Nathalie Griesbeck, MEP; Françoise Grossetête, MEP; Philippe Juvin, MEP; Elisabeth Morin-Chartier, MEP; Gilles Pargneaux.

**Germany:** Angelika Niebler, MEP; Thomas Ulmer, MEP.

**Greece:** Nikolaos Chountis, MEP; Nikos Davvetas, Konstantinos Holevas, Panagiotis Ioakimidis, Giorgos Iwannidis, Dimitris Kontopidis, Maria Eleni Koppa, MEP; Rodi Kratsa-Tsaragopoulou, MEP; Manolis Kefalogiannis, Konstantinos Kranakis, Foteni Leompilla, Despoina Limniotaki, Ilias Lostromos, Theodoros Margaritis, Nikos Markatos, Alfredo Saltiel, Eugenia Sarigiannidou, Vasilis Stamogiannis, Reggina Theakou, Aris Vatalis.

**Hungary:** Ádám Kósá, MEP.

**Ireland:** Thomas Byrne, Matt Cathy, Nessa Childers, MEP; Deirdre Clune, Emer Costello, MEP; Brian Crowley, MEP; Mark Dearey, Mary Fitzpatrick, Luke ‘Ming’ Flanagan, TJ Fay, Pat The Cope Gallagher, MEP; Marian Harkin, MEP; Simon Harris, Jim Higgins, MEP; Lorraine Higgins, Seán Kelly, MEP; Mairéad McGuinness, MEP; Róisín Murphy, Liatid Ní Riadh, Diarmuid O’Flynn, Brid Smith.

**Italy:** Suzy De Martini, MEP; Pier Antonio Panzeri, MEP; Aldo Patriciello, MEP; Patrizia Toia, MEP.

**Lithuania:** Vilija Blinkevičiute, MEP.

**Luxembourg:** Marc Angel, Georges Bach, MEP; Jean Colombera, Frank Engel, MEP; Charles Goerens, MEP; Christophe Hansen, Tom Jungen, Marianne Pesch-Dondelinger, Marie-Paule Prost-Heinisch, Viviane Reding, Isabel Wiseler-Santos Lima.

**Malta:** Roberta Metsola, MEP.

**Netherlands:** Esther de Lange, MEP; Lambert van Nistelrooij, MEP.

**Poland:** Marek Balicki, Julia Holak, Urszula Iwicza, Beata Kij, Elżbieta Lukijewskiej, MEP; Longin Pastusiak, Joanna Senyszyn, MEP; Adam Krzysztof Struzik, Ewa Węglarz, Honorata Zdrodowska.

**Portugal:** Carlos Coelho, MEP; Marisa Matias, MEP.

**Romania:** Silviu Dumitru, Decianu Octavia Sarbu, MEP; Claudiu Ciprian Tanasescu, MEP; Renate Weber, MEP.

**Slovakia:** Mikoslav Mikolásik, MEP; Anna Záborská, MEP.

**Slovenia:** Britta Bilaš, Franc Bogovič, Vida Cadonič Špelič, Tanja Fajon, MEP; Tatjana Greif, Jana Jenko, Jelko Kacin, MEP; Dušan Peter Keber, Mojka Kleva Kekuš, MEP; Monika Kirbiš Rojs, Marjana Kotnik Potopat, Igor Lukšič, Ljudmila Novak, Neža Pavlic, Alojz Peterle, MEP; Jakob Presečnik, Marjan Sedmak, Igor Soltes, Violeta Tomic, Ivo Vajgl, MEP; Milan Zver, MEP.

**Spain:** Soledad Cabezón Ruiz, Rosa Estarás Ferragut, MEP; Luis de Grandes Pascual, MEP; Sergio Gutiérrez Prieto, MEP; Juan Fernando López Aguilar, MEP; Pablo Zalba Bidegain, MEP.

**Sweden:** Cecilia Wikström, MEP.

**United Kingdom:** Martina Anderson, MEP; Richard Ashworth, MEP; Katharina Boettge, Jayne Bryant, Maggie Chapman, Peter Crane, Euan Davidson, Stephen Gethins, Toni Giugliano, Ian Hudgcock, MEP; Christine Jardine, Jean Lambert, MEP; Anna Lo, George Lyon, MEP; Linda McAvan, MEP; Iain McGill, Claude Moraes, MEP; Steen Parish, Tasmina Sheikh, Keith Taylor, MEP; Anne Thomas, Derek Vaughan, MEP; Graham Watson, MEP; Alastair Whitelaw, Glenis Willmott, MEP; Marina Yannakoudakis, MEP.
On 19 February, Alzheimer Europe (AE) held a Public Affairs meeting in Brussels. The meeting was attended by AE Board and staff members, 17 delegates from 16 member associations and two representatives of the ALCOVE Joint Action.

The AE chair, Heike von Lützau-Hohlbein, opened the meeting and AE staff then gave short presentations about:

- AE's monthly newsletter and triennial Demen-tia in Europe magazine.
- Two AE projects in 2014: Improving Conti-nence Care and Ethical Dilemmas.

An appeal was made to all members to give their input and support.

European Parliamentary Elections

The participants' attention was then turned to the European Parliament Elections in May 2014. Annette Dumas, EU Public Affairs Advisor for AE led a lively discussion concerning the importance of bolstering support for the European Alzheimer's Alliance (EAA) and the EU Dementia Pledge during the run up to the Elections. Jean Georges, AE Executive Director, encouraged member organisations to use social media such as Twitter to promote the Pledge and the EAA. He also asked that Alzheimer Europe be kept informed of any developments, in particular regarding new pledgees. [See page 14]

Care Pathways project

The main thrust of the meeting was facilitated by Ana Diaz, AE Project Officer. She presented AE’s yearbook project on comparing national care pathways for people with dementia, including background information about and experiences of the national care pathways for people with dementia and their carers. The term “care pathway” refers to how national systems seek to provide seamless care and treatment from the moment of detection and diagnosis of dementia to end-of-life.

It also refers to the experiences of people with dementia and their families with such care systems.

The meeting continued with the following presentations on the project’s five main topic areas:

1. Mapping care pathways by Anne Arndal, Denmark.
5. Navigating the pathway: information and structures available to people with dementia and their carers by Maria do Rosário Zincke dos Reis, Portugal.

In the ensuing discussion, members focused on two key questions:

• Whether existing national guidelines are binding in nature and if not, whether it would be possible or desirable to make them so.
• Whether the questionnaire on care pathways should focus on the reality of care pathways rather than just the theory or the ideal.

In addition, the following points were raised during the lively discussions:

• The great complexity and challenges in describing care pathways and the importance of being patient-centred.
• The fragmentation of information on care and care pathways in some countries, making it difficult to collate.
• The importance of considering multiple entry points to care pathways: entering the path-way all along the process is very common and a high proportion of people with dementia are not diagnosed in a timely fashion.
• The disparity and lack of coordination between medical and social care.
• The existence of geographic inequalities in dementia care (urban/rural divide and “postcode lottery” effect).
• The specific needs of younger people with dementia, which are not being met in many countries.
• Barriers to diagnosis and lack of disclosure of the diagnosis with the resulting exclusion from care pathways. This was said to be commonplace in some countries.

The timeframe for responding to the questionnaire (two months) was agreed upon and Skype support was offered by Ana Diaz for any members who required help or advice to complete it.

Heike von Lützau-Hohlbein then closed the meeting, thanking all for their attendance and stressing the importance of these meetings for better communication among members. The next AE Public Affairs meeting will take place in July 2014 in Luxembourg.
AETIONOMY: reclassifying Alzheimer’s disease to find new drug targets

Project Coordinators Duncan McHale and Martin Hofmann-Apitius explain how AETIONOMY will reclassify neurodegenerative diseases based on disease causing mechanisms.

What is the AETIONOMY project and what are its aims?

**Duncan:** The AETIONOMY project aims to bring together all publically available data from patients with Alzheimer’s disease and to organise that data using innovative approaches in order to reclassify the disease according to the causes of the disease in each patient. Alzheimer’s disease was originally described in 1906 by Dr Alois Alzheimer when he described a patient with profound memory loss and personality changes. Over the next 108 years there have been several major advances but we still classify all patients based on a combination of their symptoms and a description of the pathological changes in the brain that have taken place. AETIONOMY aims to take all of the available data it can, organise that data in a systematic way and then look to identify sub-groups of patients with Alzheimer’s disease based on the causes of their disease. This reclassification is important as it will lead to new drug targets that focus on the disease process and identify which patient should get which drug.

How will AETIONOMY collaborate with other EU projects in the field?

**Martin:** We are already in discussion with two EU-projects that are relevant for AETIONOMY in particular and research on Alzheimer’s disease in general: the VPH-DARE project is led by my colleague Prof. Alex Frangi, whom I know well from our collaboration in the FP6 project “@neurIST”. In his new project, funded in the context of the Virtual Physiological Human (VPH), Prof. Frangi addresses the question to what extent the vessel systems – not only blood vessels, but also the lymphatic system and the entire cerebrospinal fluid (CSF) system – contribute to the aetiology of Alzheimer’s disease. The interested reader will find lots of useful information on the VPH-DARE website: http://vph-dare.eu

The other project that we are in touch with is one of the leading European projects dealing with the storage and sharing of neuro-imaging data. The “NeuGrid 4 You” project (https://neugrid4you.eu) is coordinated by Dr David Manset, CEO of Nubila, a consulting firm delivering ICT solutions and professional services axed on Grid and Cloud computing with a special emphasis on e-Health and Health Information Systems. “NeuGrid 4 You” enables Europe-wide imaging studies including distributed image acquisition, cloud-based data storage, various image analysis pipelines and – most importantly – the comparison of imaging results across different studies.

**Duncan:** Within IMI, we seek active collaboration with the EMIF-AD and EPOC-AD projects. EMIF-AD aims to create an environment that allows for efficient re-use of existing health data. This includes a common information framework that will link up and facilitate access to diverse medical and research data sources. The other potential partner is the project that will come up with the best solution for the current EPOC-AD, or European Platform for Proof of Concept for Prevention in Alzheimer’s Disease. EPOC-AD aims to speed up treatments by helping pharmaceutical companies share resources in the early phases of drug testing. The hope is that together with AETIONOMY, these two projects will form the IMI-funded European Alzheimer Research Platform.

What are the main achievements and challenges of the project so far?

**Duncan:** AETIONOMY has brought together experts in computing, engineering, informatics, neurology, mathematics and drug development. The EUR 16 million project started on 1 January 2014 and to date, the project plan has been finalised and all 16 partners have started work. The first major workshop will occur in June when members of the infor-
AETIONOMY

matics work group together with the clinical group, will start to develop the clinical protocol hypotheses to test the new classification system.

**Martin:** AETIONOMY does not start from scratch: several partners bring valuable assets to the project, e.g. a computable model for Alzheimer’s disease encoded in OpenBEL, a modelling language ideally suited for the representation of causal and correlative relationships in biomedicine.

**What do you hope will be the achievements at the end of the project in 2018?**

**Duncan:** It is unrealistic to expect that within the five year period the consortium will develop a new way to classify Alzheimer’s and Parkinson’s disease that is accepted by all the medical community. Therefore, the expectation is that a novel disease classification system for both Parkinson’s and Alzheimer’s disease will be published for the community to test. AETIONOMY will run a prospective study to help validate the proposed new classification system. In addition, biomarker data from public and private datasets will be used to validate the proposed system.

**Martin:** We have set up core elements of the project in a way that they will go beyond the end of the funded period. The Luxembourg Centre for Systems Biomedicine and Fraunhofer SCAI will maintain the AETIONOMY knowledge base for an additional five year period after IMI funding has ended.

**How will AETIONOMY benefit people with dementia?**

**Duncan:** The aim of the programme is to reclassify the neurodegenerative diseases of Parkinson’s and Alzheimer’s disease based on disease causing mechanisms and to move away from phenotypic descriptions. This will provide greater information and clarity about the potential course of the diseases for patients. When new neurodegenerative therapies are discovered, then the drug can be targeted to patients based on their own dysregulated disease mechanisms. This will improve the efficiency of clinical trials and provide strong confidence to patients, prescribers, regulators and payers in terms of who needs to receive the new more expensive therapies based on current and future risks of the disease.

**Patient information is generally held under legal and ethical obligations of confidentiality. How will patient privacy be addressed in this project?**

**Martin:** An entire work package (WP4) is dealing with ethical and legal aspects of the research work we are doing. The experts working in this work package (including Alzheimer Europe) are serving as “internal consultants” for the scientists working on data acquisition, data curation, and data banking (WP2) or modelling and mining of the neurodegenerative diseases (WP3). In addition to this internal work package, the Ethics Committees of our clinical research partners (WP5) monitor and protect patient privacy in the local hospital context. The clinical study planned in the course of AETIONOMY will require approval from all Ethics committees of all clinical partners involved and all clinical study planning is thoroughly reviewed by our partners in work package 4.

“*We have set up core elements of the project in a way that they will go beyond the end of the funded period.*”

**MARTIN HOFMANN-APITIUS**
An active year for the European Working Group of People with Dementia

On 3 March, the members of the EWGPWD Executive met in Luxembourg to discuss the group’s 2014 activities.

The EWGPWD Executive consists of the Chairperson and the three Vice-Chairpersons of the group. They meet several times per year to formulate the group’s activities, which are then presented to all the members of the European Working Group of People with Dementia.

Helga Rohra, Chairperson of the EWGPWD, welcomed Vice-Chairpersons Nina Baláčková, Jean-Pierre Frognet and Agnes Houston to the meeting. Carers Marie-Anne Schreder and Jan Zámyslický were also present, while Alzheimer Europe staff attended as observers for different parts of the meeting.

Active participation in Alzheimer Europe Conferences

In 2013, the group members had a significant presence at Alzheimer Europe’s conference in Malta. They organised and manned a dedicated stand, but also gave a series of presentations during a very popular symposium. This was the first time that the group had undertaken to conceive, plan and execute all aspects of participating in a large international conference – with only occasional support from Alzheimer Europe.

The members of the Executive discussed the successful aspects of that event and also drew up a list of improvements for the group’s participation in Alzheimer Europe’s 24th Annual Conference in Glasgow later this year. They also agreed on the presentation topics for the conference; the group will be represented by speakers in the plenary sessions and also reprise its popular symposium in a larger space than last year.

The EWGPWD operates under the auspices of Alzheimer Europe, but its members are nominated by national Alzheimer associations. The members of the Executive discussed ways to improve the involvement and support of their national organisations, such as helping to promote the group’s presence at major conferences.

Improving internal and external communications

The group discussed various ways to improve internal communication, as the members live in 11 different countries. The national Alzheimer associations were again singled out as potential helpers – to ensure that members can attend events if a relative or close friend is not available, to help prepare speeches and to maintain regular contact with other members.

The meeting participants also felt that Facebook could be a good communication channel, especially as nearly all members of the EWGPWD are familiar with it. Kate Ellis, Communications Officer for Alzheimer Europe, gave a short presentation about closed user groups on Facebook, including a demonstration of how they may be used by the group. The delegates were very pleased with the relative ease of use of the system and requested an interactive workshop to take place during the next meeting of the entire group.

The EWGPWD leaflet and suggested improvements for the second edition of the leaflet, which provides an overview of the background and activities of the group. In addition, they conferred with Alzheimer Europe colleagues about contributions to AE’s monthly newsletter and the Dementia in Europe magazine. Jean-Pierre agreed to contribute an article for the next magazine issue: this can be seen on page 48.

Involving EWGPWD members in AE projects

Dianne Gove gave a short overview of the project to improve the continence care of people with dementia living at home. She explained that Helga was
already involved in this project and had contributed towards the development of guidelines. However, the project partners were looking for additional input from people with dementia and Dianne proposed to send out the draft guidelines to all the members of the group.

She also presented the 2014 topic of the ethics working group, namely “ethical dilemmas faced by informal carers of people with dementia”. While the focus of the topic is clearly on carers, it is important to ensure that a person with dementia from the EWGPWD is involved in every AE project and has an opportunity to influence the overall design including the methodology, choice of topics and communication of the findings. It was suggested that Dianne should contact Stig Atle Aavik to be the Group’s representative. As it turned out, Stig was very happy to attend, accompanied by his carer Ranveig Hoff.

Ana Diaz, Project Officer at Alzheimer Europe, gave a presentation about the creation of a database of clinical practice guidelines for dementia and another for clinical trials related to dementia. The latter is intended to be easily accessible for people with dementia and their carers. The delegates suggested that members of the EWGPWD could participate by going onto different websites, trying to find different information and reporting back what they found difficult or helpful with regard to design and navigation tools.

**EWGPWD and European elections**

Jean Georges, Executive Director of Alzheimer Europe, explained that the mandates of all members of the EWGPWD will expire in October 2014. At that time there will be elections, both for membership and for Executive positions. A maximum of 15 members will be nominated by their respective national Alzheimer associations and those members will elect a Chairperson and Vice-Chairpersons to represent them. The delegates were satisfied with all the details of the election procedures.

Jean also informed the delegates about AE’s European Dementia Pledge campaign. This simple pledge asks MEP candidates to agree to join AE’s European Alzheimer Alliance, make dementia a European health priority and support their national Alzheimer associations. Jean explained that the pledge is available in seven languages and that he would send it to all EWGPWD members. He requested that anyone receiving a response should contact his/her association and also Alzheimer Europe.

Helga reminded the delegates that the next EWGPWD meeting – with all members – would take place in May 2014 in Luxembourg. She thanked everyone for their participation and attention and closed the meeting.
A new web resource for European dementia clinical trials

Ana Diaz, Project Officer at Alzheimer Europe, presents the new clinical trial database that will connect people with dementia to research trials.

The quest for a cure

The development of a treatment to cure or more effectively treat dementia has become a priority worldwide. At the G8 dementia summit held in the UK last year, for example, leading nations committed to find a cure for dementia by 2025. The hope for a cure or an effective treatment is also important for the 8.7 million Europeans with dementia for whom such treatment could transform their lives.

The first step towards a better treatment or cure for dementia is to develop effective treatments. Potential new treatments for dementia (most often drugs) are tested in clinical trials. Clinical trials are research studies that use human participants to test treatments or approaches to the prevention, diagnosis and treatment of a disease in order to establish their safety and effectiveness. In these trials, new drugs or devices, or a new use of existing drugs or devices are tested. In short, clinical trials are a primary mechanism for developing treatments and for improving healthcare for people with dementia.

Clinical trials are carefully designed and planned studies and are usually conducted in series of four steps called phases I to IV. A typical phase I trial will test the safety and tolerability of a new investigational drug in a small sample of healthy volunteers. Phase II trials further investigate the efficacy and safety of the drug in a larger sample of patients. This phase often reveals that the drug or treatment is not as effective as anticipated. Treatments that have proven effective in phase II can progress to phase III, where the findings are confirmed in large sample populations, often involving thousands of patients. Phase IV trials are post-marketing studies, in which the long-term safety of the drug is tested in “real life” patients.

Whilst all trials are relevant and each phase has its own peculiarities, phase III trials are particularly significant for patients. This is the last phase before a new treatment can be approved and released into the market and it usually involves very large samples of participants testing a “promising” new treatment.

Transparency and availability of information to the public

In recent years, the debate about the transparency of information about clinical trials available to the public has become increasingly important, with new regulations in Europe and elsewhere now promoting greater transparency and open access to clinical trial information and results.

A number of national and international databases or registries have been established where the public can access relevant information about clinical trials. This includes trials that are currently underway for dementia, and, in some cases, the results of clinical trials that have been already completed. International examples of these resources include the American registries (e.g. clinicaltrials.gov), the international clinical trials registry platform of the World Health Organisation and the EU Clinical Trials registry.
Nevertheless, European citizens still have far too little information about trials. Today, very few people with dementia and their families know what treatments are currently being tested in their country or where trials are taking place. Despite ongoing efforts, many aspects of the existing resources are not user-friendly. For example, the type of language and the format of the records tend to be complex and lengthy, i.e. generally inaccessible for lay citizens. This becomes even more challenging when the person trying to access information has dementia. As a result, people with dementia and their families still largely depend on their treating physicians for learning about potential new treatments and for making informed decisions about their participation in trials.

**AE will connect people with dementia and high quality research**

AE is developing a dementia specific, web-based resource that will contain relevant information on clinical trials being conducted in Europe. This project is envisaged as a way of connecting people living with dementia and their families with high quality research conducted in Europe. Our aim for 2014 is to locate all dementia clinical trials in phase III that are currently active or recruiting participants and that are conducted in more than one European country.

Existing databases will be used as a source of information and to update the records in the future. The database will provide updated information relevant to dementia using dementia-friendly language and design. Currently, people with dementia and their families are not expected to contact the sponsor or the clinical trial team directly. This database will give them an opportunity to proactively participate in their healthcare and to discuss their potential participation in clinical trials with their general practitioners.

AE will expand this project over the coming years by providing other information that can help people with dementia and their families make informed decisions about trials. This may include:

- Adapting existing clinical trial information on the AE website to the needs of individuals with dementia.
- Creating a list of questions about clinical trials that people may ask their physicians.
- Publishing the experiences of people with dementia and caregivers who have participated, withdrawn or decided not to take part in a clinical trial.

This project was presented to the participants of AE’s Company Round Table in February 2014. The relevance of the project for people with dementia and their families was also discussed with members of the Executive of the European Working Group of People with Dementia (EWGPWD); the group will be closely involved in the project.

“Alzheimer Europe is developing a dementia specific, web-based resource that will contain relevant information on clinical trials being conducted in Europe.”

ANA DIAZ
Alzheimer Europe: an active partner in European projects

AE’s Dianne Gove and Alex Teligadas describe the research projects in which Alzheimer Europe is a partner.

AETIONOMY

AETIONOMY is a five-year project that began in January 2014. It aims to develop a “mechanism-based taxonomy” of Alzheimer’s and Parkinson’s disease — based on the underlying genetic or molecular causes of the variants — in order to allow tailored therapies. The project will involve the collection of clinical data, imaging and genetic data and will create a new way to combine all of these together to look for patterns which could identify sub-groups of patients with similar causes of their disease. An interview with the AETIONOMY project coordinators can be found on p. 20. www.aetionomy.eu

AFE Innovnet

The consortium is made up of 27 stakeholders from 16 EU countries, including 12 cities and five regions. Most of the partners are actively involved in the European Innovation Partnership on Active and Healthy Ageing D4 action group on age-friendly environments. The project will help local and regional authorities to respond to Europe’s demographic challenge by stimulating investment and facilitating the deployment of innovative age-friendly ICT and social solutions to help older people to age in better health and remain active for longer, lowering the pressure on social and healthcare systems and fostering longer working lives. This EU-wide mobilisation should also help develop an EU wide single market for innovative ICT based silver economy products and services. www.afeinnovnet.eu

Continence care

In the context of a joint two year project by Alzheimer Europe and SCA Global Hygiene, a set of guidelines to improve the continence care of people with dementia living at home is being developed. Due to the lack of research on this specific topic, an approach based on expert consensus has been adopted. An initial set of guidelines have been drafted by a group of experts in the fields of dementia, continence care, general practice, psychology and policy development, as well as informal carers and people with dementia. Dianne presented these at the recent Global Forum on Incontinence in Madrid. A wider consultation process is underway and the guidelines will be launched in October 2014 during Alzheimer Europe’s annual conference.

EMIF

The European Medical Information Framework project (2013-2017) is connecting data on 52 million individuals to decipher links between genetic background, biological abnormalities, brain imaging changes, mental symptoms and disease progression. The main objective is to create an environment that allows for efficient re-use of existing health data. Currently, the project includes two specific therapeutic research topics including the onset of Alzheimer’s disease. This topic aims to discover and validate biomarkers of AD onset and also identify high-risk individuals for therapeutic trials for prevention. EMIF recently completed its first year review and is well on its way to becoming the trusted European hub for health care data intelligence, enabling new insights into diseases and treatments. www.emif.eu

Ethical dilemmas faced by carers and people with dementia

Alzheimer Europe is currently writing a report about ethical dilemmas faced by people with dementia and their informal carers. The focus is on ethical dilemmas which primarily affect informal carers and people with dementia, even if other people are involved and irrespective of where the dilemma occurs. The report is being drafted by a
group of experts in ethics and dementia, as well as carers and people with dementia. It will contain background information about addressing ethical dilemmas in daily life, vignettes depicting typical situations and commentaries from experts in ethics. The report will be completed by the end of 2014.

**IMPACT**

The IMPACT project (IMplementation of quality indicators in Palliative Care Study) is coordinated by the Radboud University Medical Center in the Netherlands and Alzheimer Europe is a member of the advisory board. It is a four-year project which started in February 2011 and is built on a consortium of 12 research teams located in 12 different universities or research organisations. IMPACT will develop optimal improvement strategies to improve the organisation of palliative cancer and dementia care in Europe and to study factors influencing the effectiveness of the strategies. There will be a consortium meeting in June 2014 and the final conference, “Towards integration of palliative care in an age-friendly EU”, will take place in October 2014. [www.impactpalliativecare.eu](http://www.impactpalliativecare.eu) & [http://palliativecare2020.eu](http://palliativecare2020.eu)

**NILVAD**

The NILVAD project team is conducting a phase 3 clinical trial of Nilvadipine, an existing hypertension drug, in people with mild to moderate Alzheimer’s disease. Previous research showed that the drug also blocks production of the amyloid protein that is believed to be central to the Alzheimer’s disease process. The trial is being conducted in 21 study sites in nine European countries, with a recruitment target of 500 participants who are receiving the drug or a placebo over an 18 month period. As of May 2014, more than 220 participants have joined the study while recruitment continues until the end of the year. [www.nilvad.eu](http://www.nilvad.eu)

**PACE**

The PACE project will describe and compare the effectiveness of healthcare systems in six European countries with (Belgium, Netherlands, UK) and without (Finland, Italy, Poland) formal palliative care structures for long-term care facilities in terms of patient and family outcomes, quality of palliative care and cost-effectiveness, and in terms of staff knowledge, practices and attitudes. This will involve mapping palliative care systems across Europe, a retrospective, representative cross-sectional study of deaths in long-term care facilities in each of the six participating countries and an interventional study measuring the impact of training on the quality of the end-of-life experience.

**PharmaCog**

PharmaCog (2010-2015) is developing models to predict the efficacy of drug candidates by combining past and current data to define a series of biomarkers of dementia progression. The project aims to propose to the pharmaceutical industry and academic research laboratories new methods for successfully developing new drugs for the treatment of Alzheimer’s disease. The outcomes of the project should pave the way for delivering new drugs that will improve patients’ cognitive and behavioural symptoms and slow the progression of the disease. This should also reduce the economic and social burden of the disease. PharmaCog researchers are working to develop animal models that more closely mimic Alzheimer’s disease in humans: it is hoped that these models may be better at predicting how effective the drug will be in humans. [www.alzheimer-europe.org/Research/PharmaCog](http://www.alzheimer-europe.org/Research/PharmaCog)
Overcoming everyday challenges in Alzheimer’s disease

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Swiss national dementia strategy promotes knowledge and skills

The Swiss National Dementia Strategy was approved in late 2013. Pascal Strupler, Director of the Swiss Federal Office of Public Health, speaks about the main provisions and the difficulties that may arise during its implementation.

The Swiss National Dementia Strategy 2014-2017 was approved at the end of last year by the federal government and the cantons. The strategy aims to deliver high-quality advice, support and care for people with dementia and their families throughout the entire course of the disease. Within the strategy, 18 projects will raise public awareness, promote needs-oriented services, ensure quality of care and increase specialists’ expertise and skills.

Why does Switzerland need a dementia strategy? What is the background?

As part of its health policy strategy, the Swiss Federal Council aims to promote modern forms of care provision and to improve the integrated management of major diseases. The dementia strategy is one of the projects with which this goal will be achieved. The number of people with chronic health problems will increase significantly over the next years and decades because the population is ageing. There are likely to be around 25,000 new cases of dementia every year.

Optimised, integrated management in all phases of dementia, from early detection to palliative care, plays a major role in improving the quality of life and subjective wellbeing of those affected and enables us to ensure that they can enjoy a good quality of life despite their illness.

Care providers and patient organisations also view the dementia strategy as a very important and valuable concept: they will continue to play a dynamic and constructive role in helping to implement it. Some cantons are already implementing their own strategies, which are harmonised with the national strategy.

From your perspective, which of the defined objectives have priority? What is the biggest challenge?

Our primary focus is to improve the quality of life of people with dementia. We need to support everyone involved, in every phase of the disease.

Our primary focus is to improve the quality of life of people with dementia. We need to support everyone involved, in every phase of the disease. Early and accurate diagnosis is important in enabling people with dementia to be involved in their individual treatment, support and care. In addition, support for people with dementia and their families needs to be better coordinated, networked and developed in line with their needs. That is one of our greatest challenges. Our aim is to ensure management that is appropriate and specific to dementia in both the outpatient and the inpatient setting, and in short-term and long-term care. Those affected need to be taken seriously in their specific life situation and be involved in decisions as far as possible.

How is the strategy being funded? What is the budget for its implementation?

The strategy will be implemented using the stakeholders’ existing human and financial resources. To a large degree, the proposed projects can be
integrated into ongoing cantonal activities. Better national coordination will enable us to exploit synergies and so enhance the efficacy of the various measures.

**How will the strategy actually be implemented and how long will it take?**

The National Dementia Strategy has a solid foundation. The stakeholders agree on the need for action and on the objectives and they are working with great dedication. I am confident that they will tackle the projects within the strategy with great energy. The federal government, cantons and stakeholders will work together on the ongoing development of the various activities and will adapt them to the specific target groups and regions. The main focus of the Federal Office of Public Health (FOPH), the federal authority which is overseeing the strategy, and the Conference of Cantonal Directors of Health (GDK), which together are responsible for the strategy, will be to coordinate activities and to ensure the flow of information and communication between the stakeholders.

**Will the patients and the Swiss Alzheimer’s Association, which represents their interests, be involved?**

The Swiss Alzheimer’s Association was an essential partner during the conception and development of the national dementia strategy. This collaboration will continue to be decisive during the implementation phase, particularly in the areas of raising awareness and patient counselling. We attach great importance to providing support and respite for the families of people with dementia; several projects have specific aims to expand services in this area. For example, we will establish personalised information and welfare counselling structures, develop flexible regional respite services for day and night care and also reinforce the skills of family members and informal caregivers.

**Is there a need for closer collaboration on dementia on a European level?**

International collaboration on public health policy is one of the reasons why Switzerland enjoys such a high-quality health service. Countries with health systems similar to ours – such as Germany, the Netherlands and other EU countries – have provided us with invaluable input on ways to improve healthcare provision. This applies especially to the care of people with dementia.

Alzheimer Europe would like to thank Birgitta Martensson, Director and Susanne Bandi, Communication Manager from the Swiss Alzheimer’s Association for their major contribution to this article.
Viewpoint of the Swiss Alzheimer’s Association

The role of the cantons is crucial in implementing the National Dementia Strategy.

The Swiss Alzheimer’s Association has been calling for a national dementia strategy for years and is largely satisfied with the outcome – even if some of its requirements have not been met. The approval of the new strategy is an important step forward with plenty of potential for the future.

Both the federal government and the cantons have realised that dementia is one of the major challenges in public health policy. This has allowed Switzerland to join the growing number of countries that have made this topic a priority.

The focus is now on our 26 cantons as they begin to implement the strategy. Each canton is responsible for its own health services and the association will keep a close eye on the implementation of the various objectives and measures.

From the point of view of the Alzheimer’s Association, the following aspects are vital:

**Access to information and advice:** people with dementia and their family carers should have access to comprehensive information and individual counselling. This point is especially important as it addresses the need for support from the very onset of the disease.

**Coordination of services:** basic medical services (early detection, diagnosis, therapy, follow-up and care) must respond to actual needs: it is vital for these services to be coordinated more closely. This “case management” approach should also include crisis intervention at home.

**Knowledge and training:** carers must receive adequate and specific knowledge and training in order to respond adequately to the needs of people with dementia.

The Swiss Alzheimer’s Association will lead the strategy objective entitled “Information and public awareness”. The association is delighted to take on this task in collaboration with other partners. It is very important for people to know more about dementia and to have a better understanding of the disease.

What does it mean to live with dementia, as a person affected and as a member of the family? How can I support people with dementia? When more people start to ask these questions, we will take a major step towards a dementia-friendly Switzerland.
World Dementia Council

Alzheimer Europe highlights the recent activities of Dr Dennis Gillings and the World Dementia Council.

World Dementia Council holds inaugural meeting

Following the 2013 G8 dementia summit, a World Dementia Council was appointed to support World Dementia Envoy, Dr Dennis Gillings CBE. The 13-member council met for the first time in London on 30 April.

With the summit objective being to find a cure or disease-modifying therapy by 2025 and with the global cost of dementia at an estimated USD 604 billion (EUR 443 billion), the Council proposed plans to remove barriers to innovation, improve investment conditions and to encourage new research into dementia globally, working with governments, regulators and industry.

Dr Gillings said: “We are determined to be radical but practical in the proposals that we bring forward. We will speak plainly to governments, regulators and industry about the changes we need to see happen quickly.” Along with Dr Gillings, the members of the Council are:

- Sir William Castell, Chairman of the Wellcome Trust
- Dame Sally Davies, Chief Medical Officer at the Department of Health, England
- Dr Tim Evans, Director for Health, Nutrition and Population at the World Bank
- Dr Franz Humer, Chairman of Roche
- Dr Yves Joanette, Scientific Director, Canadian Institutes of Health Research, Institute of Aging
- Professor Martin Knapp, Director of Health, the London School of Economics
- Dr Kiyoshi Kurokawa, Professor of the National Graduate Institute for Policy Studies and Chair, Health and Global Policy Institute
- Yves Leterme, Deputy Secretary General of the Organisation for Economic Co-operation and Development
- Raj Long, Senior Regulatory Officer – Integrated Development, Global Health at the Bill & Melinda Gates Foundation
- Professor Pierluigi Nicotera, Scientific Director and Chairman of the Executive Board, German Centre for Neurodegenerative Diseases
- Professor Ronald Petersen, Director, Mayo Alzheimer’s Disease Research Center
- Dr Paul Stoffels, Global Chair of Johnson & Johnson
- George Vradenburg, President and Chairman of the Vradenburg Foundation and USAgainst Alzheimer’s

World Dementia Envoy calls for large expansion of clinical trials

Dr Dennis Gillings was appointed World Dementia Envoy by Prime Minister Cameron in February 2014. On 23 March, he spoke to The Telegraph newspaper about his mandate to lead global efforts to tackle dementia.

He pointed out that society needed to “activate” on behalf of those with dementia and “dramatically speed up” research efforts in order to secure a breakthrough. He also said that promising drugs should be given to “large populations” in order to speed the search for a breakthrough – an indicator that he will act to multiply clinical trials for potential dementia medicines.

Dr Gillings added that “I would like to see far more people with dementia being put into clinical research trials, so that once we find a drug is safe we introduce it to a wider population earlier. With HIV the patients themselves were the activists – with dementia it is different so we need communities and families to activate on their behalf.”

Finally, the World Dementia Envoy noted that “the political will” was in place to tackle the disease but said his new role would be seeking “dramatically increased investment” in research from the pharmaceutical industry.
Do more, feel better, live longer.

GSK’s goal is to improve the quality of human life - not just through our medicines and vaccines, but also through our work with communities around the world.

By partnering with non-profit organisations, we can improve the health and education of those who need it most. Targeted, sustainable programs benefiting future generations in both the developing and developed world-helping them to do more, feel better and live longer.
Dr Giuseppe Ruocco, General Director of Prevention at the Italian Ministry of Health, speaks to Alzheimer Europe about Italy’s upcoming EU Presidency.

What are the health priorities of the Italian Presidency of the EU? How will these priorities support people with dementia and their carers?

The Italian Presidency of the EU Council will focus on topics related to public health, and in this framework will deal with chronic non-communicable disease (NCD). On the issue of dementia, Italy is organising a conference – scheduled for November 2014 – during which a comparison between the Italian Plan of action against dementia and the best practices of other EU Member States will take place. This conference will be one of the follow-up events of the Dementia Conference held by the United Kingdom during its G8 Presidency.

Many EU countries are dealing with an ageing population, the increase of age-related diseases like dementia and the vulnerability of healthcare services. Will the Presidency explore how innovation can address the challenges faced by people with dementia and their carers?

All of these will be addressed by the Presidency, either during the conference in November or at other planned events such as the Conference on sustainability of health systems and on quality and safety of care.

ALCOVE, the first Joint Action on Dementia, provided valuable information on how Member States address specific issues around dementia. How can the Italian Presidency further stimulate such exchanges of best practices and encourage other joint actions or other collaborative projects on dementia?

Italy was an active partner in the ALCOVE Joint Action and is encouraging a new, similar initiative on the same issue, which has already proposed by the European Commission. We consider this a productive way to deal with problems shared among different countries of the EU.

Italy is expected to launch a national dementia strategy in March. Can you tell us what major areas will be addressed and what budget has been allocated?

The action plan is in the final steps of negotiation with the regional authorities who are responsible for its implementation. We hope that the action Plan will be adopted in the next several months. The final draft text has four main objectives:

1. Provide actions in the field of health and social policies.
2. Build an integrated network between hospitals, districts and GPs to guarantee continuity of care and the best possible assistance to patients, families and informal and formal caregivers.
3. Implement strategies and actions aimed at delivering appropriate care.
4. Reduce stigma and improve information and knowledge among health personnel and the public.

The funding of the action plan will be decided when the final version of the action plan is agreed.

“The national dementia action plan is in the final steps of negotiation with the regional authorities who are responsible for its implementation.”

GIUSEPPE RUOCO
“Currently, our major concern is to build a broad base of engaged people and draft the strategy in a collaborative way.”

PARASKEVI SAKKA

Development of Greece’s national dementia strategy

Dr Paraskevi Sakka, Chair of the Working Group for the Greek Dementia Strategy, reports on the progress and challenges of developing a sustainable national dementia programme.

Lack of resources and geographic challenges

According to ADI’s “World Alzheimer Report 2013: An analysis of long-term care for dementia”, there are 200,000 people live with dementia in Greece and 400,000 family carers looking after them. Due to rising life expectancy worldwide and in Greece, this number could almost triple by 2050. This makes dementia one of the most important medical, social and economic future challenges in Greece.

In Greece, there is no National Dementia Strategy in place. In accordance with European and global priorities, Greece started to organise and implement dementia programmes dementia since 2006, but so far the resources have been limited. There are currently very few specialised services for people with dementia: 13 day care centres and three respite care facilities in Athens, Thessaloniki and smaller towns, which are operated by the Greek Alzheimer’s Associations with government funding.

Despite their limited resources, the Greek Alzheimer Associations are very active in organising awareness campaigns, seminars for health professionals, screening programs for the public, educational programmes for carers and scientific research. However, only 5,000 people with dementia and their caregivers are able to take advantage of the existing facilities. Compared to their existing needs, the services provided are woefully inadequate. There are large areas of the country – especially rural and island areas – which are not covered by any specialist services or facilities. Overall, the major problem is the total lack of social care facilities, long stay institutions and end of life centres throughout the country.

<table>
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<tr>
<th>Members of the Working Group for the Greek Dementia Strategy</th>
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<tr>
<td>Paraskevi Sakka</td>
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<td>Fotini Koulouri</td>
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<td>Dimitris Takis</td>
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Formation of the National Working Group

As in most European countries and Worldwide, Greece needs a National Dementia Action Plan and this has been earnestly pursued by all stakeholders for many years. Under pressure from the Alzheimer’s Associations and recognising the magnitude of the problem, the Greek government recently took the first step. In November 2013 the Minister of Health assigned a national working committee, led by Dr Paraskevi Sakka, neuropsychiatrist and President of the Athens Alzheimer’s Association, to design, organise and implement this ambitious programme. The Minister of Health also signed a statute to ensure the continued existence of this committee in the future.

The key priorities of the strategy’s action plan are to raise public and professional awareness, promote early diagnosis and intervention and improve the quality of life of people with dementia and their caregivers. The recommended actions are listed below:

- Improve public awareness and reduce stigma
- Improve (early) diagnosis and treatment
- Improve support and care available at home
- Create support services for carers and families
- Improve residential/institutional care
- Improve integration of care pathways and coordination of social and medical care
- Improve training for healthcare professionals
- Establish research programmes that embrace innovative technologies
- Create legislation to support patients’ rights

Collaborating to improve the lives of people with dementia

The major challenge to achieving the above goals is unquestionably financial! Although the Minister of Health has committed himself to make funding available for its implementation, we believe that this is going to be a difficult and lengthy process. We must identify the key areas to prioritise and careful steps have to be taken. Currently our major concern is to build a broad base of engaged people and draft the strategy in a collaborative way.

We have started our effort by recording and analysing the current situation and listing the existing resources and deficiencies. So far we have organised two waves of consultation. The first was to create and distribute 500 questionnaires to the Alzheimer’s Association members and a wide number

“We intend to design and implement cost-effective policies in Greece by establishing a comprehensive network of health and social care services.”

PARASKEVI SAKKA
of professional and other stakeholders groups all over Greece. The responses have been analysed and taken into account.

In a second phase, the Ministry of Health will conduct three focus group consultations during May-July 2014. These will include experts and interested parties involved in the management of dementia from all over Greece.

Accordingly, we intend to design and implement national and cost-effective policies by establishing a comprehensive network of health and social care services. Thereafter, we will design specific actions that can be adopted to improve research and education. We will also propose improvements for the quality of life of people with dementia by creating allowances and laws to support their rights.

We expect to launch the first draft of the Strategy on World Alzheimer’s Day 2014 – you can be sure we will make this an event to remember!

**Dr Paraskevi Sakka - a professional profile**

Dr Paraskevi Sakka obtained her diploma in Medicine from the University of Athens in 1977, her title in Neurology and Psychiatry in 1982 and her Ph.D. in 1996. During 1997-2003, she developed and directed a Memory Clinic at Athens Veterans’ Hospital. Since then, she has directed the Department of Neurodegenerative Brain Diseases at Hygeia Hospital in Athens. Her research interests include the functional imaging of the brain, dementia biomarkers and non-pharmacological treatments of dementia. She is particularly interested in the social dimension of dementia and caregiver burden. Dr Sakka founded the Athens Association of Alzheimer’s Disease and Related Disorders and has been its Chairperson since 2002. She has also been the President of the Greek Dementia Society since 2010.

**The status of national dementia strategies in Europe**

Alzheimer Europe, June 2014
Eila Okkonen and Kirsti Kuusterä, respectively Executive Director and Specialist at the Alzheimer Society of Finland, discuss the consequences of recent government measures that may be detrimental for people with memory diseases and their caregivers.

Eila Okkonen

“Policy-makers have to understand that it is mandatory to change the care of people with memory diseases, even with the current economic realities.”

Economic challenges in Finland

Finland’s economic situation is relatively good when compared to other European countries. Even so, the Finnish government is implementing austerity measures and looking for ways to balance national budgets in the long term.

In late 2013, the Finnish government introduced a structural policy programme that includes reorganising welfare services and increasing the age of retirement. The programme aims to answer the economic challenges of recent years and also the aging demographics of Finland.

Eurostat has estimated that in 2020 Finland will have the oldest population of any EU country, when measured in terms of the old-age dependency ratio. Thus, Finns with memory diseases are facing far-reaching changes in the service system, not just temporary austerity measures.

The current annual cost of elderly care is EUR 3.8 billion, of which EUR 2.8 billion is spent on institutional care. An estimated 80% of people in institutional care have either mild cognitive impairment or a diagnosed memory disease. It is further estimated that without significant changes in the structure of care, by 2025 all patients in current institutional care establishments will suffer from some form of memory disease.

The government programme includes substantial reform for institutional care. This is essentially a EUR 300 million budget cut that should be met by decreasing the use of institutional care and replacing it with subsidised services and care at home. It has been discussed that staff qualification standards will be diluted and the status of quality recommendations will drop from “directive” to “optional”.

Opposite directions

During the past few years, the government has introduced various social acts and recommendations, such as the Act for supporting the social and health services for older people (2012), the National Memory Programme (2012) and revised quality recommendation aiming to guarantee high-quality ageing and improve services (2013), which provide better standards for the services for the people with memory diseases.

However, the very same government has also reduced the resources needed to accomplish them. This includes budget cuts for many municipal authorities – the main providers of health and social services – which are on top of the EUR 300 million reduction for institutional care.

From institutions to homes

Among OECD countries, Finland has a higher percentage of people with memory diseases being treated in institution or hospital settings. Fortunately these are mainly homelike setting nowadays: there are numerous examples of excellent care all across the country, stemming from a tradition that
emphasises rest and peace. However, this tradition may lead to people with memory diseases spending too much time in bed during the day.

On the positive side, the majority of people with memory diseases are living in their own homes or in care homes. The Alzheimer Society of Finland welcomes the government’s initiative to decrease the volume of institutional care: people with memory diseases should be able to live in their own homes for as long as possible, with the support and services they require. However, sufficient institutional facilities must also be maintained, as there comes a point where a person’s home is no longer the most appropriate care setting.

Finnish studies have shown that customised, person-centred care is the most cost-efficient way to provide well-being for people with memory diseases and their families. Moreover, the new government initiatives could certainly help to shift the culture of care to more individual models. However, there is a real risk that the implementation of the programme will focus on balancing budgets rather than developing care models. For example, institutional care should not be seen as a “privilege” for people with memory diseases. Whether they live in an institution or at home, people with memory diseases and their families have a right to live as meaningful life as possible and have good care.

Finland is making good progress towards the full integration of social welfare and health care services - including all primary and specialised services. The Alzheimer Society of Finland maintains that this new model provides many opportunities for more person-centred planning of care. The society will persist in its efforts to persuade the government to address the full spectrum of needs of people with memory disorders.

**Shifting cultures of care**

The key to implementing the new policies in a sustainable way is to look at recent innovations in home based care and rehabilitation, both from Finland and other European countries. Timely and professional care and rehabilitation can slow the progression of memory diseases and also help people to stay in home-based care for a longer time.

Merja Mäkisalo-Ropponen, Chair of the Alzheimer Society of Finland and Member of Parliament, recently said that “we policy-makers have to understand that it is mandatory to change the care of people with memory diseases, even with the current economic realities. Finland cannot afford to continue inhumane and expensive institutionalised care.” She also pointed out that the expertise of nursing staff is almost as important as the number of staff: a skilled nurse can perform rehabilitative care and enhance the physical, mental and social activity and wellbeing of people with memory disorders.

This cultural shift also opens possibilities and challenges to the Alzheimer Society of Finland and its local societies as they provide help and peer support to the growing number of people with memory diseases living at home and their caregivers.
Using ICT to help people with dementia

Geja Langerveld, National Programme Manager of the Ambient Assisted Living project in the Netherlands, describes how ICT can help improve the life of people with dementia.

What is the AAL JP programme?

Ambient Assisted Living is a Joint Programme of 23* countries and the European Commission. The programme aims to enhance the quality of life and independence of older adults through ICT-based solutions to contribute to sustainable care and social systems in Europe and to stimulate European companies to develop these solutions.

From 2008-2013 the AAL JP launched six calls for proposals and funded some 150 projects in different thematic areas: prevention & management of chronic conditions, social interaction, independent living, mobility, home care/ADL (activities of daily living) & support of informal carers and occupation in life. The budget for developing AAL solutions comes from the participating countries and the European Commission, with total funding of EUR 600 million over six years. Project consortia consist of private companies, organisations (e.g. seniors’ organisations, care organisations, municipalities) and R&D institutes/universities.

Currently, the European Parliament and the Council are implementing the follow-up programme, which is called Active & Assisted Living programme 2014-2020. The popularity of the programme is not in question: circa 20 countries are expected to participate in AAL’s 2014 call entitled “CARE FOR THE FUTURE; An Ageing society faces an increasing need for care, how will ICT contribute to sustainable solutions?”

The leading principles and projects in the AAL programme are as follows:

Integration of end users throughout the development process of AAL solutions. The primary end users are older adults, while informal carers, social network and professional carers are secondary end users. There are also tertiary end users (care organisations, municipalities, health insurance companies etc.) that are relevant as potential enablers or purchasers.

Focus on business aspects to bring AAL solutions to the market within 2-3 years. Many companies (particularly SMEs) participate in AAL projects and via the AAL2Business support action they can take part in training, coaching and access to investors.

Can you give us some real-life examples of how these projects can help people with dementia?

There are 30 AAL projects with a specific focus on the development of solutions for people with cognitive impairments/dementia and their carers. To make sure that their solutions are going to meet

* Countries participating in AAL JP projects: Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Luxembourg, Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, United Kingdom.
the wishes and needs of primary as well as secondary end users, these projects involve them in different stages of a project, in an iterative approach.

Understanding: investigating the wishes and needs of different user groups

People with mild dementia are interested in ICT/technology if it can support them to manage their daily activities and to cope with their situation, but just as much to have fun and participate in meaningful activities and relations. Mastering new devices with ICT/technology can give a boost to their self-esteem. Informal carers want to know that their partner/parent is safe, that emergencies are known and solved, how to react to behaviour/situations and how to deal with care issues, etc. And last but not least, they want freedom of care responsibilities now and then and practical and emotional support. Professional carers have the same concerns about safety and security: they want to support their client system and efficiently communicate with them and with other professionals.

AAL: developing solutions with different combinations of functionalities

- Signals / alarm function to professional carer or informal care (15 projects)
- Support for ADL / independent living / self-care (10)
- Orientation & navigation (9)
- Support informal care (info/advice/e-learning/experiences) (8)
- Cognitive support (7)
- Monitoring patient status (7)
- Surveillance (inside the home) (5)
- Social interaction (4) / Contacting people (4)
- Physical activity / rehabilitation / mobility (4)
- Coordination of professional care (4)
- Surveillance / localisation outside the home (3)
- Entertainment (2)

Conceptualising: conceiving and creating products and services

In this phase, products and services are regularly checked with the user groups to see if these fit their wishes and needs and to integrate their feedback in further development.

Testing: performing usability tests of the system

Tests are performed by people with dementia as well as their carers, because both user groups must be able to interact with the system. Finally, in a real-life pilot, the usefulness and added value of the AAL solution for the user groups is evaluated. An important part of the project is to develop a concurrent business case and strategy. Finally, in this process the user groups can play an important role to indicate the customer value, purchasing criteria, etc.

“The best possible outcomes are solutions which enable people with dementia and their carers to keep living their lives according to their own wishes and to experience joy, connectedness and meaning in life.”

GEJA LANGERVELD
How are ethical issues dealt with in AAL projects?

AAL projects are required to describe how they will deal with ethical issues regarding the involvement of user groups – especially people with dementia – in the project. Informed consent of the participants is always requested and projects have to describe their “exit strategy”, i.e. what will happen after the pilot has finished.

Another topic deals with ethical issues related to the technology itself (autonomy, privacy, data protection, legal regulations, liability, etc.). In the course of the project, ethical issues are discussed with the user groups and also evaluated in the trials. Among end users, privacy related to ICT/technology is often considered as a trade-off with autonomy and independence. To best ensure privacy, some solutions have different levels of authorisation for access to information gathered by the system.

What are the best possible outcomes? What challenges will have to be overcome to achieve them?

The best possible outcomes are solutions which enable people with dementia and their carers to keep living their lives according to their own wishes and to experience joy, connectedness and meaning in life. In addition, they should provide necessary functionalities for safety, information, communication, localisation, etc. Life is more than preventing risks and overcoming problems and limitations that are associated with ageing in general and Alzheimer’s disease in particular.

To achieve widespread deployment and implementation of AAL and other similar solutions, it is crucial that the ICT/technology systems are robust, reliable and operational. When using mobile devices, a specific issue for people with dementia is that they might forget to take the device with them, or to charge it in time.

AAL Project Profile: ROSETTA

The ROSETTA system uses sensors to monitor the activities of elderly people and generates alarms when unexpected events (e.g. falls) or variations in personal behaviour (e.g. straying) are detected. This system helps people living in communities to retain their autonomy and quality of life for as long as possible – and also offers some measure of respite for carers. ROSETTA focuses on the prevention, early detection and management of treatable psychosocial and physical consequences of chronic diseases that are accompanied by progressive cognitive decline and an increased risk of straying and falling during the advanced stages of the disease. www.aal-europe.eu/projects/rosetta
Other barriers are interoperability – technical as well as e.g. information and legal regulations – and finance. As yet, there is no real market demand; this makes companies hesitant to make large investments and also keeps prices high. When AAL solutions for people with dementia are implemented as part of a care system, they are often not reimbursed by insurance schemes. On the user side there is a general lack of awareness of available solutions. Fear of technology and negative attitudes can also be issues, so information and training for different types of users are important aspects of introducing and implementing ICT based solutions.

What is the role of the JPND in this project?
We began collaborating with JPND in 2013 to share knowledge on JPND and AAL JP, to identify gaps and potential benefits of collaboration and to recommend future joint actions and opportunities. In January 2014, we organised a joint workshop in Amsterdam that was attended by some 50 scientists and AAL project partners. They discussed user needs & wishes, market aspects and standards for evaluation and a report is due to be published soon.

Geja Langerveld - a professional and personal profile
Geja Langerveld holds a Master’s Degree in Psychology and has been the Dutch national AAL programme manager since 2007. She is working towards a real implementation and integration of AAL solutions in informal and professional care practice in the Netherlands. In 2001, she joined ZonMw, the Dutch organisation for R&I in the healthcare sector, to work on programmes empowering patient/care “consumers” and transparency about quality of health & long term care providers. Geja is also a quality auditor of nursing/care homes and home care organisations. She sees a lot of potential in ICT based solutions, provided that they add real value to the lives of people with dementia and their environment.
Dementia in the news

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**AMPA Monaco: comprehensive care for all people with dementia**

Federico Palermiti, Project Manager for Monaco’s association for research on Alzheimer’s disease, describes the numerous domestic and international activities of Alzheimer Europe’s newest member association.

AMPA, “Association Monégasque pour la recherche sur la maladie d’Alzheimer”, is the only association dedicated to Alzheimer’s disease in Monaco. It was founded in 1990 by the late Michel Pastor, a prominent industrialist who also had first-hand experience of the disease in his family. AMPA has been headed since 2009 by Ms Catherine Pastor, Chairperson and Professor Alain Pesce, Vice President and Head of the Monaco Geriatric Network.

**Promoting scientific research**

One of AMPA's main priorities is to gain a better understanding of Alzheimer's disease by hosting national and international scientific meetings. Monaco has been the site of several world-renowned conferences, such as the 5th CTAD - Clinical Trials Conference on Alzheimer’s Disease (2012) and the 1st International Congress on Alzheimer’s Disease & Advanced Neurotechnologies (2010).

The association also sponsors clinical research and projects for innovative support and care. For instance, AMPA was a partner in the “Alzheimer Datasharing International” project, in cooperation with Prof Sandrine Andrieu in Toulouse, France. In addition, AMPA finances projects that focus on improving the quality of life of people in day care centres and their families.

**Public awareness and information**

Another major AMPA objective is to provide information – and thereby raise awareness – about dementia among the general public in Monaco. The association regularly organises lectures and debates that are open to the public and also produces documentation that helps families to better manage their daily lives. AMPA also promotes awareness by hosting exhibitions of art and photographs created by people with dementia in various Monaco care centres.

AMPA and the Monaco Geriatric Network have been commemorating World Alzheimer’s Day since 2010, in close cooperation with government and city authorities. Each year, Memory Walks on 21 September have attracted well over 500 participants, including government officials and other prominent citizens.

In 2012, AMPA decided to expand its activities beyond Monaco with the launch of the Mediterranean Alzheimer Alliance: the MAA is a partnership of associations, scientists and health professionals working together to fight Alzheimer’s disease and related disorders in the Mediterranean region.
Sharing knowledge and expertise: the Mediterranean Alzheimer Alliance

The alliance was launched in April 2012 in Marrakech, during an international conference hosted by Espoir Maroc Alzheimer, Morocco’s Alzheimer Association. The initiative stems from the fact that Alzheimer’s disease is much more than a health issue; it also has a huge impact on social, cultural and economic sectors of each society. The only solution is an integrated package of diagnosis along with sufficient support for people with dementia, their caregivers and families.

As of May 2014, there are 15 partner countries in the MAA: Croatia, Cyprus, Egypt, France, Greece, Italy, Lebanon, Libya, Malta, Monaco, Morocco, Portugal, Slovenia, Spain and Tunisia. The MAA aims to be a source of proposals and actions at local and international level and alert national governments on the need to act and mobilise support for the fight against Alzheimer’s disease. In addition, the MAA will support Alzheimer associations in Mediterranean countries to implement practical solutions for people with dementia and their families, as well as encourage collaborations between the partner countries.

Comprehensive care for all Monaco citizens

In Monaco, people over the age of 65 represent 27% of the population. An extrapolation of French prevalence estimates shows some 400 people with Alzheimer’s disease in Monaco – among a total of 37,000 inhabitants.

Monaco’s government has been developing an extensive gerontological network since 2003. Currently, the Principality provides each citizen with tailored and adaptable services that cover all current and preventive health needs related to ageing. This programme is based in the “Rainier III” Centre for Clinical Gerontology. This facility opened in 2013 and provides comprehensive geriatric services including a memory clinic, a hospital unit and a research centre. In addition, there are two state-run retirement homes, a day care centre and a specialised unit that coordinates home care services.

AMPA maintains an active presence in all of these structures, providing advocacy, information, guidance and support to people with Alzheimer’s disease and their caregivers.

AMPA provides advocacy, information, guidance and support to people with Alzheimer’s disease and their caregivers.
Living with dementia in Belgium

Jean-Pierre Frognet, Vice Chairperson of the European Group of People with Dementia, is living with dementia in Belgium. He writes about his recent “trial period” in a day care centre.

Seven years have passed since my dementia diagnosis. My abilities continue to decline and, while I wish to remain active, it is becoming difficult to find activities to fill my day. Because of this, I recently decided to enrol in a day care centre that is close to my home.

Apart from its convenient location, the centre also seemed a good place to meet new people, get involved in a few activities and generally have a break from my usual daily routine. Moreover, it would give my wife Marie-Anne a well-deserved break.

My first day at the centre was in early December and I was feeling very stressed. All the managers and staff members were welcoming and polite, but my fellow residents were much more reserved. They all knew each other quite well and I could hardly blame them for wondering who I was and what I was doing there. All the residents except one were very old, but this did not bother me. This was, after all, a centre designed for older people. However, I soon discovered that the centre's daily activities were also designed for that age group and this is where my difficulties began.

Unfortunately, there were very few physical activities. Instead, there was a sense of torpor – much stronger than what I often feel at home. I began to worry about what I was going to do all day, especially as I was not yet “accepted” by the other residents. I bear no grudge against them - it is not unusual for older people to be wary of newcomers in a care home and I certainly had no wish to impose my presence on them.

As it turned out, the day ended on a positive note: one of the staff members began to decorate a Christmas tree, so I volunteered to help and we spent a very pleasant afternoon. The following Friday was also quite interesting, as I decided to join the centre's choir. I have lost my ability to read, so I had to concentrate very hard to remember all the words and notes. Anyone with Alzheimer's disease can tell you that this is no easy task! I was glad to take on the challenge and this made for an enjoyable day.

I spent a total of two months at the care centre but was never really satisfied with my stay. In fact, the feeling that I did not belong there grew stronger with every visit. Admittedly, this particular centre was not specifically designed for people with Alzheimer's disease. Because of this, I could not take part in certain activities like board and card games. As a result, many of my afternoons were spent sitting in an armchair, waiting for Marie-Anne to pick me up at 5 pm. This was very frustrating as I am only 62 years old and still have plenty of energy.

All of this led to my decision to stop attending the centre. I explained my misgivings to the managers –
DEMENTIA IN THE NEWS

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DEMENTIA IN EUROPE
THE ALZHEIMER EUROPE MAGAZINE

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Marie-Anne Schreder and Jean-Pierre Frognet

nearly the lack of appropriate activities for people with dementia – and we parted on friendly terms. In Belgium, there are many such centres that are open to all people. However, in my area there are no dedicated facilities for people with Alzheimer’s disease. In addition, my expectations as a “young” patient go well beyond a birthday party or a game of cards. I see a great need for specialised institutions for people with dementia, especially the younger ones who are still in good physical shape.

I also wonder when politicians and organisations will understand that younger, active patients can still lead long and productive lives. When will they provide specialised facilities, so that younger people are not confined to traditional old peoples’ homes? When and how will they find ways to help us live with dignity for the rest of our lives?

They seem to have forgotten that all of us were active when the disease was detected, but suddenly – almost overnight – we found ourselves at home and inactive. The diagnosis was thrust upon us and we had no time to make any decisions, to prepare for early retirement or to learn to adapt to this incurable disease.

Today, seven years after diagnosis, I am in good physical condition and I still have the energy and the will to live a relatively normal life. I have lost contact with many ex-colleagues and friends from my working years, but have resolved to stay as active as I can, for as long as I can. The alternative – to give in, to stop seeking contact – would only hasten my mental demise and soon I should have no more will at all.

At home, I walk my dog, listen to music and occasionally do the shopping. I would like to help Marie-Anne with household chores but cannot remember how to do them. However, there are still some things we can do together. Even so, it is important that she also carry on her own social life; she cannot be my wife, caretaker and nurse all rolled into one.

Fortunately, we have access to various services to make this possible. Every day, a caregiver visits our home to help me with my morning toilet. I have a speech therapy session once per week and the Red Cross provides me with transportation if Marie-Anne is not available. We are also following couples therapy that helps us to deal with the consequences of my condition: amongst other things, it allows us to maintain our marital relationship despite the growing bias of our caregiver and patient roles.

There is a clear need for appropriate structures to help young people with dementia – a need that is all the more urgent as our population ages. Every person, regardless of income, deserves access to high-quality benefits and services. However, to achieve this will require the cooperation and involvement of each and every one of us, young or old, healthy or living with dementia.
Portraying dementia on Czech television

A Czech TV series recently portrayed the experiences of a man that develops Alzheimer’s disease. Jana Kasparkova (MSc, RN) from the Faculty of Humanities of Charles University (Prague) and Plzen University Hospital, interviewed Martin Safranek, the principal scriptwriter of these episodes.

“Age, to us, is not a dirty word and neither is dementia!”

MARTIN SAFRANEK

“Ulice” (The Street) is the first long-running daily Czech soap opera. It has aired every weekday since 5 September 2005 and began its ninth season in 2013 with enormous popularity among its viewers. The Street portrays various everyday life situations of its residents. Love, friendship, relationships and competition are all common topics, along with crime, illness and death. Alzheimer’s disease was featured in several episodes, as the main character Vaclav Kral develops the disease and must learn to deal with its consequences.

The Street portrays many real life situations, such as Mr Kral developing Alzheimer’s disease. Who came up with the idea to include mental illness in the storyline?

The Street is a special kind of series, as the creation of individual stories involved more people than usual: we started as a team of six people, but this grew to ten and sometimes even more. It is impossible to credit a single person; we work by bouncing ideas, wishes and possibilities off each other and this eventually leads to a completed script. In the particular case of Mr. Kral’s illness, we wished to attract audiences by presenting a topic that may affect any of us. Alzheimer’s disease, whether we like it or not, is exactly that. According to current perceptions, Alzheimer’s disease is not the result of poor living habits, but rather an “intervention of destiny”. This may sound trite or banal, yet it does somehow exist and it affects us all.

Did anyone in the team have personal or professional experience with the disease?

Personal experience is not a prerequisite for professional writers. I don’t have to break my leg to show how a character feels with his leg in a cast – if that were the case, our hospitals would be full of TV writers! However, each of us has encountered Alzheimer’s disease or another form of dementia at some point in our life. We also had a particular writing team that had very personal experiences of caring for a handicapped person. This also influenced our decision to choose such a topic.
It cannot have been easy to handle this complex topic. Where did you get inspiration from?

Writers for The Street are inspired by everyday life and old age is just another everyday occurrence. It will inevitably happen to all of us, regardless of whether we see it as a blessing or a curse. Just look around – on the street, in the tram, at the park with the dog, in the store or in the bank – and you will see old age everywhere. So it is not hard to imagine the confusion that one feels when he first realises somewhere on the street that he suddenly does not know where he is going, why he no longer recognises people or why he even went out in the first place.

Did the writing team or the actors go through any special training on the topic of Alzheimer’s disease?

They are well-known stories of American actors preparing for a film for half a year. Unfortunately, The Street is not a Hollywood blockbuster, but a daily series: if you want to broadcast an episode every day, you have to produce one every day! Our daily routine does not allow time for special training, but some topics require us to consult with experts in order to make the stories believable. For the dementia episodes, members of the creative team met with such an expert to learn about the existence of medication, the different stages of the disease and what patients can or cannot do. We did this to make the story realistic, but also because we did not want to give misleading information – such as the existence of a cure – to people with mental illnesses and their families.

How did Mr Brzobohaty – the actor who played Vaclav Kral – deal with the development of his character?

This question is really for Mr Brzobohaty, but unfortunately he is deceased. However, there is an interesting story about the fate of his character Vaclav Kral. As our viewers know, Mr Kral died during an episode of the series. What they don’t know is that the scriptwriting team got into a passionate debate about whether his death would be caused by poison or by shooting. The ladies favoured poison but the men preferred firearms. Neither side wanted to retreat so we found ourselves in a stalemate. That’s when Mr Brzobotahy stepped in. He insisted that Vaclav Kral must move into a nursing home and end his days there. And that’s how we wrote it. One day, Mr Kral’s family came to visit him in the home and discovered that he had quietly passed away.

Why did you choose this topic?

The Street is the type of series that tells the story of life here and now – the life which everybody lives every day. Maybe it is a little bit better than real life: in the series people do not steal as much, kill as much or envy others as much as they seem to do in the real world. Apart from that, we try to show the world the way it is. Characters fall in love, give birth to children and grow old. Age, to us, is not a dirty word and neither is dementia! That’s why we talk about them, as well as a range of other issues.

Can the television industry contribute to improving the lives of people with dementia and their families in some way?

The television industry is a powerful wizard: it is known for its ability to influence the decisions of viewers and to affect their preferences, even those that are unrelated to entertainment. But it also affects attitudes. Perhaps this series helped to raise awareness of the issues around Alzheimer’s disease, maybe even to the point of altering the views of those people who are still healthy. If this is the case, then this tiny part of the TV production has fulfilled its mission.

Ms Kasparkova is a member of Alzheimer Europe’s ethics working group. We were very pleased to also have her as a guest journalist for this article.
Members’ news

Alzheimer Europe highlights some activities of its member associations.

9 April: France Alzheimer campaign collects 50,000 signatures

Earlier this year, France Alzheimer launched a national campaign for the French government to pass a law making better provisions for the needs of people who have lost their autonomy. About 100 people attended a FA gathering in Paris on 9 April in support of this campaign. The timing was symbolic since the law was to be presented to the council of ministers simultaneously. Sadly, the latter was postponed to a later date but FA was able to use the occasion to gather more signatures. Having now surpassed the target of 50,000, the organisation has sent the signatures, along with a chest of “souvenirs” (photos of Alzheimer’s patients and their carers) to the President, the idea being to remind Mr Hollande of the campaign promises he made.

4 April: Royal attention for dementia village in the Netherlands

On 4 April, Queen Maxima of the Netherlands hosted Sweden’s Queen Silvia on a visit to a special care facility for elderly people with dementia near Amsterdam. “De Hogeweyk” is a gated community that is built like a small town, with its own town square, houses, pub, theatre and shops. During their visit, the monarchs where shown around by Eloy van Hal, facility manager of De Hogeweyk. He said: “I felt the sincere

24 April: Belgium’s Ligue Alzheimer holds 22nd annual conference

The conference took place in Huy, Belgium and focused on the topic “L’Éthique à la recherche du bien-être”. In the opening speech, Prof. Michel Longneaux described ethics as involving respecting each person as a person and warned against definitions of personhood based on cognitive capacity or self-awareness. He emphasised three points in relation to ethics and wellbeing: 1. The need to be realistic and to accept that everything is not possible. He pointed out that it can be frustrating when carers realise that what they would like to do for the person with dementia cannot be achieved, 2. Concerns about wellbeing should not focus solely on the person with dementia but should involve a compromise between his/her wellbeing and that of informal and formal carers and 3. The wellbeing of each person is influenced by a particular socio-economic and political context which also points towards the need for compromise. Interdependency and the need for carers to consider their own well-being were further developed during the session on “autonomy and interdependence” chaired by Sabine Henry and involving the members of the Groupe des Battants (the group of fighters). In the afternoon, a series of short presentations were made on a range of topics such as palliative care, new guardianship legislation, Alzheimer cafés and theatrical improvisation.
attention of the queens. They took the time to really experience our special community.” The queens toured the entire facility and spoke to several residents. This was followed by a meeting with Gea Broekema-Procházka, director of Alzheimer Nederland, where they discussed the care of people with dementia in the Netherlands. After speaking to Queen Silvia about her personal experience with dementia, Ms Broekema-Procházka said: “It was very special to discover that we share similar experiences.”

The conference also covered EU policies in dementia, including a presentation by Annette Dumas, Public Affairs Advisor for Alzheimer Europe. Ms Dumas outlined the existing European tools that can help countries prepare and implement a national dementia strategy, as well as EU opportunities in the area of sharing best practices and joining forces, especially in the field of research.

26 February: Romania holds 4th Annual Alzheimer Conference

The fourth annual Romanian Alzheimer Conference took place between 26 February and 1 March in Bucharest, under the motto “Dementia in Romania: on the Public Agenda?” The main topic of the conference highlighted the urgent need to improve the living conditions of elderly people, with a focus on people suffering from major neurocognitive disorders.

There were also scientific presentations, such as recent diagnosis criteria for clinicians and researchers, neuropsychology and biological markers in dementia. Other presentations covered the specific needs of a patient with major neurocognitive disorders, the legal rights of people with dementia and the prevention of abuse and stigma. These were effectively illustrated by Helga Rohra, Chair of the European Working Group of People with Dementia, who spoke about the personal experiences of people living with dementia.

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20 February: Danish Alzheimer Association launches carer campaign

The Danish Alzheimer Association has launched a campaign named “I love you, but I don’t remember who you are”. It aims to raise awareness of the person behind the disease and the importance of maintaining a relationship despite changing conditions. The campaign is based on seven key messages:

- Focus on the remaining strengths of your loved one.
- Keep up relations, even if you cannot be together in the same ways as before.
- Be together in the present; the past may be forgotten and the future difficult to foresee.
- Speak openly about the consequences of the disease; this makes it easier to accept help.
- Take care of yourself, so that you have the energy to help.
- Highlight your successes; do not despair of what cannot be changed.
- Improve your knowledge of dementia.

This campaign was made in cooperation between the Danish Alzheimer Association, students at Denmark’s School for Visual Communication and various advertising agencies.
Wouldn’t it be great if Pete could find the way home?

Pete has Alzheimer’s disease. This condition not only has a profound effect on sufferers, it can also increase the burden on their families and carers. Sufferers can become increasingly vague and confused about everyday matters, which may be dangerous and upsetting for them. Late or incorrect diagnosis can exacerbate the situation. We want Pete and millions of patients like him to lead as normal a life as possible.

As well as Alzheimer’s disease, there are many other conditions with unmet medical needs: it is Janssen’s mission to develop innovative treatments for serious illnesses such as HIV/AIDS, schizophrenia, hepatitis C, tuberculosis, psoriasis, arthritis, multiple myeloma, cancer and diabetes. We make extraordinary efforts so that patients around the world can lead a better life.

Extraordinary efforts for a normal life.
Our members are helping people with dementia and their carers in 33 countries

- **AUSTRIA – VIENNA**: Alzheimer Austria
- **BELGIUM – BRUSSELS**: Ligue Nationale Alzheimer Liga
- **BULGARIA – SOFIA**: Alzheimer Bulgaria
- **BULGARIA – VARNA**: Foundation Compassion Alzheimer
- **CROATIA – ZAGREB**: Alzheimer Croatia
- **CYPRUS – LARNACA**: Pancyprian Alzheimer Association
- **CZECH REPUBLIC – PRAGUE**: Czech Alzheimer’s Society
- **DENMARK – HELLERUP**: Alzheimerforeningen
- **ESTONIA – TARTU**: Estonia Association of Alzheimer’s Disease
- **FINLAND – HELSINKI**: Muistiliitto
- **FRANCE – PARIS**: Association France Alzheimer
- **GERMANY – BERLIN**: Deutsche Alzheimer Gesellschaft e.V.
- **GREECE – THESSALONIKI**: Greek Association of Alzheimer’s Disease and Related Disorders
- **ICELAND – REYKJAVIK**: The Alzheimer’s Association of Iceland
- **IRELAND – DUBLIN**: The Alzheimer Society of Ireland
- **ITALY – MILAN**: Federazione Alzheimer Italia
- **ITALY – ROME**: Alzheimer Uniti Onlus
- **JERSEY – ST HEIлер**: Jersey Alzheimer’s Association
- **LUXEMBOURG – LUXEMBOURG**: Association Luxembourg Alzheimer
- **MALTA – MSIDA**: Malta Dementia Society
- **MONACO – MONTE-CARLO**: AMPA - Association Monégasque pour la recherche sur la maladie d’Alzheimer
- **NETHERLANDS – AMERSFOORT**: Alzheimer Nederland
- **NETHERLANDS – OSLO**: Nasjonalforeningen Demensforbundet
- **POLAND – WARSAW**: Polish Alzheimer’s Association
- **PORTUGAL – LISBON**: Alzheimer Portugal
- **ROMANIA – BUCHAREST**: Societatea Alzheimer
- **SLOVENIA – LUBLJANA**: Association “Forget-me-not”
- **SLOVAKIA – BRATISLAVA**: Slovak Alzheimer’s Society
- **SPAIN – PAMPLONA**: C.E.A.F.A.
- **SPAIN – MADRID**: Fundación Alzheimer España
- **SWEDEN – LUND**: Alzheimerföreningen i Sverige
- **SWEDEN – STOCKHOLM**: Demensförbundet
- **SWITZERLAND – YVERDON-LES-BAINS**: Association Alzheimer Suisse
- **TURKEY – ISTANBUL**: Alzheimer Vakfı
- **UNITED KINGDOM – EDINBURGH**: Alzheimer Scotland
- **UNITED KINGDOM – LONDON**: Alzheimer’s Society
24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014
Register now!

www.alzheimer-europe.org/conferences