MEP Keith Taylor hosts an Alzheimer Europe lunch debate

Birgitte Vølund takes the helm of the Danish Alzheimer Association

Corinne Cahen, Luxembourg’s Minister for Family Affairs and Integration, speaks about recent developments in dementia care

Milja Ahola & Raoul Grönqvist speak about movement recall and musical therapy

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Welcome to all our readers! I am writing this as the Chairperson of a new Alzheimer Europe Board, which was elected in October 2014. It is an honour for me to have been re-elected and I am glad to collaborate with my Board colleagues, all of whom are highly competent and bring invaluable experience to help guide AE’s work.

In December 2014, we held our first lunch debate within the new European Parliament. MEP Keith Taylor, who is also a Vice Chairperson of the European Alzheimer’s Alliance (EAA), was kind enough to host the event which focused on dementia prevention. Our other EAA members have also been helping to raise awareness about dementia and this issue includes highlights of their activities in Brussels and in their home countries.

The European Commission recently published a report on EU initiatives on dementia since 2009. These include studies on early diagnosis and best practices, as well as epidemiological research – and I am very pleased to say that Alzheimer Europe has been actively involved in nearly all of them. AE also attended the two Dementia Legacy events in the latter half of 2014. Jean Georges, our Executive Director, reports that global efforts will also target dementia care, not just a possible cure.

The past few months have seen the launch of three new national dementia strategies – which must surely constitute some kind of record! Greece and Italy are both establishing observatories to oversee the implementation of their respective strategies and we will learn more about Ireland in our next issue. There is additional good news from France, which introduced a new neurodegenerative diseases strategy. This is less focused on dementia than the pioneering Plan Alzheimer, but nevertheless aims to provide life-long care and support for people with dementia and their families. Luxembourg also features in this issue as Corinne Cahen, Minister for Family Affairs and Integration, speaks about continuing developments to expand and improve services for people with dementia.

On a European level, I was very happy to see our members adopt the Glasgow Declaration at AE’s Annual General Meeting. This cooperation highlights the shared concerns that unite our countries and is also a reminder that no single country is able to bear the burden of dementia alone.

Our special section looks back at Alzheimer Europe’s 24th Annual Conference which attracted more than 830 delegates from 40 countries. This includes 44 people with dementia, to whom I wish to express my heartfelt admiration for their courage and determination. Their positive attitude and refusal to give up the fight serves as inspiration for us all. I am equally appreciative for all the work done by my colleagues from Alzheimer Scotland and Alzheimer Europe to make this a successful and memorable event.

Looking ahead, preparations for the 25th Alzheimer Europe Conference in Ljubljana are well underway and the first abstracts have already arrived. There will be a special section about Slovenia in our next issue, which will appear in June at our first 2015 lunch debate at the European Parliament. I hope to see you at an Alzheimer Europe event soon and wish you a productive and successful year.
Prioritising Dementia

The new Alzheimer Europe Board members (absent: Helga Rohra and Sirpa Pietikäinen)

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On 20 October, Alzheimer Europe’s member associations voted in a new Board during AE’s Annual General Meeting in Glasgow. The new Board members will serve until 2016.

The Board of Directors is comprised of the four office bearers and up to seven further members directly elected by a General Meeting. The Chair of the European Working Group of People with Dementia is an ex-officio member of the Board of Directors. All directors must be members of full member organisations of Alzheimer Europe.

Heike von Lützau-Hohlbein (Germany) - Chairperson
Heike has been a member of the Alzheimer Europe Board since 2004. She became involved in the Alzheimer movement because of dementia in her family. Since 1990, she has been contributing to the Deutsche Alzheimer Gesellschaft (the national Alzheimer association of Germany) – for the first ten years as treasurer and since 2001 as chairperson. Heike worked as a consultant in the computer business but is now retired.

Iva Holmerová (Czech Republic) - Vice-Chairperson
Iva Holmerová is the Chair of the Czech Alzheimer Society, which she co-founded in 1997. A practicing physician, she is qualified in General and Geriatric Medicine and also holds a PhD in Social Gerontology. Iva is also the Director of the Czech Centre of Gerontology, the President of the Czech Society of Gerontology and Geriatrics and a committee member of the International Association of Gerontology and Geriatrics (IAGG). She is an Associate Professor of Humanities at Charles University (Prague) and a Visiting Professor at the University of the West of Scotland. Iva has been the Vice-Chairperson of Alzheimer Europe since 2010 and a Board member since 2008.

Charles Scerri (Malta)
Charles Scerri received his PhD degree in 2004 from the University of Dundee in Scotland and currently lectures on neuropharmacology at the University of Malta. He is the co-founder and General Secretary of the Malta Dementia Society, Honorary Secretary of Alzheimer Europe and member of the Mediterranean Alzheimer Alliance. He is also a member of the JPND Scientific Advisory Board and INTERDEM. In July of 2013, he was appointed as the National Focal Point on Dementia in Malta. Amongst his recent publications is the national dementia strategy document: “Empowering change: A National Strategy for Dementia in the Maltese Islands [(2015-2023)].”

Maria do Rosário Zincke dos Reis (Portugal) - Honorary Treasurer
Maria do Rosário has been practicing law in Portugal since 1987, with a focus on family law and the legal rights of people with incapacity. She is also a visiting Professor at the University of Aveiro, teaching “Legal Approach on Social Gerontology”. She served as Chairperson of Alzheimer Portugal during 2001-2012 and currently coordinates the association’s Training and Projects Department. In addition, she is a member of the JPND PPI (Patient and Public Intervention) Advisory Board. Maria do Rosário has been a member of the Alzheimer Europe Board since 2008 and the Honorary Treasurer since 2010.

Helga Rohra (Germany) - Chair of the European Working Group of People with Dementia
Helga Rohra completed her studies in languages and translation in Munich. After her studies, she worked as an interpreter. In 2007, she received a diagnosis of dementia and became a dementia campaigner. Her book “Stepping out of the shadow” and her webpage are pioneering elements in raising awareness about dementia.

In 2012, Helga was elected as the first Chairperson of Alzheimer Europe’s European Working Group of People with Dementia and represents this group in the Alzheimer Europe Board with full voting rights. In October 2014 she was re-elected for a second two year term.

Marie-Odile Desana (France)
Marie-Odile is the President of France Alzheimer, a posi-
tion she has held since 2010. Previously, she served as Vice President (2008) and Administrator (2006). She is also the former carer of her mother, who lived with Alzheimer's disease. During that time, Marie-Odile created an association of family caregivers of people with Alzheimer's disease in Aix-en-Provence. She joined France Alzheimer's Bouches-du-Rhône chapter in 2003 and has been the chapter President since 2004. Marie-Odile was elected to the Alzheimer Europe Board in October 2014.

**Sabine Henry (Belgium)**
Sabine Henry is the president of the National Belgian Alzheimer Association LINAL and also of Ligue Alzheimer ASBL, the association serving Belgium's French-speaking community. She trained as a social psychologist at the Palo Alto School and is a collaborator at the Faculty of Psychology of the University of Liège – the same career as her mother in law, who lived with Alzheimer's disease. Sabine was also the founder and Chairperson of the former “League of Health Care Users” (LUSS). Sabine was elected to the Alzheimer Europe Board in October 2014. She previously served as Vice-Chairperson from 2004-2010.

**Gerry Martin (Ireland)**
Gerry Martin is the Chief Executive Officer of The Alzheimer Society of Ireland, which he joined in May 2013. Prior to this, Gerry held leadership roles in permanent tsb for 15 years, including General Manager for the Bank’s branch network. Gerry holds an MSc (Management Practice) from The Smurfit Graduate School of Business (UCD) and is a Fellow of the Institute of Bankers in Ireland. In 2013 Gerry was appointed to the National Dementia Strategy Working Group which supported the Government with the launch of Ireland’s first National Dementia Strategy in December 2014. Gerry was elected to the Board of Alzheimer Europe in October 2014.

**Jim Pearson (UK - Scotland)**
Jim Pearson is Alzheimer Scotland’s deputy director of policy and is currently responsible for all of Alzheimer Scotland’s public policy engagement. This includes the involvement of people living with dementia and their carers through the Scottish Dementia Working Group and the National Dementia Carers Action Network. Jim has a background in welfare rights and a particular interest in promoting and protecting the rights of people living with dementia. He played a significant role in developing Scotland’s Charter of Rights, which puts human and other legal rights at the heart of every Scottish dementia strategy. Jim holds an MBA from Glasgow Caledonian University and joined the AE Board in 2014.

**Sirpa Pietikäinen (Finland)**
Sirpa Pietikäinen is a member of the European People’s Party in the European Parliament and a former Finnish Minister of the Environment. At the European Parliament, Ms Pietikäinen is a member of the Economic and Monetary Affairs Committee and is also a Vice-Chairperson of the European Alzheimer’s Alliance (EAA). In Finland, she is Vice-Chair of the Council of the national memory organisation (Muistiliitto). In her private life, she has been the carer of both of her parents. Ms Pietikäinen has been a member of the Alzheimer Europe Board since 2010.

**Jesús Rodrigo (Spain)**
Jesús Rodrigo has a degree in Sciences of Education and has spent his entire professional career in non-profit organisations, in positions of increasing responsibility. He is currently the Executive Director of the Spanish Confederation of Associations of Families of People with Alzheimer’s and other Dementias (CEAFA), a position he has held since 2005. He is working toward positioning CEAFA as a reference to the Central Government within the definition of a State Policy of Alzheimer’s disease. Mr Rodrigo was elected to the Alzheimer Europe Board in October 2014.

**Štefanija Lukič Zlobec (Slovenia)**
Štefanija has been the President of the Alzheimer Association of Slovenia since January 2014 and was Vice-President for two years before that. Štefanija became involved with dementia when her late husband began developing symptoms of Alzheimer’s disease at the age of 50. She was also actively involved in the establishment of the Working Group for the Preparation of the National Work Plan for Dementia. This Working Group was established in 2012 by the Ministry of Health. Štefanija studied Economics at the University of Ljubljana and recently retired from the Slovenian Ministry of Finance after a 20 year career. She was elected to the Alzheimer Europe Board in October 2014.
Prevention: a key element to control growth of new dementia cases

On 2 December 2014, MEP Keith Taylor hosted an Alzheimer Europe lunch debate on dementia prevention. Dr Miia Kivipelto from Sweden’s Karolinska Institutet showed how cognitive decline can be controlled by addressing multiple risk factors simultaneously.

Mr Taylor welcomed the delegates and opened the debate by saying that dementia is a challenge for every EU country but also for the EU as a whole. He noted that we cannot be complacent about dealing with the growing societal challenge that is dementia. He also stressed the need to continue developing and supporting solutions, in collaboration with national Alzheimer associations in every EU country. Mr Taylor then introduced Dr Kivipelto, the featured speaker for the debate.

“Cognitive decline can be prevented by addressing several risk factors simultaneously.”

Dr Miia Kivipelto, principal speaker and leader of the FINGER study

Keith Taylor, MEP (UK) and Vice-Chairperson of the European Alzheimer’s Alliance (EAA), hosted AE’s latest lunch debate in Brussels on 2 December 2014. This was the first EAA event with Members of the new European Parliament.

Dr Miia Kivipelto, Professor of Clinical Geriatric Epidemiology at Sweden’s Karolinska Institutet and Senior Geriatrician at Karolinska University Hospital, presented “Prevention of Dementia: Why & How”.

Preventing dementia at all ages

She began with an overview of the main types of dementia and noted a growing international recognition of the necessity to halt the epidemic growth of this non-curative syndrome. She also pointed out that high age is still the strongest risk factor for dementia and that dementia prevalence is increasing rapidly in ageing societies.

However, there is also some evidence of declining age-specific prevalence or incidence rates in the
last 10-15 years. While there is no specific proof, it is believed that this may correlate to higher educational levels, a decline in stroke incidence and vascular risk and a generally healthier lifestyle. This indirect evidence shows that prevention may be possible – and that controlling a combination of factors may be the key to controlling the dementia epidemic. The diagram below illustrates how this can be accomplished.

Managing lifestyle and vascular risk factors

Dr Kivipelto explained that it is essential to identify potential dementia risk factors as early as possible. Apart from genetic factors, there are environmental risk factors that may affect whether and when a person may develop dementia symptoms. These factors are present at various life stages, offering several possible targets and time windows for early interventions.

Dr Kivipelto commented that many of the factors are shared with cardio- and cerebrovascular diseases. In fact, the seven main dementia risk factors co-occur in around one third of all Alzheimer’s disease (AD) cases worldwide. This translates as 9.9 million potentially preventable cases out of an estimated 35.9 million cases (2010). Worldwide, a 10% reduction per decade in each risk factor would result in an 8.3% (8.8 million) reduction in AD cases, while a 20% reduction would see a prevalence decrease of 15.3% (16.2 million) by 2050.

The CAIDE (cardiovascular risk factors, ageing and dementia) risk score provides a way to track several of these factors. Dr Kivipelto helped to develop CAIDE, a tool that predicts the probability of late-life dementia based on midlife risk factors including age, sex, systolic blood pressure, body-mass index, cholesterol, physical activity and education level.

Such an approach is likely to lead to better results in preventing or postponing dementia onset.
Dr Kivipelto contrasted this with current practice, where randomised clinical trials tend to focus on a single risk factor. She believes that this limitation will continue to cause poor results, as dementia is clearly a multifactorial condition. This was further illustrated by the results of the FINGER study, which show that cognitive decline can be slowed down or even prevented by addressing multiple risk factors simultaneously.

FINGER (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) was led by Dr Kivipelto and aimed to reduce cognitive impairment in an at-risk population through a two-year multi-domain lifestyle intervention. The study began in 2009 with a group of 1,260 Finnish people aged 60-77. The participants were recruited from the existing FINRISK cohort, based on their level of cognition and CAIDE risk scores. The study included individual and group sessions on nutrition, exercise, cognitive training and social activity. Metabolic and vascular risk factors were monitored on a regular basis and regular health advice was provided throughout the trial period.

“Prevention will be a key element in controlling growth of new dementia cases.”

MIAA KIVIPELTO
The intervention period ended in February 2014 and the official study results are expected within the next few months. They will show the effectiveness of a multidomain intervention in reducing or preventing cognitive decline.

Dr Kivipelto noted that the participants were very active and motivated during the trial, with the result that several of the group activities are being continued. She added that she would like to pool the study results with those of similar studies in other countries, in the hope of identifying more people with dementia risk factors.

**European programmes for dementia prevention**

**EDPI:** The European Dementia Prevention Initiative is a collaboration of research groups from Finland, France, the Netherlands, Sweden and the UK. EDPI was launched in early 2011 as a self-funded initiative and the participants are involved in three ongoing randomised controlled dementia prevention trials in Europe. These are preDIVA (Prevention of Dementia by Intensive Vascular Care), MAPT (Multidomain Alzheimer Preventive Trial) and the FINGER study. The group is also leading HATICE, a new dementia prevention study using an internet-based intervention strategy.

www.edpi.org

**HATICE:** “Healthy Ageing Through Internet Counselling in the Elderly” aims to develop an interactive internet intervention platform to optimise treatment of dementia and cardiovascular disease in the elderly. It is funded by the EU’s FP7 programme. This intervention will be tested in a randomised controlled trial to investigate whether new cardiovascular disease and cognitive decline can be prevented. February 2015 saw the launch of a pilot in Finland and the Netherlands to evaluate the functionality of the platform. Each country will recruit 20-30 participants to test the platform and give feedback on their experiences.

www.hatice.eu

**MIND-AD** stands for “Multimodal preventive trials for Alzheimer’s disease: towards multinational strategies”. This new project is financed by the JPND and will be coordinated by Dr Kivipelto. The other project partners are the University of Eastern Finland, INSERM (France), the University of Amsterdam (Netherlands) and Universität des Saarlandes (Germany). Alzheimer Europe will also participate.

**Alzheimer Europe presents new publications**

Dr Kivipelto was followed by AE Chair Heike von Lützau-Hohlbein, who presented two recently published AE publications. The 2014 Dementia in Europe Yearbook is a comparative report on national policies and practices. It addresses different aspects of the pathways to timely diagnosis of dementia and of the post-diagnostic care and support available to individuals living with dementia in 30 European countries. The other new report is about the ethical dilemmas sometimes faced by people with dementia and their carers. In addressing ethical dilemmas, the authors focus on some of the more problematic aspects of living with dementia but with the positive aim of trying to make such issues less of a problem.

Ms von Lützau-Hohlbein also presented the Glasgow Declaration, which was launched at the Alzheimer Europe Conference in October 2014. In broad terms, the Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Mr Taylor joined Ms von Lützau-Hohlbein in thanking Dr Kivipelto and all the delegates for their participation and support.

Delegates at the lunch debate included Irish MEPs Nessa Childers and Deirdre Clune, along with representatives of MEPs Biljana Borzan (Croatia) and Sirpa Pietikäinen (Finland). There were also representatives from the European Commission, the French Permanent Representation to the EU, the pharmaceutical industry and representatives from 11 Alzheimer Europe member associations.

Alzheimer Europe’s next lunch debate will take place in June 2015 at the European Parliament.

“A substantial proportion of Alzheimer’s disease cases are potentially preventable.”

MIIA KIVIPELTO
AE presents the Executive Board of the European Alzheimer’s Alliance

Alzheimer Europe presents the new leaders and objectives of the European Alzheimer’s Alliance in the European Parliament

Since 2007, greater awareness about the challenges of dementia and Alzheimer’s disease has led to an impressive number of European and national developments. This can be attributed to the coordinated efforts of the members of the European Alzheimer’s Alliance in the European Parliament, Alzheimer Europe and its members.

The Alliance was set up in 2007 with the aim of influencing the European agenda in the field of public health, research and social policies. It is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) committed to support Alzheimer Europe and its members to make dementia a public health priority in Europe. Today, the Alliance can count on the support of 86 members from 26 Member States and 6 political groups. It is gratifying to see that, for the first time, all Irish and Slovenian MEPs are members of the Alliance. We hope other countries will follow suit.

Despite the great achievements of the past years, a lot still remains to be done to answer the needs of the nine million Europeans who have dementia and those of their carers. During this new mandate, the work of the Alliance will continue and be largely articulated around Alzheimer Europe’s political priorities embedded in the “Glasgow Declaration”.

Alzheimer Europe and its members invite all MEPs to join the Alliance as an indication of their support to our cause. Their contributions are on a voluntary basis and all suggestions are welcome.

As part of its awareness-raising activities, Alzheimer Europe will continue to communicate widely about the Alliance and its members’ engagement in all its communication streams (newsletter, magazine, Facebook and Twitter).
Alzheimer Europe and the dementia community warmly thank all MEPs who have been instrumental in the setting up of the Alliance and supported its activities over the years.

The Alliance Bureau

Françoise Grossetête (EPP, France) was one of the first MEPs to support the setting up of the Alliance and has been its Chair since 2007. Her unfailing engagement and political work at European and national level has greatly influenced the European agenda and the preparation of the French Alzheimer Plan 2008-2012.

Nessa Childers (S&D, Ireland), Vice-Chair, has actively contributed to raising awareness by organising events at European and national level, working very closely with The Alzheimer Society of Ireland.

Marisa Matias (GUE-NGL, Portugal), Vice-Chair for a second mandate, has relentlessly included dementia in her parliamentary work, participated in national discussions to devise a national strategy and participated in Alzheimer Portugal memory walks.

Sirpa Pietikäinen (EPP, Finland), Vice-Chair, has been a dedicated dementia campaigner, as a member of the Finnish Alzheimer Association and through her work in the European Parliament. In 2010, she was elected to sit on the Alzheimer Europe Board.

Frédérique Ries (ALDE, Belgium), Vice-Chair, has strong links with the dementia community in Belgium and has actively supported the work of the Alliance in her parliamentary work. She further took the opportunity of World Alzheimer’s Day to raise awareness about the disease at EU level.

Keith Taylor (Greens/EFA, UK), Vice-Chair, has greatly supported the work of the Alliance and the Alzheimer’s Society in the UK and contributed to raising awareness about the challenges of dementia at European and national level.

www.alzheimer-europe.org/Policy-in-Practice2/European-Alzheimer-s-Alliance
The European Alzheimer’s Alliance in action

The European Alzheimer’s Alliance is a group of MEPs willing to make dementia a health priority in the European Parliament. Alzheimer Europe gives an update of their recent activities.

Nessa Childers, Alliance Vice-Chair (Ireland), hosted a “meet and greet” event between The Alzheimer Society of Ireland and the Irish MEPs in the European Parliament on 2 December. The aim of this event was to give MEPs an opportunity to meet with members of The Alzheimer Society of Ireland team, while giving the organisation an opportunity to thank them in person for their support for people with dementia and their carers.

All Irish MEPs have signed the European Dementia Pledge and this event provided a valuable opportunity to revisit the pledge. It was also a good opportunity to update MEPs on the latest regarding dementia care and to discuss how we can continue to make dementia a European priority.

Martina Anderson, Lynn Boylan, Matt Carthy, Mairead McGuiness, Marian Harkin and Liadh Ni Riada all took part in the event, while Brian Hayes was represented by his assistant. Ms Childers and Deidre Clune also attended the lunch debate organised the same day by Alzheimer Europe on the prevention of dementia.

The Alzheimer Society of Ireland said it would build on the success of this event by hosting another in early 2015.

On 1 October, Françoise Grossetête, Chair of the European Alzheimer’s Alliance (France), met a group of people with dementia and their carers in the European Parliament. This event took place during the “Meeting without Frontiers” (“Rencontre sans frontières - Begegnung ohne Grenzen”), an initiative co-organised by France Alzheimer Vaucluse and Alzheimer Gesellschaft München (Germany).

The participants of this initiative included people with dementia, their carers and representatives of the local Alzheimer associations. They were delighted to meet Ms Grossetête and thanked her for taking the time to hear their testimonies. They were keen to explain their needs and suggest areas of action for the policy makers. In turn, Ms Grossetête gave them insights into her work on dementia in the European Parliament and explained how the European institutions dealt with dementia.

The participants also met Magda Aelvoet, former Belgian Minister and MEP and sitting Board Member of the King Baudouin Foundation (Belgium). Ms Aelvoet presented the Foundation’s work in the field of dementia.

In September, Andrey Kovatchev (Bulgaria) regretted he could not take part in the events organised by
Alzheimer Bulgaria on the occasion of World Alzheimer’s Day. He nevertheless sent the organisation a letter in which he praised the work of the organisation and acknowledged the problems faced by people with dementia and their carers in Bulgaria.

Mr Kovatchev stressed that healthcare was a personal priority and that the organisation, people with dementia, their carers and the professionals could rely on his support within the European Parliament to overcome the obstacles people with dementia and their carers face when confronted by the disease. He added that ensuring access to good quality healthcare for patients must be a European priority.

As in previous years, Merja Kyllönen (Finland) visited a dementia home in Finland, dressed-up as Santa Claus on Christmas Day. She has indicated that each visit has been a rewarding experience to her while bringing life and fun to the home residents.

In November 2014, Sirpa Pietikäinen, Alliance Vice-Chair (Finland), attended a seminar on the topic of memory diseases among people still of working age. The seminar was organised by the Finnish Memory organisation Muistiliitto. Ms Pietikäinen pointed out the need to raise awareness about this issue and the need of flexibility in workplaces to ensure that a worker with a memory disease can continue working within his/her limits for as long as possible.

Throughout the autumn, Ms Pietikäinen also mentored the project on “Remote carers”. The project was organised by a local memory organisation in the city of Oulu. She gave insights on her own role as a “half remote carer”: during her work days in Brussels she is in close contacts with the carers looking after her mother back in Finland.

Keith Taylor, Alliance Vice-Chair (UK), hosted an Alzheimer Europe (AE) lunch debate on 2 December. Miia Kivipelto, Professor of Clinical Geriatric Epidemiology – Karolinska Institute and Senior Geriatrician – Karolinska University Hospital, Sweden, presented some recent findings about the prevention of dementia. Chairperson Heike von Lützau-Hohlbén presented AE’s Yearbook 2014 comparing the national care pathways for people with dementia living at home in Europe. She also presented Alzheimer Europe’s Glasgow Declaration – which calls for the creation of a European Dementia Strategy and national strategies in every country in Europe – and called upon all MEPs to express their support by adding their signatures. Mr Taylor became the first MEP to sign the Glasgow Declaration.
The European Working Group of People with Dementia welcomes new members for second term of office

In October 2014, the EWGPWD began its second term of office by electing a new Board and preparing activities for 2015.

The European Working Group of People with Dementia (EWGPWD) began its second two-year term of office at a meeting held on 19 October 2014 prior to the 24th Alzheimer Europe Conference in Glasgow. The meeting was attended by eight members of the group, five carers and two representatives from Alzheimer Europe. The group welcomed two new members, prepared for the Conference, elected a new Executive Board and planned activities for the year ahead.

Looking back at a successful first term
The meeting was led by Helga Rohra, Chairperson of the EWGPWD, who began by welcoming two new members: Hilary Doxford (nominated by the UK Alzheimer’s Society) and Helen Rochford Brennan (nominated by The Alzheimer Society of Ireland). Helga also thanked the group members and their carers for their active participation and dedication during the two first years of the group’s existence. She expressed her admiration for everything the group had accomplished and noted that they seemed to have grown, both personally and as a group. The meeting attendees joined to pass on their best wishes to the members who had been unable to attend. They also wished all the best to those who would no longer be part of the group: Stig Atle Aavik (Norway), Jean-Pierre Frognet (Belgium), Ingegärd Nousard (Sweden), Dermod Slevin (Ireland) and Daphne Wallace (UK - England).

Preparing for the Alzheimer Europe Conference
As in 2013, the EWGPWD members had planned many activities during the AE conference. As a group, they would operate a dedicated booth while Helga, Nina, Agnes (along with her daughter Donna) and Jean-Pierre had also prepared presentations for the plenary and special sessions. During the meeting, they went over their schedules and rehearsed their talks. This was followed by a guided tour of the conference venue, including the meeting room and rest area that were reserved for people with dementia.

Election of the new Executive Board
The members of the group voted in the new Executive Board as shown below. Helga Rohra was unanimously re-elected for a second term. The office holders will serve until 2016.

Chairperson: Helga Rohra (Germany)
Vice-Chairperson: Helen Rochford Brennan (Ireland)
Vice-Chairperson: Hilary Doxford (UK - England)
Vice-Chairperson: Agnes Houston (UK - Scotland)

Activities in 2015
The group members agreed to identify clear objectives for the year, along with an evaluation to gauge their effectiveness at the end of the year. They will also continue to chronicle their activities on the AE website. The EWGPWD will hold its next meeting in the early months of 2015 in Luxembourg.
Delegates at the EWGPWD meeting in Glasgow

About the EWGPWD

The European Working Group of People with Dementia was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with members electing their own Board and setting an agenda of activities. The Chairperson of the EWGPWD is also an ex-officio member on the Board of Alzheimer Europe with full voting rights.

Contact: info@alzheimer-europe.org
www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia
Alzheimer Europe presents three new publications for 2014

AE’s 2014 reports focus on care pathways, ethical dilemmas and good continence care.

AE’s 2014 Yearbook focuses on care pathways for people with dementia living at home

Alzheimer Europe's new comparative report contains information on national policies and practices addressing different aspects of the timely diagnosis of dementia and of the post-diagnostic care and support available to individuals living with dementia in 30 European countries.

The report outlines the main similarities and differences in the processes that people need to follow to be diagnosed and to access the support and care in these countries. It also highlights some of the gaps and main challenges that these individuals may experience. In doing so, the report shows that there is not always a single, linear pathway that may suit every person and every country.

The pathways to get a diagnosis of dementia are complex and are likely to be multifactorial. Many people living with dementia in Europe are still not diagnosed and often the diagnosis comes too late. Every person with dementia has the right to a high quality, timely diagnosis, if they so wish. There is now clear indication that people can live well with dementia. Nevertheless, without the right support and care this may not be possible. Getting the necessary support and care depends on several factors.

Among them, availability and appropriateness are key, as are the informational aspects and the navigability of the complex health and care systems involved in the diagnosis and care of people with dementia.

Alzheimer Europe is very grateful to the member associations that provided and reviewed the bulk of the content of this report. Jean Georges, AE’s Executive Director, said: “We hope that this report will enable readers to gain an impression of the complexities of the different dementia care pathways which currently exist in Europe. We also hope that it can provide the basis for further discussion and development of care pathways in these countries.”

AE’s new report focuses on the ethical dilemmas faced by carers and people with dementia

This report is about the ethical dilemmas sometimes faced by people with dementia and their carers. In addressing ethical dilemmas, the authors focus on some of the more problematic aspects of living with dementia but with the positive aim of trying to make such issues less of a problem.

Having dementia or living with someone who has dementia often means being confronted with new situations, experiences and challenges. Ideally,
people with dementia, as well as their family, friends and carers, will receive appropriate support, be valued and continue to live meaningful lives within their community. However, living with dementia is not always easy.

This publication is mainly written for people with dementia and for those who care for and about them. It aims to help them to recognise, understand and assess the issues at stake, adopt the best approach for them and the other people involved and hopefully feel at peace with themselves in the knowledge that they have done their best. The report might also serve as a workbook for voluntary workers or new employees or perhaps for discussion groups of informal carers facilitated by an expert.

The way an ethical dilemma is resolved might not always be the outcome one would ideally have hoped for, but it may be the best outcome possible for the people involved and in the particular circumstances.

Part 1 of this report provides background information about ethics and ethical dilemmas. Part 2 focuses on specific ethical dilemmas and is divided into seven sub-sections covering the whole course of dementia. In each sub-section, after a brief introduction, there are one or two short stories reflecting situations and dilemmas often experienced by people with dementia and family members/carers. This is followed by an ethical commentary on the key ethical issues involved. Part 3 describes an ethical approach which may be helpful when reflecting on ethical behaviour and attitudes. Finally, the report includes general guidance on how to approach ethical dilemmas and ideas about how to avoid some common mental traps in thinking about them.

Dianne Gove, Chair of AE’s Ethics Working Group, wishes to thank all the members of the group who gave freely of their time, expertise and enthusiasm to make this report a valuable resource.

AE releases report and guidelines on continence care

“Improving continence care for people with dementia living at home” provides information about incontinence and dementia, explaining how the continence care of people with dementia living at home should be understood in the more global context of the long-term care of people with complex care needs. It also explores the experience and challenges faced by people with dementia and continence problems who live at home and also those of informal carers. This is followed by statements from people with dementia and their carers, highlighting their needs and desire in relation to continence care and in the wider context of their rights as equal and valued citizens.

The guidelines are designed to address a wide audience and are hopefully accessible to many people with dementia and their carers. They may also serve as a useful source of support or tool to help health and social care professionals to consider some of the issues which are specific to the continence care of people with dementia within the community setting, as opposed to residential or nursing care. Dianne Gove, Director for Projects for Alzheimer Europe, said: “Continence care must respond to the needs and wishes of people with dementia to travel and to play an active role in the local community and wider society.” She also wishes to thank all the experts that were involved for their invaluable contributions.

This project was a joint effort between Alzheimer Europe and SCA. Alzheimer Europe is very grateful for the funding received from SCA and for the fruitful collaboration between the two organisations.

All three publications are freely available for download on Alzheimer Europe’s website.
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Luxembourg continues to expand and improve services for people with dementia

Corinne Cahen, Minister for Family Affairs and Integration, speaks to Alzheimer Europe about recent developments in caring for people with dementia in Luxembourg.

Alzheimer Europe (AE): Luxembourg’s national dementia plan was launched in May 2013. What have been the main achievements since then?

Corinne Cahen (CC): Dementia represents a growing challenge for our society. Today, more than 6,000 persons are affected in Luxembourg; estimations speak of 8,500 in ten years. Considering that for one person who suffers from dementia, more or less three members of his family and friends are indirectly affected; more or less 30,000 persons will be affected by dementia by 2025!

The Luxembourg government wants to guarantee these people the best possible quality of life as well as provide help for their families. That’s why we have developed the national dementia plan, which defines the priority measures for the coming years. Its aim is to improve medical coverage and care in order to preserve the quality of life, the autonomy and the rights of the people who suffer from dementia. We want to allow dementia patients to live their remaining years with dignity. The action plan also pays particular attention to the support of the family and circle of acquaintances.

In the last few months, various projects have been launched:

• An identification sheet in case of the disappearance of people affected by dementia has been realized in association with the Police and different actors of the sector of the elderly. This identification sheet records all the data of an elderly person and can, in case of their disappearance, help to find the person. The Ministry of Family Affairs and Integration will set up a model of training in psychology-geriatrics, which addresses nurses and assistants working in the ambulatory and stationary fields.

• A website completely dedicated to dementia has also been created.

AE: The Family Ministry’s new website on dementia was launched in October 2014. Can you give us an overview of its content?

CC: The website launched on 1 October 2014 at www.vivreavecunedemence.lu (French language) or www.liewematdemenz.lu (German) gives affected persons, their families, as well as the general public a lot of useful information on dementia.

The content of the site is structured following the different stages of the sickness, from the first signs to diagnosis and on to treatment.

The site is made very interactive thanks to video testimonies of affected persons and professionals working in this field in Luxembourg.

The site gives answers to many important questions (what is dementia, what are the signs, what are the treatments, who to contact, etc.) and con-
tains numerous links to associations working in this field, as well as other national and international sites on the same subject.

**AE**: What is the public perception of the website? What kind of feedback have you received?

**CC**: A lot of persons have already visited the site and their feedback is very positive. Affected persons and their families are happy to find all the information they need at one address.

But the site is also very important for the general public. Dementia unfortunately remains a taboo subject and it is important to raise awareness for dementia and eliminate the taboo surrounding it.

The aim is to better inform citizens about the disease, so they have a better understanding of the difficulties which affected people and their loved ones face.

But improving knowledge on dementias also helps as a preventive measure, to favour the establishment of early diagnosis, which results in better care being provided.

I would like to note that people can also inquire more about dementia by e-mail (info@liewematdemenz.lu) or by telephone (Seniorentelefon 2478 6000).

**AE**: What were the next steps for the website and the other elements of the national strategy?

**CC**: The site will be improved by a specialised agency, following the feedback we have received over the last few months. Moreover, a mobile version will be developed.

We will continue to inform people about the site, via the press, social media, but especially via our partners who are directly in contact with elderly persons, such as retirement homes, Senior Citizens Clubs, etc.

Different events will be organised in the framework of an awareness campaign on dementia. For example, a song about dementia will be composed by a popular Luxembourgish artist and will be presented for the very first time at the “Rock um Knuedler 2015”, one of the biggest open air festivals in Luxembourg.

We are also discussing the possible creation of an information centre on dementia with ALA (Association Luxembourg Alzheimer).

In addition, we continue to encourage associations and other actors in the sector to offer specialised activities to people affected by dementia or open their normal activities to them. It is important to allow persons with dementia to continue to take part in social life like any other member of our society.

We have to allow each individual to continue to be who they were whilst helping them cope with the changes caused by dementia.
Greek Parliament approves national dementia strategy

In September 2014, the final draft of the Greek Dementia Strategy was presented to the public by the Athens Association of Alzheimer’s Disease and Related Disorders, in collaboration with the Greek Ministry of Health. In December, the Greek Parliament enacted a law to ensure the implementation of the strategy. Dr Paraskevi Sakka, President of the Association, reports on the event.

Improving the lives of 600,000 people affected by dementia

According to the latest figures, there are more than 200,000 people living with dementia in Greece and over 400,000 caregivers looking after them. This number will increase dramatically in the years to come, making dementia one of the most crucial medical, societal and economic challenges in Greece – as in the rest of the world. Despite the lack of a national dementia strategy, Greece has organised and implemented several individual dementia programmes since 2006. In particular, the Greek Alzheimer Associations have actively supported patients and their families and conducted awareness campaigns for the public. Unfortunately, the services provided are woefully inadequate compared to actual needs. Overall, the main problem is a lack of social care facilities, long stay institutions and end of life centres throughout Greece.

Recognising the magnitude of the issue and responding to lobbying efforts from the Alzheimer Associations, in October 2013, the Greek Minister of Health assigned a working group to develop a National Dementia Action Plan. The working group was headed by Dr Sakka and consisted of specialised doctors and other health professionals, caregivers, lawyers, health economists and members of the Alzheimer Associations. In September 2014, the group presented the final draft of the strategy to the Ministry of Health after a consultation period.

Launch event attracts over 2,000 delegates

On 26 September, on the occasion of World Alzheimer Month, the Athens Association of Alzheimer’s Disease and Related Disorders, in collaboration with the Greek Ministry of Health, organised a launch event to officially present the final draft of the Greek Dementia Strategy to the public. The launch event was very successful and attendance was much higher than expected: more than 2,000 people with dementia, their families and members of the public came to witness this much-awaited event.

Prominent delegates included the Minister of Health and other high ranking government officials, as well as representatives of most political parties and the Church. There were also delegates from the Greek Alzheimer Associations and other organisations, including Iva Holmerova, Vice Chairperson of Alzheimer Europe.

The event began with a one-act theatrical piece about the challenges of everyday life faced by a woman with dementia and her caregiver husband. The piece was highly praised by the audience, with very realistic and moving performances by the actors. The first speaker was Ms Katerina Papakosta, Deputy Minister of Health. She gave an inspiring speech addressing the unmet needs of people with
dementia in Greece, with a particular focus on the lack of social facilities and services in the country. She affirmed the government’s commitment to develop legislation to support patients’ rights and to provide funding to implement the Strategy. Members from all political parties in the Greek Parliament also declared their willingness to support the implementation of the Dementia Strategy. Ms Papakosta was followed by John Kyriopoulos, Professor of Health Economics at Greece’s National School of Public Health and an expert in dementia economics. Prof. Kyriopoulos presented the various pressing financial and social aspects of Alzheimer’s disease. The star performer of the evening was clearly Mr Palliginis, who has lived harmoniously with his beloved spouse for over 40 years. He gave an enthralling account of living with her and also her deterioration over a period of several years after a dementia diagnosis.

These events were coordinated by a team of popular Greek television reporters, who managed the programme and then moderated a panel discussion. This panel included scientists, politicians, caregivers and journalists who commented on the evening’s presentations and encouraged dialogue with the audience. As a result, caregivers’ voices and complaints were heard, priorities were set and promises were delivered in a very enthusiastic atmosphere.

This was the first time that a dementia event was so widely publicised in the Greek media, providing an excellent opportunity to promote public awareness and interest in the growing need to develop a dementia strategy in Greece. Dr Sakka outlined the key points of the Greek Dementia Action Plan and declared that it is high time for the country to design cost-effective policies, to establish a comprehensive network of health and social care services and generally improve the quality of life of people with dementia and their families. Several weeks later, in December 2014, the Greek Parliament enacted a law to ensure the implementation of the strategy.

The National Observatory for Dementia and Alzheimer’s disease

This law, supported by the entire Greek political spectrum, authorises the establishment of an independent strategic public institution: the National Observatory for Dementia and Alzheimer’s disease. The Observatory will act under the guiding principles of respect, support and promotion of patients’ rights and will fulfill the following objectives:

- Ensure the implementation and subsequent updates of the National Action Plan.
- Provide official guidance to the Parliament, the Ministry of Health and other public authorities on legislative and policy measures related to dementia.
- Coordinate and promote the work of public and non-governmental agents and associations, in order to ensure efficient services to patients and their caregivers.
- Provide specific guidance for organising and promoting the national policy in research and education.

The Observatory has an interdisciplinary profile, engaging health professionals, scientists, caregivers and other members with specific expertise. Their five-year mandate will be renewable once, but its operation may not be affected by governmental changes.
France launches a neurodegenerative diseases strategy

Alzheimer Europe presents the new French “Neurodegenerative Diseases Plan 2014-2019” that was released in November 2014.

In France, over 850,000 people have Alzheimer’s disease or another form of dementia, 150,000 have Parkinson’s disease and over 85,000 have multiple sclerosis. The quality of life of people with these diseases and their carers is hugely impacted.

The rationale of the new plan is enshrined in the national health and research strategy. It stems from the work already done on disability and the steps forward that the new law on the adaptation of society to ageing will allow. The evaluation of the last Alzheimer Plan (2012-2014) made in 2013 recommended to keep the momentum of the actions undertaken and to open the initiative to other similar diseases.

Neurodegenerative diseases (NDDs) share many characteristics: they are disabling, often lack a cure and demonstrate common development mechanisms which need to be better understood. They are all medical and social challenges to policy makers.

The plan will nevertheless recognise the specificities of each disease. This transversal approach is both an innovation and a challenge, at the frontier between a targeted health strategy and a global strategy. The plan will create synergies and consensus around the common issue of neuronal protection.

The Plan has four strategic areas that cover 96 measures:

**Provide life-long care and support in the whole country**

Forty measures will seek to provide equal access to a personalised and life-long care pathway early in the disease development, improve the early identification of symptoms, the quality of the diagnosis and its announcement, as well as train professionals to improve the quality of their response.

They will raise awareness and develop easy-to-use tools that will help individuals identify the early symptoms and seek early medical advice, facilitate early access to neurologists who will devise a care plan, provide professionals with improved diagnostic tools and the capacity to propose a post-diagnosis package, promote the role and support of disease-specific associations, act early on risk factors to avoid health degradation, promote synergies between disease-specific professionals, ensure cross-country tailored support through experts centres and networks, improve home, medico-social and end-of-life care and promote a disease-friendly society.

**Adapt society to the challenges of NDDs and decrease their individual and societal impact in daily life**

Nineteen measures will seek to improve a person’s capacity to live with the disease, improve societal acceptance of the disease and fight stigma, ensure that society is inclusive and respectful of the people affected by the disease, stimulate social and proximity links to avoid isolation, support family carers, tackle the financial consequences of the disease, promote actions that will enable people with the disease work longer, promote autonomy at home and in society, create solidarity and recognise individual rights and ethical reflection as levers of change.

Social innovation (supported by the silver economy), the use of new technologies, adaptation of living environments to promote autonomous living and mobility improvements should stimulate interactions and social links to fight isolation. An evaluation of the needs of informal carers will
be carried out prior to providing them with adequate support such as training, respite or psychological support.

Alleviating the economic consequences of the disease will include adaptation of the working conditions for people with the disease, access to substitute income when ceasing a professional activity and the engagement of all parties.

**Develop and coordinate NDDs research**

Cross-fertilisation of research in NDDs is a major component of this plan. Twenty-six measures should improve coordination of pre-clinical, clinical, epidemiological, human sciences and social research.

Several institutes working in neurosciences, cognitive sciences, neurology, psychiatry, public health and health technologies will form the Steering Committee in charge of implementing the plan. The committee will develop a research structure and tool to implement the plan. This will reinforce translational and clinical research in NDDs, as well as identify and label regional educational and research excellence centres that ensure a care-research continuum. The committee will ensure that platforms, cohorts and tools dedicated to NDDs research are involved and that their actions are coordinated.

Promising international sites will be identified and international cooperation developed in the framework of the International Network of Centres of Excellence in Neurodegeneration. France will continue to be involved in JPND, the joint programming of research in NDDs, and in the Global Action Against Dementia initiated by the G7 countries. A positive image of research will be developed for the public, while opportunities to participate in clinical trials will be offered to people with the disease and their family. There will also be a database containing stories from researchers, patients, carers and children confronted by affected parents or grandparents. Its aim will be to support research in social and human science on NDDs.

To better understand NDDs, cohorts will be reinforced and the interoperability and access to databases will be facilitated. Brain donations will be promoted and neurodegenerative disease risk factors will be identified in population-based studies. Biomarkers and imagery research will be expanded and new tools will be developed for cognitive and behavioural follow-ups. In addition, a “Big Data” group will be set up: this will become the link between national initiatives in the field of “omics” investigative methods.

Specific attention will be paid to understanding NDDs, in order to identify therapeutic goals and initiate innovative clinical trials. The efficacy of non-medical interventions will be tested and a multimodal approach for pain management will be promoted.

**Ensure that the plan inspires public policies and health democracy**

Eleven measures will help develop partnerships between patient organisations and national and local actors, the understanding and resolution of problems linked to collective representation of people affected by a disease and the promotion of joint actions between local health agencies and patient organisations.

The plan aims to promote European and international cooperation to find innovative solutions, such as the exchange of best practices, the continued adoption of the ALCOVE recommendations and the activities of the Global Action Against Dementia group. In addition, the plan must be compatible with the “Open Data” strategy.

The governance of the plan relies on highly recognised professionals who will lead its implementation: Prof Michel Clanet and Prof. Joël Ankri (respectively President and Vice-President of the Follow-up Committee) and Prof. Etienne Hirsch (President of the Steering Committee). The Follow-up Committee rallies patients and carers organisations, representatives of professionals and specialist organisations, health, social and support services, local actors, research bodies and policy representatives from various DGs and health administrations.

*The entire text of the plan can be found on the following website:* www.social-sante.gouv.fr/IMG/pdf/Plan_maladies_neuro_degeneratives_def.pdf
On 14 November 2014, the Italian government hosted a conference entitled “Dementia in Europe: a challenge for our common future” in Rome. Dr Charles Scerri, Honorary Secretary of Alzheimer Europe (AE) and a speaker at the conference, reports on the proceedings.

The aim of this conference was to introduce activities on dementia on an EU level together with seeking a wider approach that includes the contribution of other international institutions and bodies in order to maximise the possibility of larger cooperation. The audience was welcomed by a representative of the Italian Minister for Health followed by an opening speech by John Ryan, Acting Director for Public Health, Directorate-General Health and Consumers of the European Commission. The conference had five themes and the topics and presenters are shown below.

**EU dementia activities**

Core results and major findings from the ALCOVE Joint Action
Pierre Krolak-Salmon, from the French coordination office of the “Alzheimer Cooperative Valuation in Europe” Joint Action, described the project that brought together 30 partners from the health and scientific authorities of 19 countries during 2011-2013. Their aim was to improve knowledge on dementia and its consequences, as well as promote the exchange of information to preserve health, quality of life, autonomy and dignity of people living with dementia and their carers in Europe.

**The EU Joint Programme—Neurodegenerative Disease research (JPND)**
Adrianna Maggi, JPND Vice-Chairperson, outlined the activities of the research consortium. JPND is the largest global neurodegenerative research initiative, with 28 participating countries from the EU and beyond. It is based on the principle that we cannot tackle neurodegenerative diseases by acting as single countries. The JPND partners seek to increase coordination of national research programmes to improve impact and effectiveness.

**Innovative practices identified by the European Innovation Partnership on Active and Healthy Ageing (EIP AHA)**
This was presented by Jorge Pinto Antunes, from the European Commission’s DG SANCO. The EIP AHA gathers public and private shareholders that work on shared interests, activities and projects to find solutions that meet the needs of the ageing population. There are three priority action areas: prevention, screening and early diagnosis; care and cure; active ageing and independent living.

**International dementia activities**

**WHO Perspective**
Tarun Dua, from the WHO’s Mental Health and Neuro-Degenerative Disorders Unit, gave a global overview of dementia prevalence rates and economic impact. She also outlined the WHO’s dementia activities, such as the recent “Dementia: a public health priority” report. Currently, the organisation is mapping the directions of dementia research, with an aim of identifying improvements in health system efficiency and intervention delivery.

**Follow-up of the 2013 G7 Commitments**
Dennis Gillings, World Dementia Envoy, identified lack of knowledge, isolation and inadequate funding as the main barriers to progressing on dementia
research. He also mentioned that intense competition among healthcare priorities makes it difficult for policymakers to invest heavily in a dementia crisis 20 years in the future. However, the corporate sector has no such constraints and there are now 300+ agents in development for dementia. Dr Gillings suggested that measures such as tax incentives and accelerated regulatory pathways can be used to encourage and accelerate further industry investment. He ended his presentation with the reminder that “our goal must be to deliver a generation of progress in a decade.”

The role of patient and carer associations at international level

Dr Scerri’s presentation focused on AE’s role in making dementia a European priority. This includes such initiatives as the Paris and Glasgow Declarations and participation in EU programmes: ALCOVE, JPND, IMI – the Innovative Medicines Initiative, Horizon 2020 and EIP AHA. AE also operates the European Dementia Observatory and produces reports on consent, proxy-decision making and dementia policies in different countries. The European Alzheimer’s Alliance (a group of MEPs that is growing in number), the Dementia Ethics network and the European Working Group of People with Dementia (EWGPWD) are further examples of AE’s work.

The new Italian National Strategy

Teresa di Fiandra (DG Prevention, Italian Ministry of Health) presented the country’s new national plan on dementia. The plan was developed by the Ministry in close cooperation with the regions, the NIH and the three major national patient/carer associations. The plan, which was approved in October 2014 by the state and the regions, will be implemented according to local situations and monitored at national level.

Strengthening activities at national level

This was followed by a series of presentations from countries that are developing or renewing their national dementia plans. Finland and Sweden were covered by Francesca Mangialasche (Karolinska Institutet, Sweden) while the Maltese plan was presented by Dr Scerri.

The way forward

The new European Joint Action on Dementia was presented by Geoff Huggins, Director of Health and Social Care Integration, Scottish Government. The new JA will have three areas of focus: diagnosis and post-diagnostic support, secondary prevention and care coordination. Due to launch in March 2015, the JA aims to develop principles to improve the quality of care and support offered to people with dementia and their families and carers.

Prof. Ninoslav Mimica (Alzheimer Croatia) attended the conference as a representative of the Ministry of Health of the Republic of Croatia. Dr Luisa Bartorelli (Alzheimer Uniti Onlus) and Gabriella Salvini Porro (Federazione Alzheimer Italia) jointly delivered a presentation on the role of patient and carer associations in the Italian context.

The conference was closed by Vito De Filippo (Undersecretary of State at the Italian Ministry of Health) and Jürgen Scheftlein from the European Commission’s DG Sanco. The need of further collaboration and the possibility of a follow-up to this conference were addressed by Latvia and Luxembourg, the countries that will take over the EU Presidency in 2015.
European Commission reports on key dementia activities since 2009

In October 2014, the Commission published a report on the implementation of its 2009 Communication on a European initiative on Alzheimer’s disease. Alzheimer Europe presents the results and how they were implemented at EU and national levels.

The Communication aimed to set out actions that would support the Member States in tackling dementia in four strategic areas: early diagnosis and promotion of well-being with age, epidemiological knowledge of dementia and coordination of research, best practices for care of people with dementia and respect of their rights.

Early diagnosis of dementia and promotion of well-being with age

Under its work package “timely diagnosis of dementia”, the 2011-2013 ALCOVE Joint Action on dementia developed five strategy models to explain how health policy can plan and benchmark service provision for the diagnosis of dementia at national and local level. In 2013, the Commission’s Joint Research Centre supported corresponding initiatives and developed quality assurance tools to enable reliable measurements for the diagnosis of Alzheimer’s disease.

IMI (Innovative Medicines Initiative), a public-private partnership between the European Commission and the pharmaceutical industry, dedicated EUR 53 million to EPOC-AD, a European platform to facilitate proof-of-concept for the prevention of Alzheimer’s disease.

The European Innovation Partnership on Active and Healthy Ageing, launched in 2011, will develop innovative solutions for people with dementia spanning the prevention of frailty and cognitive decline, supportive environments and ICT solutions. The European Pact for Mental Health and Well-Being of 2010 also includes dementia. The associated Joint Action launched in 2013 will develop a common framework of action on mental health and well-being by 2016.

The “e-Health Action Plan 2012-2020” supports research, development and innovation in the field of diagnosis of neurodegenerative diseases.

Epidemiological knowledge and coordination of research

ALCOVE’s work package on “Epidemiological data on dementia” presented an improved estimate of the prevalence of dementia in the EU population and identified a set of recommendations for future data collections of estimates of dementia prevalence.

ALCOVE also studied the use of antipsychotics in people with dementia in nursing homes. A shared “Toolbox for Antipsychotic Limitation in Dementia” was developed to address the safety and ethical issues around the use of antipsychotics.

The Joint Action on European Community Health Indicators Monitoring (ECHIM) developed a specific indicator on dementia and other health services indicators where dementia is one of the diseases monitored. The feasibility of these indicators was then assessed and some conclusions presented.

The 7th Framework Programme for Research and Technological Development 2007-2013 allocated EUR 327 million to research on Alzheimer’s disease to around 300 projects with the aim of improving the quality and timeliness of diagnosis, treatment and quality of life of people with dementia and their carers.

The Human Brain Project started in 2013 in order to generate new knowledge in neuroscience and deliver models for human brain functioning. IMI allocated EUR 56.4 million to EMIF (European Medical Information Framework), a project that will facilitate access to medical and research data.
The EU supported the Member State-led Joint Programming on Neurodegenerative Diseases (JPND), which coordinates a common research strategy and alignment of national programmes. Its priorities are to find causes, develop cures and improve care structures for people with dementia. Since 2011, around EUR 68.5 million have been committed for actions, mainly translational calls.

Horizon 2020, the new EU research programme (2014-2020), has allocated EUR 1.2 billion to the “Health, demographic change and well-being” work programme and calls with direct relevance to dementia. The development of innovative treatments and technologies and ICT approaches to self-management of health are also included.

The second phase of IMI (IMI2) started in 2014 and has identified neurodegenerative diseases as a priority.

**Best practices for care of people with dementia**

The ALCOVE Work Package on BPSD (Behavioural and Psychological Symptoms of Dementia) developed recommendations on the organisation of care and structures for people experiencing BPSD to enhance the person’s possibility to live at home as long as possible.

The Open Method of Coordination has united Member States to agree on common objectives on the accessibility, quality and financial sustainability of long-term care. “A Voluntary European Quality Framework for Social Services” has been developed by the Social Protection Committee and is implemented on a voluntary basis by the Member States. To support work on long-term care, the OECD published in 2013 a report “A good life in old age? Monitoring and Improving Quality in Long-term Care”. It focuses on three aspects generally accepted as critical to quality care: effectiveness and care safety, patient-centredness and responsiveness, and care coordination.

The EU-Health Programme 2008-2013 has provided core funding to Alzheimer Europe through operational grants and financial support for its annual conferences.

**Respect of the rights of people with dementia**

Based on existing models in Member States, ALCOVE has developed recommendations for the assessment of the competences of people with dementia and for advance directives. Four models for competence assessment have been presented.

EU activities to implement the UN Convention on the Rights of Persons with Disabilities were embedded in the European Disability Strategy 2010-2020. They aim to tackle the existing barriers faced by people with disabilities and promote the effective implementation of the Convention.

The European Parliament initiated two calls in 2009 and 2010 to address elderly abuse, especially with those in need of long-term care and assistance. The aim was to improve the understanding of the issue, look at existing mechanisms and tools for prevention and to develop options for improving their implementation.

In 2009, Alzheimer Europe set up the European Dementia Ethics Network as a European network for the rights and dignity of people with dementia. The operating grant from the Commission enables the organisation to develop consensus positions on themes such as the use of assistive technology, ethics of dementia research, ethical issues linked to the freedom of people with dementia or ethical issues linked to the perceptions of portrayal of dementia and people with dementia.

**Member States activities**

The survey to monitor Member States efforts to improve the health and quality of life of people with dementia and their families shows significant improvement since 2009: seven countries now have a dementia plan, nine are working on a strategy while seven others include dementia in other relevant strategies.

**Global dimension of EU action on dementia**

Under the impulse of the UK in 2013, the “Global Action Against Dementia” supported by the G7 Health Ministers will strive to identify a cure or disease-modifying therapy for dementia by 2025 and increase the amount of collective funding for dementia research.
“Global action against dementia” completes 2014 agenda

The “Global action against dementia” group organised two Global Dementia Legacy events in late 2014. Alzheimer Europe reports on the proceedings.

“Harnessing the power of discoveries & maximising academia-industry synergies”

The second in a series of four Global Dementia Legacy events took place on 11-12 September 2014 in Ottawa. The event was co-hosted by Canada and France through the Canadian Institutes of Health Research (CIHR) and the French National Alliance for Life and Health Sciences (Aviesan).

Some 200 delegates were in attendance, including government leaders, experts from the research and industry sectors, representatives from health charities and people with dementia and their caregivers. The event aimed to:

• Explore collaborative opportunities for research into novel diagnostic, pre-emptive and therapeutic approaches to dementia.
• Provide a better understanding of the impact of the paradigm shift in pharmaceutical research.
• Foster a collective approach to problem-solving, using expert panel discussions to identify practical and creative solutions.

Opening and closing remarks were provided by Canada’s Minister of Health and Minister of State for Seniors, the Global Dementia Envoy, and the French Ambassador, as well as by representatives of the two host institutions, the US National Institute on Aging, the UK Department of Health, the Japanese Ministry of Health, Labour and Welfare, the Alzheimer Society of Canada, Brain Canada, dementia caregivers and people living with dementia.

Recognising that the prevention, modification, treatment, care and eventual cure of dementia would require significant investment in medical research and technologies, a series of panel discussions took place over the course of the two days to explore different facets of industry-academia collaboration related to dementia research. The panels were aimed at identifying best strategies/approaches for fostering collaborations between academic and private-sectors and at highlighting out-of-the-box ideas from related fields where this kind of synergy had already occurred.

Key players from more than 20 charitable organisations, academic institutions, private-sector companies, government agencies and others provided their unique perspectives on important lessons learned through their work, which were followed by questions and comments from discussants and the plenary.

Canadian Health Minister, Rona Ambrose noted the significant impact of dementia on society and made a number of announcements regarding the Canadian Government’s approach, including:

• The release of the report “Mapping Connections: An Understanding of Neurological Conditions in Canada”.
• The release of the “National Dementia Research and Prevention Plan”.
• The intention to work with the Alzheimer Society of Canada (ASC) to bring the “Dementia Friends” programme to Canada within a year.
“New care and prevention models”

The third event was hosted by Japan on 5-7 November 2013 and focused on new models for care and prevention. Several people living with dementia were in attendance, including three members from the Alzheimer’s Association of Japan’s Dementia Working Group, who were speakers at the event.

Japanese Prime Minister Shinzō Abe highlighted the importance of dementia care provision and stressed the commitment of the Japanese government to take global action against dementia. His government’s Health, Labour and Welfare Minister, Yasuhisa Shiozaki announced the launch of a new Japanese dementia strategy – an update to the 2012 “Orange Plan”.

The Organisation for Economic Cooperation and Development (OECD) launched a dementia care report during the event, stating that dementia is the fastest growing cause of disability in the world today and emphasising the need to develop and implement policies to improve care and to share knowledge across the international community.

Jürgen Scheftlein of the European Commission’s Directorate General for Health (DG SANCO) presented results from the first European dementia action plan and was keen to emphasise the positive impact European collaboration has had on dementia care and research. A second plan will be prepared for 2015-2018.

Sessions on prevention and risk reduction highlighted intervention studies COGNICISE from Japan and THISCE from Taiwan, both combining physical exercise and cognitive training as well as other interventions combined to try to delay the onset of dementia. Alzheimer Disease International (ADI)’s Professor Martin Prince presented the conclusions from this year’s “World Alzheimer Report” on dementia and risk reduction.

The event also highlighted innovative care solutions using information and communications technology (ICT) to help support people with dementia and increase independence. The importance of person centred care was also emphasised by Professor Dawn Brooker from the University of Worcester and Professor Graham Stokes from Bupa (UK), who showed the link between high standards of care and a decreased need for antipsychotics.

In closing, Dr Saxena, Director of Mental Health, Neurological Disorders and Substance Abuse at the World Health Organisation (WHO), announced that the first WHO Ministerial Conference on Global Action Against Dementia would take place in Geneva, Switzerland in March 2015. Health Ministers from the 193 member states will be invited, along with various international organisations. The aim is to spread the work done by the G7 countries to the rest of the world.

Jean Georges reported that he was pleased to see there had been a shift, taking on board the calls for more focus on dementia care, rather than only talking about a possible cure. He noted, however, that it was apparent the G7 countries were still uncertain as to how to work together on this new area of focus and that there seemed to be more clarity around the cure element of discussions, in terms of how to move forward. He also commented that combining age-friendly projects - such as the WHO initiative on age-friendly environments or the European Innovation Partnership on Active and Healthy Ageing - could be a useful direction to take.
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.
Dementia in the news

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Denmark: aiming for a dementia-friendly society

Birgitte Vølund, the new Chairperson of the Danish Alzheimer Association, is a registered nurse and holds a Master's degree in gerontology. Birgitte is also an independent consultant and leader of courses on dementia and authority issues in Danish municipalities. In this article, she speaks to Alzheimer Europe about her aspirations in her new role.

It is a pleasure for me to have this opportunity to present myself to the European Alzheimer associations and other people engaged in the cause of dementia.

In 2014 I was elected chairman of the Danish Alzheimer Association. It is an honour to represent this important association. Together with a very well-functioning secretariat and engaged and competent volunteers throughout Denmark, I will work whole-heartedly to set agendas for professional work and society’s treatment of people with dementia and their families. In Europe, I want to contribute to a strong focus on dementia as a crucial political issue.

Twenty-five years ago, there was in Denmark an incipient realisation that the care offered to people with dementia and their families was professionally, humanely and ethically inadequate, and that our knowledge of dementia was insufficient. At the time, I was the leader of a municipal residential home for the elderly and together with frustrated professional and family carers I focused on how to improve and professionalise care. After further studies on dementia and dementia care, I became interested in breaking new ground and better conditions for people with dementia. “What can we do better and how?” were questions I posed at seminars and lectures for professionals and meetings with families and volunteers. It was clear to me that enhanced knowledge of dementia was of great importance. Now I have my own firm, offering supplementary education and training for professionals working with people with dementia. Also, I am engaged in the general development of social services in Denmark, participating in educational and developmental projects.

It is the first time the Chairperson of the Danish Alzheimer Association is not a relative of a person with dementia, but has a background of working professionally. Is this a problem? Time will tell, but my strength is many years’ experience and engagement and widespread contacts in the field.

As Chairperson, my main objective is to work towards a dementia friendly society, guided by the following principles and policies:

- Dementia should be a cause for all people, not only those affected by the disease; no one should be deprived of social contacts because of dementia.
- Dementia should be high on the agenda of legislators, and good intentions of equality in health should apply in practice to people with dementia.
- There should be intensive research into the emergence, risk factors and treatment of dementia.
- Resources should be at hand to secure qualified care to persons with dementia and their families, offering necessary social and personal support to make everyday life function in good and in hard times.

In short, everyday life with a dementia disease is challenging and often stressful. It is difficult to remove that burden from the afflicted persons, but together we can try to make life with dementia worth living.
Franco-German cooperation brings together people with dementia

The international award-winning “Meetings without frontiers” programme has attracted people with dementia since 2012. In 2014, a group of 44 people enjoyed a trip to Durbuy, Belgium.

Since 2012, France Alzheimer Vaucluse and Alzheimer Gesellschaft München have joined forces to organise a holiday for people with dementia and their carers. The initiative “Meeting without frontiers” (Rencontre sans frontières - Begegnung ohne Grenzen) is an opportunity to share experiences, learn how other countries support people with dementia and their carers and share a privileged moment together away from their familiar environment.

After France hosted the first reunion (2012) and Germany the second (2013), the chapters decided to organise the 2014 reunion in Belgium. Thus a group of 24 people from Germany and 20 more from France arrived in the city of Durbuy.

As in previous years, the people with dementia, their carers and the organisers lived in a dementia-friendly rented house. They shared daily tasks such as shopping and cooking and played games or danced in the evenings. During the day, they went on various excursions, such as visits to local Alzheimer associations, markets, farms and towns. In addition, the group had the privilege to be invited by Françoise Grossetête, Member of the European Parliament and Chair of the European Alzheimer’s Alliance, to see the European Parliament while visiting Brussels.

This innovative European initiative received a Robert Bosch Foundation award in 2013 and 2014. The Foundation’s “Let’s Go” (On y va – auf geht’s) project rewards voluntary projects that bring European citizens together. The “Meeting without frontiers” programme meets that goal: Alzheimer’s disease is the vector that allows synergies between people with dementia and their carers from different countries while giving a new perspective about the disease.

In 2015, “Meeting without frontiers” will return to France and preparations are already well underway.
World Alzheimer’s Day 2014

Alzheimer Europe takes a look at some of the activities of its member associations to mark World Alzheimer’s Day.

Austria
Alzheimer Austria held a music therapy session, led by German music therapist Simone Willig and designed for families and professional caregivers. A large number of interested participants learned about music’s effects on body and soul.

Bulgaria
This year, Alzheimer Bulgaria’s traditional press conference attracted representatives from the Ministries of Health and of Labour and Social Policy. The association also held an awareness drive that included short cognitive tests for elderly members of the public.

Croatia
Alzheimer Croatia held Alzheimer’s Cafés, organised a multimedia theatre performance in Zagreb Concert Hall and led two Memory Walks. These were bolstered by focused campaigns on advocacy and public awareness that reached nearly 50% of Croatian media audiences. As a result, Alzheimer Croatia has made further steps to develop a national network of regional associations.

Finland
Muistiliitto’s 43 local member associations led numerous “Memory Week” activities around the country. These included memory walks, memory cafes and lectures. There were also church services, in cooperation with the Evangelical Lutheran church, which has published guidelines for memory-friendly services.

France
This year, France Alzheimer chose the theme of intergenerational links in caring for people with dementia. The association organised conferences, debates and sporting events nationwide, including more than 300 information and public awareness sessions.

Greece
Alzheimer Hellas conducted activities throughout September, including two scientific conferences, a press conference and awareness events where elderly people could take part in a memory test. These activities were enhanced by dedicated TV and radio spots produced by a famous local actor.

Ireland
The Alzheimer Society of Ireland (ASI) held public information events throughout the country and – together with the Irish Dementia Working Group – produced various new information materials on living well day-to-day and driving and dementia. ASI also produced two radio adverts and two new short films about living with dementia.

Italy
In Rome, Alzheimer Uniti Italy (AU) held their 16th Annual Congress, which focused on the new National Dementia Plan. AU also held an Alzheimer Café, ran an awareness campaign and led an excursion to the Vatican for people with dementia. Local AU affiliates organised similar activities in many other Italian cities.

Luxembourg
Hereditary Grand Duke Guillaume and Princess Stéphanie of Luxembourg joined a Memory Walk organised by the Association Luxembourg Alzheimer. This was one of various activities around the capital city to raise awareness and show solidarity with people living with dementia.

Monaco
AMPA organised its traditional Memory Walk and Gala Dinner that helped raise funds to help “fight the disease of the century” and also raised awareness of dementia. In a local TV interview, Prof. Alain Pesce, AMPA VP, deplored the lack of a cure but spoke about non-pharmacological medical options to alleviate some of the symptoms and also to help with prevention.

Norway
The Norwegian Health Association held its annual campaign to raise awareness and funds for dementia research and local activities. The “Demensaksjonen” event featured fundraising events, public meetings and award ceremonies in many local communities. The campaign netted more than 130 press clippings from local and national media.
Portugal
Thousands of people joined the 4th annual Alzheimer Portugal Walk, which took place in 15 towns all around the country. There were record numbers of participants and participating towns. Media coverage has also grown, making this the perfect event to enhance public awareness of dementia as well as for fund-raising.

Slovenia
Spomlčica and its local chapters organised several Memory Walks under the theme “Dementia: Can we reduce the risk?”. In Ljubljana, the event was sponsored by mayor Zoran Janković and included musical and theatre performances as well as dementia awareness activities.
Living with dementia in Finland

Raoul Grönqvist, D.Sc. (Tech.) and member of the European Working Group of People with Dementia and Milja Ahola, MA, his wife and caregiver, share their experiences with movement recall and musical therapy.

A Finnish museum once commissioned me to create a series of short animated films on the different stages of shoemaking. In order for me to convey something of the process, I first had to understand for myself how the machinery once used to work.

A shoemaking machine stood, mute, in the bowels of the museum. An academic, a retired importer and a master shoemaker had gathered around it, wondering how it might have worked back in the day. The academic knew the theory behind it. The importer was familiar with the technical specification, in other words, with what the machine used to do. The shoemaker had operated the machine for decades. He grabbed an unfinished shoe, turned it this way and that in his hand until it felt just right and then approached the machine. With his other hand, he felt for a lever, with his foot he searched for a pedal. If the hand could not find what it was looking for, it was clear something was missing. The master shoemaker could not explain in words how the machine worked. And yet he had the knowledge that led his hand to the right lever, that directed his foot to the correct pedal and that told him which part was missing. It was movement recall, that silent knowledge amassed over the years, that was telling him how to finish the shoe.

Two years ago, we attended a rehabilitation course, run by the Finnish social security institution KELA. At an exercise class for patients and their families, we were invited to gather round in a circle. Touch your nose with your left hand and your ear with your right – and then the other way round. The movements help to activate the brain and stimulate your memory. I suspect few of us can be bothered to do exercise if we fail to see the point of it. Raoul was fascinated by the basketball hoops. We managed to talk one of the younger guys in the group to play with him. I could hardly believe what I was seeing, as Raoul, a former Junior Finnish Basketball Champion, started shooting hoops after a break of more than 30 years.

Immediately, the search was on for someone for Raoul to play with. We found a team, who only played for fun, but had a coach. A coach, as it turned out, who had previous experience of working with disabled players. He immediately welcomed the memory-impaired candidate: “Join us, come and have a go,” he said. After the game, Raoul radiated happiness: “Worth it, even if it was the last time.”

Raoul went on to play with the team until it disbanded. After that, he continued to train one-on-one with his personal assistant. After one particular training session, the master player said, with evident relish: “The boy is starting to get there, he’s learning how to grab the ball properly.”

People with memory impairment want to pursue leisure activities that they are interested in, whether that is something they have always been involved with, or something they have always
wanted to try. When you are drawing up a rehabilitation plan, it would be a good idea to ask what the client wants, what they like and what sort of exercise they enjoy.

Raoul has played classical guitar for 50 years. He has used music to express his joys and his sorrows. As his illness has progressed, it has become harder for him to read music and he can no longer commit longer pieces to memory. The fingers work perfectly but the notes just fall apart. And with his sharp ear for a melody, what was once a pleasure and a release has become a source of disappointment. Raoul stopped playing completely a couple of years ago.

We wondered what we could do to help. Formal tuition we rejected outright. Then we heard about musical therapy. In musical therapy you play an instrument and talk about your feelings. Progress has been slow but rewarding. Raoul has his guitar out every day now. Each time, he plays for longer. He perceives the notes differently from before. He now reads them in clusters.

For Raoul, musical therapy is an excellent form of rehabilitation. His brain and hands remain active and playing is once again a source of joy and pleasure. When he plays at the day centre he attends, he is also able to share that joy with others. Sadly, there is currently no public funding available in Finland to provide tailored rehabilitation for people with memory disorders. Those receiving a disability pension receive no financial support for musical therapy.

Everyone suffering from memory impairment should have the right to rehabilitation that is tailored to them. Rehabilitation must start with the needs of the individual and reflect their life experiences. Rehabilitation must begin when the person is still able in mind and body and keen to put their skills and abilities to use.

This article was originally published in MEMO, the journal of the Finnish Society for Memory Disorders Expertise.
Alzheimer and the Mediterranean - working together for a better understanding

Alzheimer Portugal and AMPA (the Monegasque Association for Research on Alzheimer’s disease) hosted a conference of the Mediterranean Alzheimer Alliance (MAA) in Lisbon on 11-12 November 2014.

The MAA is a network composed of Alzheimer’s associations, scientific experts and health care professionals from the Mediterranean region which aims to share and exchange knowledge and practices but also to make propositions on a local and international level. The MAA was formed in 2013 and now includes 14 countries: Cyprus, Croatia, Egypt, France, Greece, Italy, Lebanon, Malta, Morocco, Monaco, Portugal, Slovenia, Spain and Tunisia. The alliance’s activities are coordinated by AMPA.

With over 200 participants, this conference was a true success and also an opportunity to support Alzheimer Portugal in its national mobilisation for the fight against Alzheimer’s disease. Delegates presented national initiatives and discussed a wide range of topics, including research, non-pharmacological interventions, care for people with dementia and government strategies for Alzheimer’s disease. For instance, Samia Adbul-Rahman (Egypt) explained that there is no stigma attached to Alzheimer’s disease in her country; however, normalisation of the disease is problematic and the official term for dementia is rarely used, due to a general consensus that it is offensive. Tunisia’s Leila Alouane explained how to incorporate elements of a Mediterranean type of diet into one’s daily life. Dianne Gove, Director for Projects for Alzheimer Europe, presented AE’s work on the ethical implications of how dementia is perceived and portrayed. Luis Amado, former Minister of Foreign Affairs of Portugal, drew attention to the economic and financial crisis as well as the geopolitical environment. Finally, Federico Palermiti and Salomé Nicaise from AMPA presented the preliminary results of the “Alzheimer and the Mediterranean” report, which will be published in 2015 by the MAA. This report includes an update of the needs of the MAA countries and an analysis of the emerging issues in the region. The results will show several differences between countries, such as prevalence and economic costs. However, they also underline common points specific to the Mediterranean, including lack of training and awareness and strong family solidarity, which justifies the union of these countries.

During the conference, there was a strong call for further initiatives, both within the MAA and on a national level, in order to push governments to recognise Alzheimer’s disease as a national public health priority.

In 2015, the MAA members will convene in Greece and Slovenia and they will also be involved in various academic and scientific collaborations, including a study on non-pharmacological interventions. In addition, AMPA will coordinate the training initiatives for the opening of an Alzheimer Centre in Essaouira, Morocco.

For more information, please contact fpalermiti@ampa-monaco.com
The 24th Alzheimer Europe Conference opened on 20 October 2014 under the theme “Dignity and autonomy in dementia”.

Highlights from the plenary sessions of the Glasgow Conference.

Adopted on 20 October 2014, the Glasgow Declaration also calls on world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Over 96% of delegates would recommend future AE conferences to their colleagues.
AE Conference opens with a focus on rights and autonomy

The 24th Alzheimer Europe Conference opened on 20 October 2014 under the theme “Dignity and autonomy in dementia”.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe (AE), opened the ceremony by welcoming the delegates and thanking Alzheimer Scotland for the excellent cooperation in co-hosting the conference. She added that AE could not have chosen a better conference venue, as Scotland is a shining worldwide example for the recognition of dementia as a national priority.

Ms von Lützau-Hohlbein also reported that AE’s Annual General Meeting had just adopted the Glasgow Declaration, which would be officially launched following the opening ceremony. In broad terms, the Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

She was followed by Henry Simmons, Chief Executive of Alzheimer Scotland.

Upholding the rights of people with dementia

Mr Simmons said that Scotland is beginning to see a positive transformation in the health and social care system that provides for people with dementia. This improvement has been achieved by the cooperation of local communities, partners in all sectors and government leaders. He added that at the heart of this transformation is a fundamental belief in the human rights, dignity and autonomy of every person living with dementia in Scotland.

The challenge for dementia organisations, practitioners and policy makers is to make sure that we never forget that behind every statistic, every number, every figure is an individual, a family member, a person and most importantly, a citizen. Every citizen has the right to choose, the right to control and the right to be included in every aspect of his or her care. Mr Simmons ended with the promise that “we cannot and we will not allow anything to be lost in our fight to ensure the rights of people with dementia and their families.”

Involving people with dementia and their carers

The keynote speaker for the evening was Geoff Huggins, Scotland’s Acting Director of Health and Social Care Integration. His presentation, “A rights based approach to developing and implementing Scotland’s National Dementia Strategy”, showed how a collective and all-inclusive effort has led to a highly effective programme of services and assistance for people with dementia and their carers.

The main priority of the first dementia strategy (2010-2013) was to increase the dementia diagnosis rate in Scotland. Ensuring early diagnosis is vital to help people build their personal resilience and knowledge and also to live comfortably at home for as long as possible. Diagnosis is also the means of access to the appropriate treatment and support. By 2011, the rate of dementia diagnosis in Scotland had reached 65%, an increase of 23 points. The first dementia strategy also included the development of national standards of care, a framework for workforce development and the reduction of antipsychotic drugs.

Mr Huggins stressed that “rights are at the heart of what we do”, explaining that the dementia strategy was specifically designed to take account of the
needs of people afflicted with dementia and their families. Their involvement in the process was clearly beneficial – Mr Huggins cited them as the source of some of the best ideas – and will certainly continue.

He then described the three main requirements that were identified during the development of the current (2013-2016) Scottish dementia strategy.

1) Offer care and support to people with dementia and their carers in a way that bestows comfort and wellbeing and also respects their humanity. Mr Huggins referred to this requirement as “a moral imperative”.

2) Continue improving services and support, beginning with diagnosis and throughout the course of the illness. Mr Huggins stressed that this should include carers’ support needs that are stated and defined by them, not by service managers or clinicians.

3) Recognise that increasing life expectancy will mean a corresponding increase of support and care over time.

Mr Huggins concluded that dementia is not about numbers, costs or projections into the future; it is about person to person care. This will require a lasting commitment to provide skilled dementia care workers and also to involve people with dementia and carers in all aspects of care and support.

**Dignity, respect and autonomy**

The next speaker was Jeanette Maitland, a founding member of Alzheimer Scotland’s National Dementia Carers Action Network (NDCAN). Ms Maitland presented “Dignity, respect and autonomy”, describing these words as essential requirements for all levels of support and care for people with dementia and their carers.

Dignity: it is our duty to provide adequate cover and support for people with dementia and their carers at every level, thus allowing them to retain their feeling of self-worth and value.

Respect: it behoves us all to show respect toward people with dementia, so that they may continue to enjoy their sense of value, warmth, acceptance and inclusion.

Autonomy: the progression of dementia often causes the erosion of autonomy. It is essential for families to plan ahead, so that the person with dementia and all care partners may develop an equitable solution.

The final speaker was Henry Rankin, Chair of the Scottish Dementia Working Group (SDWG). Living with dementia himself, he extended a special welcome to the numerous delegates with dementia who attended the conference. Mr Rankin said that partnership was a guiding principle of the SDWG – adding that working in partnership is the best way to help people with dementia and their carers.

Mr Rankin noted that both the SDWG and the European Working Group of People with Dementia (EWGPWD) would be holding special sessions during the conference. He hoped to see many audience members at these sessions, which would be developed and directed by people with dementia who attended the conference. Mr Rankin also thanked the Life Changes Trust for the bursary scheme that allowed more than 40 people with dementia to attend the conference.

The opening ceremony concluded with the official signing of the Glasgow Declaration by the speakers and also Mr John Laurie, Convener of Alzheimer Scotland.
Dignity and autonomy in dementia

Alzheimer Europe held its 24th Annual Conference in Glasgow during 20-22 October 2014. This article looks back at some highlights of the plenary sessions.

The 2014 conference was co-organised with Alzheimer Scotland and attracted more than 830 delegates, including 44 people with dementia. The programme included some 190 speakers and 170 poster presentations. Apart from the plenary sessions, delegates also attended 28 parallel sessions about legal, ethical and scientific aspects of living with dementia. These included four sessions dedicated to Alzheimer Scotland’s activities and special symposia focused on clinical trials, nutrition and cognitive function. The European Working Group of People with Dementia (EWGPWD) also organised and directed a very popular special symposium entitled “Snapshots of our lives”.

Promoting a rights-based approach to dementia

The first plenary session of the conference was chaired by Dr Charles Scerri, General Secretary of the Malta Dementia Society and Honorary Secretary of Alzheimer Europe. Colin McKay, Chief Executive of the Mental Welfare Commission for Scotland, opened the session with a presentation on Scotland’s national human rights plan. He noted that “a human rights approach is a real driver for change” and described how legislation and policy affecting Scottish people with dementia has made a fundamental shift in the last 15 years. This has led to significant improvements in health and social care practice, including a growing emphasis on the involvement of people with dementia and their carers in controlling their own support.

He was followed by Matthias Kloth, Administrator in the Directorate General of Human Rights and Rule of Law of the Council of Europe. Mr Kloth spoke about the Council’s recent Recommendation on the Promotion of Human Rights of Older Persons. This seeks to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all older persons, and also to promote respect for their inherent dignity.

Grainne McGettrick, Manager for Research and Policy Advocacy at Acquired Brain Injury Ireland, presented the UN Disability Convention as an...
instrument for people with dementia and their carers. She explained that dementia has not had the same exposure to human rights discourses as other forms of disability. In recent years, however, a number of rights-based initiatives have emerged. As a result, there is increasing dialogue on dementia and this is beginning to translate into international dementia policy.

The last speaker was Maja Groff, Senior Legal Officer at the Permanent Bureau of the Hague Conference on Private International Law. Ms Groff spoke about globalisation and the protection of vulnerable adults abroad. In particular, she outlined the provisions of the “Hague 2000 Convention”, such as rules on jurisdiction, applicable law and international recognition and enforcement of protective measures. The Convention also establishes a mechanism for cooperation between the authorities of Contracting States.

Dementia strategies and policies

Henry Simmons, Chief Executive of Alzheimer Scotland, chaired the second plenary session, which consisted of presentations and a round table discussion on dementia strategies and policies. The first speaker was Alex Neil, Scotland’s Cabinet Secretary for Health and Wellbeing, who got a rousing reception from the audience. He began by pointing out that the social health of people with dementia is just as important as their physical and mental health. He also commented that “people with dementia must be involved in policy making; they can tell us better than anyone what we need to do” and pointed out the need to increase rates of diagnosis and improve the post-diagnostic support process. Following his speech, he became the first European Minister to sign the Glasgow Declaration.

The next speaker was Jürgen Scheftlein, Policy Officer in the European Commission’s Directorate-General for Health and Consumers. He gave an overview of EU initiatives on dementia, such as the ALCOVE (Alzheimer Cooperative Valuation in Europe) project and EIP-AHA - the European Innovation Partnership on Active and Healthy Ageing.

This was followed by a round table discussion among the following dementia experts: Geoff Huggins, Dr Dorothée Knauf-Hübel (Head of the Division de la Médecine Curative at the Luxembourg Ministry of Health), Benoit Lavallart (responsible for the French Alzheimer plan among various Ministries), Dr Scerri and Marc Wortmann (Executive Director of ADI). They discussed the challenges of sharing best practices among countries that have varying cultures and definitions of patient needs and expectations. They also spoke about implementing dementia strategies in small coun-

“A successful strategy means speaking to people with dementia when designing policy.”
Alex Neil
tries such as Luxembourg and Malta. The panellists agreed that a successful dementia strategy requires political commitment at the highest levels, including long-term funding. Finally, they expressed their support for the Glasgow Declaration: a European Dementia Strategy would clearly be beneficial in countries that lack a strategy, but also as a benchmark where strategies are already in place.

**Involving people with dementia**

The third plenary session focused on involving people with dementia and was chaired by Daphne Wallace, a retired physician who is living with dementia herself. The first speaker was Helga Rohra, Chair of the European Working Group of People with Dementia (EWGPWD), who spoke about the changes in how people with dementia are perceived since her own diagnosis seven years ago. She noted that people with dementia are now active delegates at many events, including international events such as the G7 Global Dementia Legacy conferences. Ms Rohra also pointed out the continuing need for investment to improve the lives of people with dementia today.

She was followed by Amy Dalrymple, Head of Policy for Alzheimer Scotland, who explained how the organisation’s “8 Pillars Model” aims to be an integrated health and social care model of support for people with dementia. The model upholds the rights of people living with dementia, including being respected as an individual within their community. It also promotes the best possible quality of life for people living with dementia, with the use of combined resources wherever possible. The 8 Pillars Model is currently being tested in five areas of Scotland.

Marie-Jo Guisset from the Fondation Médéric Alzheimer presented the activities of EFID, the European Foundations Initiative on Dementia. EFID aims to improve the lives of people with dementia by enabling a dementia-friendly and inclusive environment in communities across Europe. Ms Guisset focused on the “EFID Awards”, a successful campaign to reward local initiatives that promote social inclusion of people with dementia.

The final speaker was Prof. Myrra Vernooij-Dassen, Director of Nijmegen Alzheimer Centre in the Netherlands. She presented the ongoing work of INTERDEM, a European research network on early detection and psycho-social interventions in dementia. The group’s current focus is on dignity and the role of stigma in dementia. Prof. Vernooij-Dassen underlined the importance of addressing both of these issues, as they can have a significant impact on the quality of life of people with dementia.

“It is no longer a shame to have a family member with dementia.”

*Myrra Vernooij-Dassen*
Innovation and care

The last plenary session was chaired by Henry Simmons and concentrated on innovation and care. Prof. Debbie Tolson, Director of the Alzheimer Scotland Centre for Policy and Practice, showed examples of practice innovation in policy development, evidence-informed care and enabling the work force to become agents of change. Innovation within dementia practice implies introducing something new that makes a positive contribution, often as a result of new knowledge. Prof. Tolson outlined the process and conditions by which an idea for a new improvement can be developed to become accepted as a standard in policy.

She was followed by Dr Dianne Gove, Director for Projects for Alzheimer Europe, who presented AE’s report on improving continence care for people with dementia living at home. The report provides guidelines for people with dementia, carers and health and social care providers. It also explores the challenges faced by people with dementia and continence problems who live at home and also those of informal carers. Statements from people with dementia and their carers are included which highlight their needs and desire in relation to continence care and in the wider context of their rights as equal and valued citizens.

Hugh Masters, interim Associate Chief Nursing Officer for Scotland, explained how specialist nurses and dementia champions are driving change in acute hospital care for people with dementia. Improving acute care has been a priority in both of the country’s National Dementia Strategies. Mr Masters explained the improvements that have led to safe, effective, dignified and person-centred care, once admission to hospital is unavoidable for people with dementia.

The final presentation was made by Dr Kai Saks, Associate Professor of Internal Medicine at the University of Tartu, Estonia. She presented the findings of the “RightTimePlaceCare” project, which developed best practices for the transition from formal professional home care to institutional long-term nursing care facilities. The study concluded that carers’ needs must be addressed alongside those of people with dementia, both when choosing an institution and also after the transition is made.

The conference ended with an invitation to attend the 25th Alzheimer Europe Conference in Slovenia. This was followed by closing remarks from Henry Simmons and Prof. Iva Holmerova, Vice-Chairperson of Alzheimer Europe. The 24th Alzheimer Europe Conference received funding from the European Union in the framework of the Public Health programme.
Snapshots from Glasgow
AE members adopt the Glasgow Declaration and call for a Pan-European dementia strategy

Adopted on 20 October 2014, the Glasgow Declaration calls on world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Alzheimer Europe is very pleased to announce that the Glasgow Declaration was unanimously approved by delegates from 26 member associations during AE’s Annual General Meeting. Jean Georges, Executive Director, said: “In Europe, there are many good examples of collaborative initiatives on dementia. The time has now come to bring these initiatives together under a comprehensive European strategy. The new Commission President should appoint a Commission official to coordinate all ongoing EU initiatives and link them with global developments by the G7, G20 and the World Health Organisation.”

On 21 October, Alex Neil, Scotland’s Cabinet Secretary for Health and Wellbeing, became the first European Minister to sign the declaration. By the end of the Glasgow conference, more than 120 people had signed the declaration.

Alzheimer Europe is very grateful to all the signatories for their clearly heartfelt support!
Alzheimer Europe’s Glasgow Declaration

As signatories, we commit ourselves fully to promoting the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.

We affirm that every person living with dementia has:

- The right to a timely diagnosis;
- The right to access quality post diagnostic support;
- The right to person centred, coordinated, quality care throughout their illness;
- The right to equitable access to treatments and therapeutic interventions;
- The right to be respected as an individual in their community.

We welcome the growing recognition of dementia as a public health priority on a national and European level and call upon European governments and institutions to recognise the role that they have in ensuring that these rights of people living with dementia are respected and upheld. In particular, we:

Call upon the European Commission to:

1. Develop a European Dementia Strategy;
2. Designate a high level EU official to coordinate the activities and research in the field of dementia of existing programmes such as Horizon 2020, the Ambient Assistant Living Programme, the European Innovation Partnership on Active and Healthy Ageing, the Joint Programme on Neurodegenerative diseases research and the Innovative Medicines Initiative;
3. Set up a European Expert Group on Dementia comprised of Commission officials, representatives of Member States and civil society to exchange best practices;
4. Financially support the activities of Alzheimer Europe and its European Dementia Observatory and European Dementia Ethics Network through its public health programme.

Call upon Members of the European Parliament to:

1. Join the European Alzheimer’s Alliance;
2. Support the campaign of Alzheimer Europe and its member organisations to make dementia a European priority and create a European Dementia Strategy;
3. Make themselves available for people with dementia, carers and representatives of Alzheimer associations from their country.

Call upon national governments to:

1. Develop comprehensive national dementia strategies with allocated funding and a clear monitoring and evaluation process;
2. Involve people living with dementia and their carers in the development and follow up of these national strategies;
3. Support national Alzheimer and dementia associations.

We welcome the international recognition of dementia as global priority and acknowledge the work of Alzheimer’s Disease International and the G7 group of countries in driving forward global action on dementia and call upon the international community to:

1. Build on the success of European collaboration on dementia and involve European initiatives in the development of a global action plan on dementia;
2. Include and consult Alzheimer associations and people with dementia in the decision making process and definition of a global research agenda;
3. Adopt a holistic approach to research priorities to include psycho-social, care, socio-economic and health systems research to ensure that research aims to benefit people living with dementia now, as well as people who will do so in years to come;
4. Substantially increase the funding dedicated to all areas of dementia research;
5. Promote dementia as a priority in other international bodies including among the G20 group of countries, the Organisation for Economic Cooperation and Development (OECD), the World Health Organisation (WHO) and the United Nations.
832 delegates from 40 countries attended Alzheimer Europe’s 24th conference in Glasgow

Breakdown by country

United Kingdom 479 / Netherlands 36 / Italy 29 / Germany 28 / Finland 24 / Iceland 22 / Ireland 20 / Norway 18 / Switzerland 18 / France 15 / Luxembourg 14 / Turkey 13 / Belgium 12 / Austria 11 / Spain 11 / Denmark 8 / Japan 7 / Greece 6 / Singapore 6 / USA 6 / Australia 5 / Czech Republic 5 / Hungary 5 / Sweden 5 / Jersey 4 / Slovenia 4 / Israel 3 / Cyprus 2 / Gibraltar 2 / Malta 2 / Monaco 2 / Poland 2 / Brazil 1 / Canada 1 / Croatia 1 / Estonia 1 / Portugal 1 / Romania 1 / Russia 1 / Slovakia 1

Europe/World A-Z

Europe

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ALZHEIMER EUROPE RECEIVED FEEDBACK FROM 92 DELEGATES INDICATING THAT:

- Over 84% of delegates found all plenary sessions to be good/very good
- Over 94% of delegates found the topics in parallel sessions to be good/very good
- Over 86% of delegates found the conference website to be good/very good
- Over 96% of delegates would recommend future Alzheimer Europe conferences to their colleagues
Our members are helping people with dementia and their carers in 31 countries
25th Alzheimer Europe Conference
Dementia: putting strategies and research into practice
Ljubljana, Slovenia
2-4 September 2015
Mark the dates!

www.alzheimer-europe.org/conferences