Michel Goldman talks about the Innovative Medicines Initiative.

Adriana Maggi discusses the progress of the JPND initiative.

José Manuel Barroso, President of the European Commission, discusses how Europe can help people with dementia.

Joseph Cuschieri hosts a lunch debate on the European Dementia Monitor.

SPOTLIGHT on Alzheimer Europe’s 23rd conference in Malta.
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by Heike von Lützau-Hohlbein,
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Welcome

This issue of Dementia in Europe magazine will appear during our first 2014 lunch debate at the European Parliament – which will also be the last dementia debate in the current Parliament. I would like to thank all 71 MEPs of the European Alzheimer’s Alliance for their support, particularly their efforts to bring the challenges of dementia to the forefront over the past five years. You can read about these efforts in the following pages, as over 30 MEPs kindly responded to our request for highlights of their achievements and future priorities.

Our last lunch debate was hosted by Joseph Cuschieri, MEP (Malta) and was dedicated to a presentation of the European Dementia Monitor – a benchmark of national dementia policies. This is one of Alzheimer Europe’s new publications, along with the 2013 Yearbook that showcases national policies relating to the care and support of people with dementia and their carers. I would like to thank Mr Cuscheri for his time and effort, especially as he was also an active supporter of our recent annual conference in Malta.

I am also very grateful to Mr José Manuel Barroso, President of the European Commission, who found the time to speak about how the EU is helping people with dementia. Mr Barroso clearly states that the EU is always keen to help member states resolve their health issues, including the rising financial and societal costs of dementia.

These concerns are not limited to Europe. Last December, I was fortunate enough to attend the G8 Dementia Conference in London. The outcomes from this meeting appear to be very positive; in fact I was surprised to realise how far we have come since I became involved with dementia many years ago.

On the scientific front, we are pleased to include interviews with representatives from both JPND and IMI. Adriana Maggi, Vice Chair of the JPND Management Board, explains how the programme supports projects and how patient and carer organisations can participate in its work. Michel Goldman, Executive Director of IMI, talks to us about IMI’s continuing efforts to address challenges in drug development. Alzheimer Europe is currently involved in three IMI projects, namely Aetionomy, EMIF and PharmaCog.

This issue also carries a special section on the 23rd Alzheimer Europe Conference, which took place in Malta in October 2013. Looking back, I am still overwhelmed by the relevance and quality of the presentations, as well as the dedication and enthusiasm of the delegates that made this conference a great success.

On behalf of all the Board and staff members of Alzheimer Europe, I would like to wish our readers a very healthy and productive 2014. We look forward to seeing you at our lunch debates, public affairs meetings and at the 24th Alzheimer Europe Conference in Glasgow.
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Comparing and benchmarking national dementia policies

On 3 December 2013, Joseph Cuschieri, MEP (Malta) and member of the European Alzheimer’s Alliance, hosted Alzheimer Europe’s 15th lunch debate which was dedicated to a presentation of the “European Dementia Monitor”.

Joseph Cuschieri welcomed all 40 participants – including fellow MEPs Anneli Jäätteenmäki (Finland) and Marina Yannakoudakis (UK) – to this debate. Delighted to be hosting this event, he explained that his being a member of the European Alzheimer’s Alliance is an important part of his work. Dementia is a challenge for all EU Member States: over seven million Europeans live with dementia and there are some 21 million informal carers. The cost of formal and informal care per patient per year is estimated to be EUR 21,000. The impact of this complex disease is vast and with no known cure, ways at delaying the onset and improving the quality of life of people with dementia need to be pursued.

It is imperative to address both the stigma associated with the disease and the fact that the treatment and care of people with dementia differs between EU Member States. All have a part to play: citizens need to be informed and aware while EU institutions and national governments need to collaborate. Policy makers and practitioners need to be informed and enlightened and the lunch debate would help to do this.

European Dementia Monitor

Jean Georges (Executive Director, Alzheimer Europe) thanked Joseph for his support. He explained that the aim of European Dementia Monitor (EDM) is to benchmark national dementia policies which will help lobbyists to compare, on a regular basis, various issues for people with dementia both at EU and national levels.

The EDM offered an exciting new way to work as Alzheimer Europe and national Alzheimer associations had collaborated alongside pharmaceutical companies. Jean acknowledged the general support of GE Healthcare, GlaxoSmithKline, Janssen, Lilly, Nutricia, Pfizer and Sanofi and particular support in data provision by Lundbeck, Merz and Piramal.

The EDM is based on data from existing, well-established and trust-worthy sources. Comparable data is a challenge and, to overcome this, the EDM is based on a simple point system which will enable the results to be presented in a simple and clear table.
Prevalence

By applying the EuroCoDe prevalence rates to the 2012 UN population statistics, it is possible to estimate the number of people living with dementia in the EU at 8.7 million. However if non-EU Alzheimer Europe members (Iceland, Monaco, Norway, Turkey and Switzerland) are also included, the figure would be 9.2 million. This calculation could be used as a benchmark figure when considering other issues. Considerable differences are found when comparing prevalence of people with dementia as a percentage of the population between countries. Overall it ranges from between 0.44% (TR) to 2.09% (IT). Amongst others, Turkey has a young population which will impact on this figure.

Diagnosis

Although the vast majority of countries were found to have diagnostic guidelines in place, several countries did not (CY, EE, IE, IT, JE, LU, MT, MC, PT, CH and TR). Some countries have put in place specific incentives to encourage GPs to diagnose dementia (DK, FR, NL, UK (Eng and Scot)). On the other hand, two countries (IT and RO) make it impossible for GPs to take an active role in diagnosis. A key element of the diagnostic infrastructure is the ability to offer access to an MRI scan. Again, a wide range of results reached from two MRI machines per 10,000 people with dementia (HU) to 23 (TR). In the future, amyloid imaging could be more widely used in the diagnostic process and this will require PET machines. Data from the WHO Health Resources Database was applied which showed variations from zero (CY, IS) to 3.6 (DK). This would suggest that, should we want to change the way in which diagnosis is done, there are real challenges ahead in terms of the existing diagnostic infrastructure.

Availability and reimbursement of medication and nutrition

Alzheimer’s disease medicines (donepezil, rivastigmine, galantamine and memantine) as well as the existence of a strategy to reduce the use of antipsychotics were considered. Three countries (JE, SE and UK) offer all four drugs with full reimbursement and have a strategy in place to reduce the use of antipsychotics. Other countries varied with regard to which drug could be reimbursed and whether antipsychotics were being targeted via a strategy. A relatively new area of treatment is that of medical nutrition and the availability of the nutritional drink “Souvenaid” was considered. Cost issues aside, it was found that Souvenaid was available in seven countries (BE, DE, IE, IT, NL, ES and UK).

Clinical trials

Jean highlighted five big clinical trials (AE58054, gantenerumab, MK-8931, solanezumab and TRX0237) which are currently being carried out across the EU. In order to ascertain whether people with dementia in the EU have access to these, the website www.clinicaltrials.gov was accessed. “The results so far have revealed that there are a wide range of differences between European countries on each issue examined.”

JEAN GEORGES
Unfortunately, for over half of the countries it was not possible for people with dementia to access any of these trials. Of the other 14 countries where clinical trials were active, only one offered access to all five (ES) and three countries (DK, PT and CH) offered access to just one.

Care services availability

Alzheimer Europe identified those care services which should be made available in all EU countries and asked national associations to indicate whether each service was sufficiently available for people with dementia in their country. In some countries these vital services were either not available or not in sufficient numbers to really benefit people with Alzheimer’s disease (BG, PL, PT, RO and TR) whereas in others the reverse was true (MC). Whilst it could be argued that smaller countries may find it easier to organise such services, the analysis revealed that some larger countries (AT, BE, DK and FI) were also able to do so.

Dementia strategies

A priority of Alzheimer Europe has been the call for national dementia strategies. The analysis revealed a geographical division in this area. In 2006 only France had a strategy in place whereas in 2013, the majority of northern and central European countries have developed, or are in the process of developing, a strategy. This situation contrasts starkly with that in much of Eastern Europe, where there appears to be no interest, commitment or even indication that the governments support such a strategy.

Dementia research and funding

Countries’ approaches to dementia research were found to be highly variable throughout the EU. Members of Alzheimer Europe supported dementia research to the tune of EUR 12.6 m. Three countries (DE, FI and UK) were able to provide the contribution their government dedicated to dementia research (which amounted to EUR 140 m for the three countries) but on the whole it was difficult to ascertain the individual amount given by Member States. This was due to the fact that the research was fragmented and across different budgets.

Legal issues

Variations were also evident in each country’s approach to legal issues. Alzheimer Europe advocates the use of advance directives, the possibility of appointing a person as financial and health care proxy and it supports a person with dementia’s right to vote, rather than being perceived as a ‘non-citizen’. Four countries (AT, FI, NL and UK [E & S]) complied with these recommendations but at the other end of the spectrum six countries (CZ, LT, MT, NO, PT and TR) only complied with one recommendation.

International and EU conventions

There are six conventions which Alzheimer Europe believes should be signed and ratified. Slovenia had ratified the most (five), many had ratified four or more (CY, EST, GR, FR, HU, LU, SI and UK [E & S]). Again, there were huge differences in approaches to this by Member States and two countries had ratified only two or less (IE and MC).

Size and budgets of Alzheimer associations

Members of Alzheimer Europe make an enormous contribution which should be recognised. Currently, membership consists of 36 national Alzheimer associations from 32 countries across Europe. Employing over 3,800 staff, the associations total expenditure amounted to some EUR 190 m in 2012. Jean stressed that we should all be very proud of the work that they carry out and fully support them: indeed, this was an area which needs to be looked at in more detail, especially with respect to governmental support. The size of the associations varies hugely from country to country. A figure
representing the amount of money per person with dementia was calculated for each country which revealed that it was not necessarily those with the largest budget which had the highest allocation per person with dementia, as this title went to Luxembourg with EUR 2,528 spent by the association per person with dementia.

Conclusion

Jean explained that it was necessary to use the data with caution as it is in its very raw quantitative (not qualitative) form and it should be noted that there were many questions which could not be answered on a comparative basis. Elisabeth Calov and Marina Yannakoudakis concurred, suggesting a cautious approach when interpreting the data.

In addition, even if some data appears very positive, it might hide a negative situation. Nevertheless, the results so far have revealed that there are a wide range of differences between European countries on each issue examined and this is useful as shortcomings can be identified. This will be a priority for Alzheimer Europe in 2014. It is also envisaged that the findings will be published in a scientific journal by the end of 2014.

Jean also emphasised the enormous role that the European Alzheimer’s Alliance has played in lobbying for change for people with dementia. He called on MEPs to indicate their continued support by signing the European dementia pledge which confirms their willingness to become members of the EAA after the European elections and to make themselves available to people with dementia in their own country.

Marina asked Jean to what extent the differences in the statistics were due to the fact that Alzheimer associations varied in their abilities and scope to influence the agenda. Jean acknowledged that there is a real connection between the awareness of dementia in a country and how effective an association has been. He also called on politicians to come together with the associations in order to make a real difference to the lives of people with dementia.

Heike von Lützau-Hohlbein, Chairperson, Alzheimer Europe thanked Joseph and Jean for the debate. She emphasised the need to share the work of Alzheimer Europe, learn from each other and highlight differences across Europe.
Members of the European Parliament speak out on dementia

Alzheimer Europe asked members of the European Alzheimer’s Alliance and supportive Members of the European Parliament to highlight past achievements and future priorities.

Martina Anderson (United Kingdom, Northern Ireland)

As a carer myself, for my mother who suffers from Alzheimer’s disease, I understand personally the challenges faced by those suffering from dementia-related diseases but also for those who care for them.

In the next parliamentary mandate, I would particularly like to see research into neurodegenerative diseases such as Alzheimer’s disease being prioritised, especially within the context of Horizon 2020, to better address the societal challenge of rapid demographic changes which is already happening and will only intensify over time.

It is important that all countries make the most of this programme, the only one to receive an increase in funds in the multiannual financial framework (MFF), to increase research in dementia-related diseases. Early diagnosis and treatment is absolutely essential here.

Elena Oana Antonescu (Romania)

I believe that working alongside the European Alzheimer’s Alliance can make a difference in how Alzheimer’s disease and other types of dementia are tackled by national and European social and healthcare policies. All the members of the Alliance have shown in the past a high level of dedication and determination in the actions undertaken in order to help people affected by these illnesses.

Over the course of the next mandate, I believe that two priorities need to be addressed by the European and national leaders altogether. On the one hand, it is clear that more funding needs to be directed towards research in dementia. On the other hand, I believe that social and public policy measures need to be adopted in order to raise awareness about dementia and its challenges and foster a more inclusive society that understands the people affected by these conditions, integrates them and does not physically or emotionally isolate them from society.

Maria Badia i Cutchet (Spain)

As rapporteur for the Specific Programme implementing Horizon 2020, I defended an adequate budget for Research and Innovation in Europe. One of my priorities was the Health and Wellbeing sector, which has a dedicated budget of EUR 7.5 bn, the highest budget among the seven Societal Challenges addressed in Horizon 2020. I consider that the structure of this programme, targeting specific diseases such as Alzheimer’s disease, and the new features of the framework programme, covering the whole innovation cycle, will make a difference in the near future in the acceleration of research results in Europe.

I hope that in the future the European Parliament continues supporting science and innovation in this field as well as other aspects related with this illness.

Nessa Childers (Ireland):

Dementia is a major public health issue with massive social, political and economic implications, and it is for this reason that I have had a passionate involvement with the issue throughout my parliamentary term.
In 2011, I organised a seminar entitled ‘Shared Priorities – Dementia and Alzheimer policy in Europe and Ireland’ which focused on the EU Joint Action on Alzheimer’s initiative. The seminar was held in partnership with the Alzheimer Society of Ireland and offered a platform for policy and planning experts from Europe and Ireland to explore ways in which to help people with dementia and their families as well as ways in which to prevent the onset of dementia.

It is critical that when dealing with public policy around dementia we have to be very careful to avoid discrimination against illness of later life. While it may not be the intention, health systems often reflect a discriminatory mind-set when it comes to spending policy where there it is acceptable to put a cap on medical care for older people that would not be tolerated in cancer care or care for children.

Ole Christensen (Denmark)

As a Member of the European Parliament and the European Alzheimer’s Alliance, I consider it of the utmost importance that we raise awareness about dementia and Alzheimer’s disease. Considering the fact that Alzheimer’s disease and other forms of dementia affect millions of Europeans, the European Parliament must act to spread information about best practice care and in general work to raise awareness among national authorities and civil society.

Brian Crowley (Ireland)

I am delighted as Vice Chair of the European Alzheimer Alliance in the European Parliament to continue my support for Alzheimer Europe. With our ageing population we must push progress forward. Community wide health concerns must remain a priority for us all and patients and their families must be at the centre of all our decisions.

Joseph Cuschieri (Malta)

Through my engagement with the European Alzheimer’s Alliance, I am glad I can help respond to the needs of people with dementia and of their carers. It is clear to me that Alzheimer’s disease must attract broad policy attention and call for immediate action.

Despite progress made over the past years, it is imperative that the next European Parliament remains responsive to the challenges of Alzheimer’s disease and find solutions in collaboration with the Alzheimer associations on the ground.

I was most delighted to recently host a lunch debate when Alzheimer Europe presented its European Dementia Monitor. I find it highly interesting to compare and benchmark how EU countries deal with the rising number of people with dementia. This tool will help us, policy makers, to fine-tune our national and European dementia strategies.

Rosa Estaràs Ferragut (Spain)

We are facing a big health problem that affects the whole society and requires a global response.

The EU strategy should include a policy to prevent Alzheimer’s disease in order to avoid structural problems that could increase state spending to make front to ageing population.
One big issue to address is how to ensure that, in the early stages, people with neurodegenerative diseases can continue working and contributing to society.

Administrations should take into account the social and health work performed by caregivers, 88% women, who suffer severe physical and mental strain that requires us to ensure their well-being.

**Nathalie Griesbeck (France)**

As it affects all Europeans without any distinction, the fight against neurodegenerative diseases and Alzheimer’s disease in particular must remain a public health and research priority of the next European Parliament.

All MEPs who will renew their mandate and all those new to the European Parliament will be confronted with a double responsibility. First, to continue raising awareness about the disease and its challenges and revive the synergy that we have established at the Europe level between the different actors during this current mandate. Second, to intensify our action to make sure Europe becomes a centre of excellence in scientific research on Alzheimer’s disease. This is fundamental: it is imperative to stimulate research in order to better understand the disease. Without understanding the disease, it will be extremely difficult to take action.

That is what I have supported since 2007 alongside Alzheimer Europe and as a member of the European Alzheimer’s Alliance and what I intend to continue to do with my European Parliament colleagues in the coming 5 years.

**Françoise Grossetête (France)**

As Chair of the European Alzheimer’s Alliance, I wish to address my sincere gratitude towards all national Alzheimer associations who daily provide support to the families and the people with Alzheimer’s disease.

At European level, a lot still remains to be done. However, I am most appreciative of the recent financial investments of the EU and the implementation of an unprecedented joint programming of research aiming to pool resources and rally the best scientific competences in Europe. Horizon 2020, the new EU research programme that has just been adopted has been allocated over EUR 70 billion for the period 2014-2020. This is an unprecedented effort towards research in Europe. It is indeed one of the most important research and innovation investment worldwide. Part of this budget will go towards financing European research programmes in age-related diseases.

**Fiona Hall (United Kingdom)**

I hope that the increased EU budget for research and the focus on active aging will stimulate new lines of enquiry, such as mapping of early changes in the brain using innovative imaging techniques to identify the key factors causing the onset of the disease.

I also hope that exchange of best practice at a European level could lead to a raised level of public awareness about behavioural changes in the very early stages of the disease. This could contribute to more accurate and sensitive interpretation of behaviours such as lack of inhibition which might
otherwise be dismissed as eccentric or inappropriate, and thus help to ensure earlier diagnosis and protection of vulnerable individuals.

Anneli Jäätteenmäki (Finland)

The EU must invest more in research. What is more, the EU should actively support the formulation and the implementation of national action programmes. For an ageing Europe, Alzheimer's disease and related illnesses are a matter of urgency and a common problem.

Mocja Kleva Kekus (Slovenia)

Our rapidly ageing population means that the costs for addressing dementia will continue to increase. In order to tackle this problem, we need improved coordination between Member States as well as effective guidelines to prevent and treat patients and the people around them. More should be done in the direction of home care and day care centres with a special programme for people with dementia. Dementia can no longer be set aside. It is time to start addressing this problem publicly and take the necessary steps to improve the lives of the people living with this disease.

Jean Lambert (United Kingdom)

There is a lot of expertise and good practice across the EU that can really help those caring for people with Alzheimer's disease and other dementias: we need to develop better ways of bringing together and sharing that information so it can be used more effectively.

I know from Carers' and other organisations, that there is also a need for better quality and greater support for those informal carers and that we need to develop better training, support and pay for those who provide much of the everyday, professional care.

Obviously, we also need to continue research as to the causes, prevention and treatment of the condition: one which is often so devastating for sufferers themselves and also for those who love and care about them.

David Martin (United Kingdom, Scotland)

With an increasingly ageing population in the European Union, issues such as dementia are moving further up the political agenda – and rightly so. I believe that as dementia is one of the most pressing long-term challenge facing our health and social services in the EU it must become a public health priority in Europe.

We must do all we can by working with organisations such as Alzheimer Europe to find effective treatment, and also put resources into research and prevention: examining whether lifestyle choices, such as changing our diet and exercising could reduce the risk of developing the disease. As well as this we must find resources to help those, often close family, who are caring for the dementia sufferers – this is an issue we must tackle together.

Marisa Matias (Portugal)

Being the rapporteur of the European Parliament for Alzheimer’s disease and other dementias was one of the biggest honours I had during these last years. All the networks and efforts which came
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For the future we have nothing to invent, we just need to put into practice all the good declarations that have been produced and implement them as we keep fighting together for dignity and justice. And that means a lot of work.

Linda McAvan (United Kingdom)

Like many people, it was when loved ones were affected by neurological disorders that I became much more aware of the need for more research into the causes of neurological disorders and for better care for those living with these conditions. I have therefore been very pleased as an MEP to work alongside the European Alzheimer’s Alliance to get the EU to pool knowledge and resources to tackle Alzheimer’s and related conditions.

A special workshop on ‘Alzheimer’s Disease and Other Dementias’ was organised by my committee in 2010. The workshop gave MEPs, representatives of the EU institutions, patient associations and scientific experts the chance to come together to establish best practice, as well as share our personal experiences of knowing and caring for those with Alzheimer’s.

A great deal of my time in this Parliament has been spent on health issues, including work on medicines safety to ensure that there is proper monitoring of the side effects of medicines and clinical trials, to make sure new medicines are properly trialled before they reach the market.

We know that times are tough and that there is real pressure on resources at present, but with an estimated 1 in 6 people over 80 in the UK suffering from some form of dementia, that’s over 6 million people in the EU, we cannot afford not to act, now and into the next parliament.

Mairead McGuinness (Ireland)

At a time when research around Alzheimer’s looks very promising for the future it is time to keep the foot on the pedal in terms of support for such research to ensure that the promise is delivered.

Equally we need to ensure that political priority across Europe is given to this research and also to other important issues including appropriate care, social support, public health policy and the law.

Gay Mitchell (Ireland)

Alzheimer’s disease is a major public health challenge and it is very important that we progressively raise awareness about this disease in order to get the attention of key players at a European and national level. This will help to improve research, funding and treatment for Alzheimer’s. Networking is vitally important to progress this issue and we need to network the key players as much as possible. It also matters who is sent to the Parliament and Commission to lobby on behalf of Alzheimer’s, people must be mandated to take decisions when lobbying.

Claude Moraes (United Kingdom)

In my role as Chair of the Intergroup on Ageing and Intergenerational Solidarity, I have worked closely with Alzheimer Europe throughout this Parliamentary term and will continue to do so in the
future to ensure that Alzheimer's remains a key health priority throughout the EU.

In the next Parliament, we need to continue our work in these vital areas but also examine some of the challenges faced by dementia patients. We should particularly focus on how to ensure that products, services and the environment in general are accessible for persons suffering from dementia and their informal carers as well as facilitating active and independent living, all with the aim of improving the quality of life and independence of both groups.

We need to do everything we can to ensure that this vulnerable group of persons and their carers are adequately protected and supported whilst working to make improvements in care.

Angelika Niebler (Germany)

The European Union acknowledges the importance of greater European collaboration on Alzheimer's disease and related disorders. However we need to do more. I believe that the European awareness about the necessity to fight dementia and address the difficulties of people with dementia and their families should be raised further.

The key tool in the fight against dementia is undoubtedly research. Therefore, I am glad that the research on the disease of Alzheimer is included into the next European research programme, “Horizon 2020”, which stresses the importance of research especially with respect to societal challenges such as aging population. Hopefully, the research especially in this regard will contribute to successfully fighting against Alzheimer’s, thus giving hope to people suffering nowadays from Alzheimer’s and their families.

Alojz Peterle (Slovenia)

As Co-Chair of Health Working Group within the European Parliament's Environment, Public Health and Food Safety Committee I pay particular attention to dementia and raising public awareness about this disease.

In the next mandate, it will be the time to make dementia a priority and the European Parliament shall commit itself to meaningful, shared steps to drive forward dementia research and support investment in dementia research to attract, develop and retain the best scientists, clinicians and care professionals.

Besides, the creation of National Alzheimer’s Plans in each Member State and the development of a European Action Plan on Alzheimer’s disease the European Parliament shall be stimulated.

Working together with the EU institutions, Member States, the research community, non-profit organisations and industry we will aim to transform the lives of people with dementia also by encouraging dementia-friendly environments allowing them to retain as much dignity and autonomy as possible.

Sirpa Piitikainen (Finland)

During the next European Parliament legislature, guaranteeing non-discrimination through the adoption of the equal treatment directive is the priority issue. It is a key tool to address silent discrimination that especially people with memory disabling diseases face in societies.

Also stronger focus needs to be put on those caring for patients. We need a European level strategy
for carers which introduces the ways to achieve a decent level of status, benefits and leaves for carers.

**Dagmar Roth-Behrendt (Germany)**

The silent, often ignored way of dementia into one’s family life hits everybody always unprepared. There are “only” two real challenges for us to tackle: (1) Invest as much as possible into any research to postpone, delay and ease the disease, and perhaps at some day: prevent and heal it. (2) As long as we are not there yet: inform, inform, inform. Friends and family have to understand what happens with their beloved ones, and need practical and psychological support to be able to help the dement person to live without fear, while recognising that the known world vanishes slowly. The affected ones need as much stimulation, respect and assistance in daily life as possible to help them keep their dignity during their life.

**Brian Simpson (United Kingdom)**

Dementia is becoming ever more prevalent and I believe there is a clear need for a European strategy to tackle the challenges surrounding the condition. I hope that in the next mandate, Members of the European Parliament will give the issue the attention it deserves and continue to work to find pan-European solutions for the challenges facing both dementia patients and those that care for them.

**Lambert van Nistelrooij (Netherlands)**

Europe is ageing fast. The number of people with dementia increases. There is an unacceptable gap between the European priorities and the funds we spend on age-related diseases. There is a misbalance in the European spending. For instance, the energy research receives 10 times more budget. We need to change.

**Derek Vaughan (United Kingdom)**

In my position as Labour MEP for Wales, and member of the European Alzheimer’s Alliance, I am keen to promote discussion and awareness of Alzheimer’s disease within the European Parliament. I have recently signed the Written Declaration on the challenges of neurodegenerative diseases in the workplace, and hope that this will help raise the profile of the challenges faced by people with dementia at work. I would like to see the stigmatisation of people with dementia, the lack of social support and the lack of understanding of the disease addressed during the next European Parliament mandate.

**Angelika Werthmann (Austria)**

Dementia is an issue which is gaining more and more centre stage in our society and in politics as well, and which will increasingly demand attention in the future – not only due to the demographic developments. I see the strengthening of the public dialogue between politics and the civil society as a core task for all parties involved. It is a basic principle of the European Alzheimer Alliance to make information public and to realise them in political concepts, which contributes to the building of communication networks on all levels.
Among the challenges for the future are the high economic costs of dementia (especially in respect to the unfavourable development of the relation between employed persons and dementia sufferers), where, simultaneously, the personal fates and needs of the affected people and their relatives have to be kept in mind.

Glenis Willmott (United Kingdom)

I have worked closely with Alzheimer Europe throughout this Parliamentary term, from trying to improve prevention by working on risk factors such as nutrition and alcohol, to improving treatments by encouraging and supporting dementia research in my role as rapporteur for the Clinical Trials Regulation.

I have also tried to ensure that research and projects focusing on the ageing population and dementia get sufficient funding through the EU’s Health Programme and Horizon 2020.

In the next Parliament we need to continue this work, but I think we also need to look at some of the challenges around employment and social care faced by both dementia patients, and by their carers. With the ageing population, and the worldwide rate of dementia set to double every twenty years, this is a problem we cannot ignore.

Corien Wortmann-Kool (Netherlands)

I myself as an MEP have been engaged with the cause of dementia in Europe during my terms as Member of the European Parliament on many occasions. Alzheimer’s disease is posing serious challenges to the health of a growing number of Europeans and I have always emphasised this. In addition, my husband is Director of Alzheimer’s Disease International, which means that I am very sensitive to this huge problem and the urgent need for Europe to make more of an effort.

The role of the Alliance in the Parliament must not be underestimated. In the past years, more awareness within the European Parliament has been raised. More importantly, more funding for research and coordination on the side of the Commission has been put in place. These steps will enhance health and ageing of European citizens.

However, many challenges remain in the next mandate of the European Parliament. I want to mention further efforts with regard to medicine development for Alzheimer’s disease. Also, the awareness of Alzheimer’s and its implications in the future still has to be raised both in the Parliament, in Europe and our Member States. I have good hope the Members of the European Parliament will continue their effort in the next legislative term.

Marina Yannakoudakis (United Kingdom)

We need to find a cure for Alzheimer’s; too many people’s lives are affected by this terrible disease. In my London constituency alone, 68,000 people have developed dementia with thousands more relatives and carers are feeling its effects. Dementia is estimated to cost the British National Health Service GBP 23 billion a year. By investing in a cure, we can bring relief to the millions affected by Alzheimer’s as well as helping our overstretched health systems.
Alzheimer Europe presents the 2013 Dementia in Europe Yearbook

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

Alzheimer Europe's latest offering is a report on the provision of care, the training of health and social care professionals and support in the home, the community and in nursing homes. For each country, the report includes details of the national dementia strategy and/or any related policy provisions.

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

Most of the reports were written by, or with the assistance of, Alzheimer Europe's member associations. AE is very grateful for their cooperation and hopes that the Yearbook will provide a useful overview of how different countries have addressed these common issues.

This Yearbook also contains Alzheimer Europe's Annual Report for 2012.

Comparable prevalence of dementia across 33 countries

The first section of the survey provides background information such as the prevalence of dementia, by sex and age group and also expressed as a percentage of the total population. The latter is a handy reference: it allows each country to be compared to the 1.55% EU average.

Amongst EU countries, three (CY, IE, SK) are well below this average and five more (CZ, LU, MT, PL, RO) are slightly below it. Ten countries (BG, DK, EE, HR, HU, LT, LV, NL, SL, UK) have a dementia rate that is very close to 1.55% and six others (AT, BE, ES, FI, GR, PT) are slightly higher. Finally, four countries (DE, FR, IT, SE) have much higher rates than the EU average.

Outside the EU, Turkey has a much lower prevalence rate while Iceland is only slightly lower. Jersey and Norway are on a par with the Member States and Switzerland is slightly higher. The comparative tables can be seen below [OR] on page X.

The report shows a total of 9.25 million people with dementia in 33 European countries, of which two thirds are women. This includes 8.7 million people in the 28 EU Member States with the remainder in Jersey, Iceland, Norway, Switzerland and Turkey. All figures are based on Alzheimer Europe calculations, using 2012 population statistics from the United Nations and two sets of prevalence rates – namely those from the EURODEM study (1991) for the younger age groups and those from the EuroCoDe study (2008) for the older age groups.

People with dementia mainly live at home

The first report section also shows the place of residence of people with dementia. While exact figures were difficult to come by, it is clear that most people with dementia live in their own homes. This is the case in many of the countries where data were available, irrespective of any other demographic factors. The survey also attempts to estimate the percentage of people with dementia who live in nursing homes, residential homes, hospitals or psychiatric establishments.

Finally, this section covers the ratio of staff to patients within these care centres; as may be expected, these data were not universally available
and the ratios varied greatly between countries. In general, countries with active dementia strategies have more specialised facilities and staff that are specifically trained in the care of people with dementia in residential care.

Organising care and support for people with dementia

The second section of the yearbook explores the overall organisation of care and support and also how specific aspects are addressed. For some countries, this includes a description of the legislative structures that control health care policy, both on national and local levels. Wherever possible, details are provided of specific benefits or services that are available to people with dementia.

Training for professionals

The final section of the 2013 Yearbook addresses the availability of training programmes for social and healthcare professionals. This section begins with a table showing the types of professionals that provide care and support to people with dementia in residential care or living at home. In most cases, these professionals are nurses, auxiliary staff and allied health professionals. However, there are also some countries where GPs and specialists provide care or support beyond medical treatment. This may include training staff in dementia care or being involved in the organisation of care and support.

Wherever possible, the table is followed by a detailed description of the training programmes that are available for these health and social care professionals. This may include degree courses and professional courses that lead to state certification.

This is followed by a description of how this training is organised, such as whether the local government provides legislation for this type of education.

Support for informal carers

The final part of this section looks at the various national policies addressing support for informal carers of people with dementia. The service offer varies widely but may include respite, training and counselling or similar support. In many cases, national Alzheimer associations provide some form of support, as they are intimately familiar with the challenges that face informal carers.

Role of the national Alzheimer association

Each country report concludes with an overview of the services offered by the national Alzheimer association. The most common services are telephone helplines, legal advice, news publications and websites. Many associations conduct awareness campaigns and provide counselling and support groups such as Alzheimer Cafés. Day care centres and training sessions are also widespread but home respite services exist in fewer countries. Several associations are able to offer home help and home care while only a few provide incontinence help or assistive technologies.

It is important to note that Alzheimer associations often provide services that are not covered by national authorities. Similarly, associations do not need to provide services that are already covered by their governments. This report does not aim to highlight the more prolific organisations, but rather to provide an overall picture and, perhaps, provide inspiration for future service offerings.
The status of national dementia strategies in Europe

Countries with national dementia strategy in place
Countries with government commitment to develop a dementia strategy
Countries with other political support to develop a dementia strategy
Countries with no support to develop a dementia strategy

The Dementia in Europe Yearbook 2013 is available for sale on the Alzheimer Europe website.

For more information, please see www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks or contact info@alzheimer-europe.org

Alzheimer Europe, January 2014
## Dementia prevalence in 28 EU countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
<th>% of population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>45,938</td>
<td>99,494</td>
<td>145,432</td>
<td>1.73</td>
</tr>
<tr>
<td>Belgium</td>
<td>62,972</td>
<td>128,309</td>
<td>191,281</td>
<td>1.77</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>37,851</td>
<td>72,042</td>
<td>109,893</td>
<td>1.49</td>
</tr>
<tr>
<td>Croatia</td>
<td>20,394</td>
<td>46,682</td>
<td>67,076</td>
<td>1.53</td>
</tr>
<tr>
<td>Cyprus</td>
<td>4,333</td>
<td>6,917</td>
<td>11,250</td>
<td>1.07</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>45,532</td>
<td>97,778</td>
<td>143,310</td>
<td>1.36</td>
</tr>
<tr>
<td>Denmark</td>
<td>29,715</td>
<td>55,847</td>
<td>85,562</td>
<td>1.53</td>
</tr>
<tr>
<td>Estonia</td>
<td>5,469</td>
<td>16,252</td>
<td>21,721</td>
<td>1.62</td>
</tr>
<tr>
<td>Finland</td>
<td>29,287</td>
<td>62,945</td>
<td>92,232</td>
<td>1.71</td>
</tr>
<tr>
<td>France</td>
<td>375,843</td>
<td>799,113</td>
<td>1,174,956</td>
<td>1.85</td>
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<tr>
<td>Germany</td>
<td>517,136</td>
<td>1,054,968</td>
<td>1,572,104</td>
<td>1.92</td>
</tr>
<tr>
<td>Greece</td>
<td>75,392</td>
<td>126,375</td>
<td>201,767</td>
<td>1.77</td>
</tr>
<tr>
<td>Hungary</td>
<td>43,636</td>
<td>105,291</td>
<td>148,927</td>
<td>1.50</td>
</tr>
<tr>
<td>Ireland</td>
<td>17,895</td>
<td>31,574</td>
<td>49,469</td>
<td>1.08</td>
</tr>
<tr>
<td>Italy</td>
<td>414,975</td>
<td>857,341</td>
<td>1,272,316</td>
<td>2.09</td>
</tr>
<tr>
<td>Latvia</td>
<td>8,902</td>
<td>26,812</td>
<td>35,714</td>
<td>1.60</td>
</tr>
<tr>
<td>Lithuania</td>
<td>12,567</td>
<td>34,768</td>
<td>47,335</td>
<td>1.44</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>2,327</td>
<td>4,662</td>
<td>6,989</td>
<td>1.34</td>
</tr>
<tr>
<td>Malta</td>
<td>1,878</td>
<td>3,423</td>
<td>5,301</td>
<td>1.26</td>
</tr>
<tr>
<td>Netherlands</td>
<td>83,247</td>
<td>162,314</td>
<td>245,561</td>
<td>1.47</td>
</tr>
<tr>
<td>Poland</td>
<td>150,371</td>
<td>350,721</td>
<td>501,092</td>
<td>1.31</td>
</tr>
<tr>
<td>Portugal</td>
<td>62,260</td>
<td>120,266</td>
<td>182,526</td>
<td>1.71</td>
</tr>
<tr>
<td>Romania</td>
<td>90,484</td>
<td>179,820</td>
<td>270,304</td>
<td>1.26</td>
</tr>
<tr>
<td>Slovakia</td>
<td>17,834</td>
<td>40,774</td>
<td>58,608</td>
<td>1.07</td>
</tr>
<tr>
<td>Slovenia</td>
<td>9,324</td>
<td>22,711</td>
<td>32,035</td>
<td>1.57</td>
</tr>
<tr>
<td>Spain</td>
<td>280,149</td>
<td>538,197</td>
<td>818,346</td>
<td>1.75</td>
</tr>
<tr>
<td>Sweden</td>
<td>60,479</td>
<td>112,656</td>
<td>173,135</td>
<td>1.82</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>360,581</td>
<td>677,210</td>
<td>1,037,791</td>
<td>1.65</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2,866,771</td>
<td>5,835,262</td>
<td>8,702,033</td>
<td>average 1.55</td>
</tr>
</tbody>
</table>

## Dementia prevalence in 33 European countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jersey</td>
<td>483</td>
<td>918</td>
<td>1,401</td>
</tr>
<tr>
<td>Iceland</td>
<td>1,487</td>
<td>2,435</td>
<td>3,922</td>
</tr>
<tr>
<td>Norway</td>
<td>25,932</td>
<td>51,226</td>
<td>77,158</td>
</tr>
<tr>
<td>Switzerland</td>
<td>44,201</td>
<td>89,521</td>
<td>133,722</td>
</tr>
<tr>
<td>Turkey</td>
<td>134,927</td>
<td>196,586</td>
<td>331,513</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>207,030</td>
<td>340,686</td>
<td>547,716</td>
</tr>
</tbody>
</table>

*Note: Total for EU-28 plus Jersey, Iceland, Norway, Switzerland and Turkey: 9,249,749*
With a large consortium of 29 partners from 16 Member States, AGE submitted last May a proposal in response to a call launched by the European Commission. The overarching goal of the AFE INNOVNET project is to support the European Innovation Partnership on Active and Healthy Ageing D4 Action Group on Age-Friendly Environments (AFE) by setting up a large EU wide community of local and regional authorities (LRAs) and other relevant stakeholders across the EU who want to work together to find smart and innovative evidence based solutions to support active and healthy ageing and develop AFES across the EU. Special attention will be paid to include the concept of dementia-friendly communities in the vision of AFE that will be promoted through this thematic network.

Together we want to:
• mobilise a wide range of LRAs, industry, research centre/universities, civil society organisations – to link up, benefit from each other’s experience and work together to promote initiatives on AFE across the EU;
• develop methodologies to help LRAs assess the socioeconomic impact of AFE and the benefits of involving older people in the co-production of AFE solutions;
• develop a repository of replicable notable and best practices in innovative ICT and services solutions with associated socio-economic evidence;
• facilitate pilot projects clustering to stimulate local/regional investment in ICT and services innovation and thus local/regional economic activity;
• facilitate public access to research/expertise and generic methodologies in the field of AFE and dementia-friendly communities;
• ensure convergence and strong coordination with WHO Age-Friendly Cities and Healthy Cities initiatives;
• facilitate information-sharing between all interested stakeholders in the field of AFE;
• launch an EU Covenant on Demographic Change to create the necessary political and technical framework to bring together in a more formal and long-term structure LRAs – and other stakeholders – across the EU who want to cooperate and implement smart and innovative evidence based solutions.

In January 2014, AGE received funding approval for the AFE-Innovnet project. The organisation will now open up the thematic network to new interested parties. For more information, see www.age-platform.eu
Ethical issues on the ways that dementia is portrayed and perceived

Dianne Gove, Director for Projects at Alzheimer Europe, reports on the work of the European Dementia Ethics Network in 2013.

In 2009, Alzheimer Europe established the European Dementia Ethics Network with the aim of encouraging ethical reflection on a range of topics of relevance to the lives of people with dementia and their carers. In 2013, the multi-disciplinary working group reviewed the literature and reflected on the different ways that people with dementia are perceived and portrayed within society, as well as the ethical implications of this for people with dementia. The group was chaired by Dianne Gove and the members, to whom we would like to express our gratitude, were Debby Gerritsen, Bénédicte Gombault, Fabrice Gzil, Jana Kasparova, Jan Oyebode, Sirpa Pietikaïnen, Christine Swane, Baldwin Van Gorp, Aino Valtanen, Richard Wallace and Daphne Wallace. The working group explored the perceptions and portrayals of dementia of different groups in society (e.g. the general public, people with dementia, carers and healthcare professionals), the use of language and the influence of the media and film-makers. With regard to ethical issues, we considered whether, and if so in what way, various perceptions and portrayals of dementia might be beneficial or potentially harmful to people with dementia.

The way that people perceive and portray dementia is important as it can have a positive or negative impact on the way that people with dementia are valued and how dementia is addressed within society. It may, for example, affect the standard of care people with dementia receive, the importance given to medical treatment, their involvement in research and the kind of research carried out, social inclusion, expenditure on care or support and the extent to which their human rights and dignity are respected. Perceptions are communicated to people with dementia through words, gestures, intonation and even avoidance but people with dementia are part of the society in which the socially constructed meanings associated with dementia are developed. Consequently, when people suspect or find out that they have dementia, those perceptions may influence their expectations in relation to their future lives and how they will be treated by other people, as well as their self-concept and self-esteem.

The report starts with an overview of explanatory models, which reflect how people make sense of dementia, covering for example its origin or cause and beliefs about how it is experienced. On the one hand, a historical development can be detected in the focus on certain models at different points in time but on the other hand, some cultural differences can be detected and it became clear that the various models are not exclusive. For example, the perception of dementia as part of natural ageing, a biomedical condition or a mental disorder does not exclude it being perceived as a disability or due to spiritual forces.

The words and metaphors that people use in connection with dementia are rich in symbolism and significance, sometimes used strategically to achieve certain goals, sometimes used without much reflection. The impact of the language surrounding dementia is considerable and reflection on the possible ethical implications suggests that there are very few expressions which can be considered as wholly “good” or “bad”. For one person a word or metaphor might represent hope or help them to cope (either with dementia or with caring for someone with dementia), whereas for another it sums up dread and loss of the self. Some words and metaphors are used liberally and paint a very biased picture of dementia, whilst others are avoided and considered demeaning, depersonalising and insult-
Certain metaphoric representations of dementia may contribute towards fear and the stigmatisation of people with dementia.

Metaphors of the zombie, the “empty shell” and of people fading away can communicate a very daunting image of dementia. Similarly, as has been the case with cancer, a great deal of fighting terminology is used and catastrophic references to dementia such as a tsunami, disaster, time bomb and epidemic. Whilst this may serve to draw attention to the need to address the care and support of people with dementia, such metaphoric representations of dementia may contribute towards fear and in turn towards the stigmatisation of people with dementia.

Even standard medical terms are sometimes used with great caution due to an awareness of the possible impact on people’s lives and wellbeing, although some people consider it important to use such terms, precisely as a means to overcome stigma. We consider the possible need to abandon terms which are considered by people with dementia as offensive but at the same time question whether the introduction of new official terms for dementia and Alzheimer’s disease are likely to change the way that the underlying, newly designated condition is perceived. Words clearly matter. They describe, communicate and reinforce our current perceptions of dementia. With awareness, we can try to use them positively to challenge portrayals of dementia and promote a more positive image of dementia and of people with dementia.

An exploration of the way in which the existence and experience of dementia are perceived and portrayed reveals a range of philosophical beliefs about what it means to be a person and how dementia affects this experience and state of being. Turning to the perceived characteristics of dementia, we find a few key stereotypes which focus on the end stage of dementia, on people with dementia having no quality of life and on vulnerability. Here the challenge perhaps lies in acknowledging the diversity of people with dementia, interacting with them, recognising that they have something to offer and reflecting on the numerous factors which influence how they are perceived, portrayed and subsequently treated.

This report reflects a social constructivist philosophy of the way that we make sense of the social world in which we live. This approach emphasises the importance of interacting with others in a process of meaning making. In today’s society, this happens directly through the people we encounter but also indirectly through the media and films. We therefore also reflect on the concept of frames and counter-frames, as a means to present a more nuanced and hence realistic perception of dementia and on the way that the portrayal of dementia in films affects people emotionally and may influence their understanding and expectations in relation to dementia.

Having described numerous ways of perceiving and portraying dementia, we consider how this relates to the experience of people with dementia and to what they are telling us. More and more people with dementia are stepping out of their comfort zones, writing or standing up in public and describing their personal experience. It is important to listen to them, to hear what they are telling us and to avoid discounting their valuable insight if it does not fit in with our current perceptions. We also need to bear in mind how people with dementia feel about the way that they are portrayed and perceived. In the last part of the report, we provide a short set of general guidelines to encourage a balanced perception of dementia and to consider when addressing, referring to or portraying people with dementia.

It is hoped that this report will contribute towards the recognition of people with dementia as unique, valued individuals and the promotion of their dignity, wellbeing and rights through greater attention and sensitivity to the way they are perceived and portrayed.
Policy Watch

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40 G8 Summit
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The challenge of dementia in Europe

José Manuel Barroso, President of the European Commission, talks with Alzheimer Europe about how Europe can help people with dementia and, in particular, about the Communication on “Strengthening the social dimension of the economic and monetary union”.

Alzheimer Europe (AE): President Barroso, some nine million people have a form of dementia in Europe. This has a huge social and economic impact on society which will be further exacerbated by the ageing of the population. How is the European Union helping Member States deal with this challenge?

President Barroso (PB): It is estimated that up to 14 million people will be affected by dementia by 2040. This will inevitably affect the organisation and financing of our healthcare and long-term care systems.

The organisation and financing of health care systems, and the delivery of medical care, is the responsibility of Member States. However, the EU can improve the context in which Member States operate their health systems and support them in their actions. As part of our economic governance process, healthcare and long-term care related issues form part of the country-specific recommendations, which the Commission addresses to Member States. Such recommendations relate not only to cost-effectiveness, but also to the accessibility of health care.

While there is no one-size-fits-all solution for all countries, it is part of our European model that access to healthcare is a fundamental right and health a value in itself.

While there is no one-size-fits-all solution for all countries, it is part of our European model that access to healthcare is a fundamental right and health a value in itself. Health is also a key component for economic success and social cohesion. Health is an asset, and investing intelligently in health, not just financially, but also through cooperation, coordination and political will, will yield returns for society and the economy.

The EU, within its competences, is keen to support Members States’ efforts to address the challenges that national health systems are faced with, including the expected growth in dementia and its impact on society.

This is why in 2009 the Commission launched a European initiative on Alzheimer’s disease and other dementias. Within this framework, our health programme supported Member States’ action to identify and exchange good practices, for instance on the timely diagnosis of dementia and the appropriate use of medicines from 2010 to 2013.

In addition, in the past six years the Commission invested EUR 401 million from its research programme on research and innovation in neurodegenerative diseases, including in particular Alzheimer’s disease, dementia and Parkinson’s disease.

Our European innovation partnership on active and healthy ageing has further brought together around one thousand public and private stakeholders from all across the EU to shape innovative solutions, for instance in assisting elderly people to live healthy and independent lives or in creating dementia-friendly environments.

Finally, this year the Commission launched the human brain project as part of our future and
Stakeholders’ involvement in EU policy-making is essential and contributes to the ownership and efficiency of its policy orientations and their implementation.

PRESIDENT BARROSO

emerging technologies initiative that supports our Europe 2020 strategy. We will provide one billion euro over ten years to develop computer-simulated models of the brain.

AE: Under your leadership, the Commission adopted a Communication on “Strengthening the social dimension of the economic and monetary union (EMU)” on 2 October 2013. How can the social challenges of dementia be addressed under this focus?

PB: In response to the crisis, over the last five years the EU has taken considerable steps forward in terms of economic governance. The purpose of our communication “Strengthening the social dimension of the economic and monetary union (EMU)” was to highlight that, to be sustainable in the long term, Europe’s EMU now needs to strengthen its social dimension.

In this regard, the communication marked a further step towards consolidating the social dimension of the EMU. The aim is to better address problems of divergence between Eurozone countries’ employment and social situation. If the performance of Eurozone countries is looked at against a number of indicators, such as unemployment rates or the real gross household disposable income, the extent of this divergence between countries is significant.

To detect major employment and social problems earlier and in the context of the European Semester, the Commission will monitor, for example, the working age population at risk of poverty, income inequalities and the real gross disposable income of households.

The social challenges of dementia are indeed relevant in this context.

AE: Caring for a person with dementia may have a significant economic impact on individual carers but equally on society as a whole due to lost wages. Does the Communication address the work challenges faced by informal carers and make concrete proposals to allow for a better reconciliation of work and care?

PB: Indeed. A 2011 study on the costs of brain disorders in Europe estimated that in 2010 dementia led to medical costs of almost EUR 17 billion, and non-medical costs of EUR 88 billion.

To meet the Europe 2020-target to increase the employment rate of 20-64 year-olds to 75%, while meeting an increase in the number of care-dependent older people, we need to make it easier for the situation of family carers to be taken into account.

Allow me however to clarify that the communication did not aim to address these specific challenges related to employment of informal carers. Neither did it discuss other specific challenges. The objective was to propose a framework for the earlier identification of employment and social challenges in the Eurozone countries in the context of

“Stakeholders’ involvement in EU policy-making is essential and contributes to the ownership and efficiency of its policy orientations and their implementation.”

PRESIDENT BARROSO

Alzheimer Europe
the European Semester and to promote necessary reforms in response to them.

**AE: The Communication recommends strengthening social dialogue. How can organisations such as Alzheimer Europe contribute and be active partners in implementing the strategy at national level?**

**PB:** Organised civil society and individual European citizens have a stake and a role to play in building the social dimension of the EMU and the EU. Stakeholders’ involvement in EU policy-making is essential and contributes to the ownership and efficiency of its policy orientations and their implementation. The Commission requests that Member States identify how social partners and other relevant stakeholders have been involved or consulted in the process when they submit their national reform programmes, which detail reform measures.

**AE:** In your “State of the Union” address in September, you expressed your faith in science and the need to invest more in innovative technologies. How will the European Union pave the way for more European collaboration on scientific, technological and social research in the field of dementia?

**PB:** Research and innovation are key contributors to achieve our Europe 2020 goals of growth, jobs, competitiveness, quality of life and social inclusion. The innovation union policy is key to reach those goals by removing obstacles to innovation and by putting in place the conditions that will smooth the path from lab to market. The new EU framework for research, Horizon 2020, will be one of the main tools to implement the innovation union policy.

In this context, research and innovation in the area of Alzheimer’s disease can particularly contribute to the main targets of the EU2020 strategy in several ways. It can help improve the quality of life of people affected by brain disorders. It can help better include patients in society by re-integrating them into work life. Finally, it can help create jobs and increase European competitiveness with innovative medical products.

The Commission’s proposal for Horizon 2020 sets up the framework for the EU’s future research and innovation programmes for 2014-2020, with a budget of more than EUR 70 billion.

Horizon 2020 will be structured around three pillars: ‘Excellent science’, ‘Industrial leadership’ and ‘Societal Challenges’. There will be plenty of opportunity for research on dementia in all three pillars of Horizon 2020, and in particular within the ‘Health, demographic change and well-being’ challenge, which will address improving diagnosis, understanding and treating diseases, or promoting integrated care.
AE Conference sets ambitious goals
Maltese and EU officials open the conference with optimism

Living well in a dementia-friendly society
The conference focused on integrated care, prevention and dementia-friendly societies

Snapshots from Malta

EWGPWD: active participation of people with dementia
The European Working Group of People with Dementia operated a stand and organised a special symposium during the conference

Demographics of a successful conference
Conference gets high ratings from 529 delegates from 44 countries
AE Conference sets ambitious goals

Throughout Alzheimer Europe’s 23rd conference considerable interest was evident from policy makers. The opening ceremony, held on the eve of the conference, was no exception, focusing on the situation in Malta and the EU response to dementia. Alzheimer Europe reports on this unique event.

Opening Alzheimer Europe’s 23rd conference, Stephen Abela, Chairperson of the Malta Dementia Society (MDS), explained that over the last 15 years there has been much progress made in relation to dementia care in Malta. He paid tribute to the work of the Society, which has acted as a key player in this and also acknowledged that such progress would not have been possible without the collaboration of Alzheimer Europe. Indeed, the conference in Malta had a particular strength which lay in the fact that it reflects the aims of Alzheimer Europe: the exchange of good and best practice and to learn from positive experience of other countries. He was delighted that the theme of the conference, “Living well in a dementia friendly society”, had attracted wide support.

Heike von Lützau-Hohlbein, Chairperson, Alzheimer Europe, welcomed delegates. She highlighted the importance of countries recognising that dementia is a priority and was encouraged that there are now 11 national dementia strategies in Europe and a further nine being developed. She looked forward to collaborating in the forthcoming G8 Dementia Summit. Ms Lützau-Hohlbein emphasised the support given by members of the European Alzheimer’s Alliance and also by the European Commission to this cause.

Anyone with reservations about the contribution which people with dementia can make would have been won over by the eloquent and captivating Helga Rohra, Chairperson of the European Working Group of People with Dementia (EWGPWD). She illustrated not only the enormous contribution people with dementia make, but also highlighted the value their input brings to the table. She said, “people with dementia are standing in front of you and talking to you. We are advising AE and are involved in the planning, developing and evaluation of its activities. We are the experts. We are the only ones who can tell you what it feels like when pictures of your life fade. Dementia is a political, economic and social challenge but there is also the human challenge.”

His Excellency Dr George Abela, President of Malta reminded the audience that it is estimated that every four seconds there is a new case of dementia in the world and that dementia is a major public concern on which there is no option but to act without delay. He called for a meaningful dialogue on the challenges and the need to eliminate stigma, increase awareness and to have in place structures which will enhance timely diagnosis and quality of care. President Abela highlighted that one of the unique characteristics of Malta is that it has long been a melting pot of different civilisations where integration has been key.

Godfrey Farrugia, Minister of Health for Malta, hoped that the conference would increase our understanding and knowledge of dementia, promote health and well-being and offer responses to the needs and expectations of people with dementia. He believed that the provision of good quality health care be at the top of the agenda and called...
for training and educational programmes, support for carers' needs, timely diagnosis, research, health promotion, access to high quality dementia health services and the fostering of best practices.

Plans to have a dementia strategy for Malta by the end of 2013 were highlighted by Franco Mercieca, Parliamentary Secretary for the Rights of Persons with Disabilities and Active Ageing as well as by Marvin Formosa, who stepped in to read the speech on behalf of Marie-Louise Coleiro Preca, Minister for the Family and Social Solidarity. Malta was one of the first countries to recognise the importance of national dementia plans with work beginning in 2009. Mr Mercieca emphasised that the government of Malta is committed to making dementia a priority and is confident that this will produce a positive change.

All government representatives spoke of their delight at Malta hosting its first international conference on dementia, emphasising the importance which international collaboration has if progress is to be made.

The opening ceremony concluded with a keynote lecture by Martin Seychell, Deputy Director for General Health and Consumers from the European Commission. He reflected on the World Health Organisation’s World Alzheimer report (2013) which stated that dementia will become one of the greatest challenges of health systems and that countries will not be prepared for this challenge unless action is taken. Mr Seychell explained that there has been significant progress to support and prepare for the challenges ahead at both the EU and Member State level. Indeed, a central element of EU policy and concern across Member States is the promotion of active and healthy ageing. He gave various examples: ALCOVE looked at the epidemiology, timely diagnosis, rights and autonomy and dignity, supports systems in place for people with dementia. The European Innovation Partnership on Active and Healthy Ageing is looking at innovative ways to coordinate comprehensive interventions. The European Commission approach “Investing in Health” sends the message that dementia costs should not be seen as a cost burden but as an investment in the economy which can pay great dividends provided the right choices are made. In research, the joint programming of research in neurodegenerative diseases (JPND) addresses scientific and societal challenges while the EU invested EUR two billion into brain research and innovation through FP7, the current European Framework Programme for research.

In the future, the EU will continue to address this challenge by the provision of funds for brain research through Horizon 2020, “IMI2” (the next Innovative Medicines Initiative due to start in 2014) and by participating in the Human Brain Project. Neurodegenerative diseases will be a health priority of the next Health Framework Programme which starts in 2014, and by addressing the challenge of dementia through all policy areas. Member States have a key role to play as they are primarily responsible for the development of healthcare at national level: an ultimate objective is that all Member States adopt national strategies on dementia. The EU will continue to support Member States in the field of neurodegenerative diseases with a planned report on the strategy on Alzheimer’s disease due in 2014 and also discussions ongoing to follow up the work done in the ALCOVE project.

The concluding remarks by Mr Seychell were extremely well-received: he said that the message is that the European Commission does not, and will not, give up on the fight against dementia. In addition, the Commission highly recognises and values the contributions which people with dementia and NGOs make in the fight against dementia.

The tone of the conference was set and the anticipation high!
Alzheimer Europe’s 23rd annual conference took place in St. Julian’s, Malta on 10-12 October 2013. Alzheimer Europe takes a look at some of the highlights.

The theme of Alzheimer Europe’s 2013 conference was “Living well in a dementia-friendly society”. Held in Malta, this international conference brought together over 520 delegates from 44 countries representing a wide range of backgrounds within the field of dementia (including people with dementia, carers, national and international policy makers, healthcare professionals, researchers and national Alzheimer associations). Participants were able to choose from over 110 presentations in plenary (dedicated to integrated care, prevention, innovation and dementia and a dementia friendly society) and parallel sessions, special symposia and workshops. People with dementia actively took part as presenters in both the plenary and parallel sessions.

Integrated care

Angiolina Foster, DG Health and Social Care Integration, Scotland, told delegates of a world-first initiative being carried out for people with dementia in Scotland. She explained that the Scottish government had pledged to offer post diagnostic support for one year to every person diagnosed with dementia. This is being achieved by focusing on a person-centred plan which encapsulates the whole network of support in an integrated way. She said that the way in which a country handles dementia reflects the kind of society it wants to create and illustrates what it values at its heart. In Scotland, the government advocates that “people with dementia are first and foremost human citizens with human rights and they should be visible and valued as part of our communities”. The government believes that the best form of medicine is human intervention. Consequently, it supports the creation of environments where personal connections and networks are enriched.

The use of advance directives in the care of people with dementia was considered by Chris Gastmans, Professor of Medical Ethics, KU Leuven, Belgium. He cautioned against the over emphasis on individual autonomy and also against the under emphasis on dialogue and understanding. Advance directives can be considered as dignity-enhancing care instruments. However, it is necessary that when drafted, a continuous dialogue between carer and person with dementia exists, that the wishes of the “then” and “now” self are respected and that an awareness is maintained that legal instruments can never replace dialogue and interpretation amongst the people involved. He emphasised the need to fight against current moves related to euthanasia for people with dementia and said that we should instead prove that life with dementia is a dignified life and focus on the ethical issues of how to help people in an appropriate way in their daily lives.

Gráinne McGettrick, Policy and Research Manager, the Alzheimer Society of Ireland, highlighted the fact that Dementia Palliative Care (DPC) is about living well with dementia and is a part of good dementia care. DPC combines the two worlds of palliative care and dementia which enables all parties to share information and organise care in a systematic and integrated way. The Alzheimer Society of Ireland has been involved in a number of palliative care projects which have highlighted the difficulty in talking about dementia and palliative care in an open and meaningful way. The Society has carried out research to build consensus about DPC. This was not achieved as they found many polarised views about DPC, but the debate has started. The Society is particularly well-placed to help
people appreciate that DPC is about making the journey of dementia better for all.

The enormous impact of young onset dementia (YOD) was illustrated by Jacqueline Parkes, Head of the Mental Health Research Group, University of Nottingham, UK. There are particular challenges which arise in relation to YOD. For example, because of a lack of awareness and understanding about YOD, the disease can prove difficult for people to recognise and this delays diagnosis. Access to geriatricians is patchy and in addition, support is lacking. The devastation to both the family and society can be immense, especially as people with YOD are often of working age. The University’s Dementia Research Network has identified that people with YOD and their carers wish to be actively supported in re-building their social networks and receive both timely and appropriate access to formal integrated pathways.

**Prevention**

By sharing the findings from the Cochrane Systematic Review (2013), Martin Orrell, Professor of Ageing and Mental Health, University College London, UK, highlighted the benefits which case management appears to have in the prevention of institutionalisation and/or hospitalisation for people with dementia. Led by Siobhan Reilly, the screening process included over 8,000 abstracts resulting in just 13 studies being selected for consideration. Preliminary analyses indicated that case/care management for people with dementia not only diminishes the need for institutionalisation, but also reduces behavioural and psychological symptoms and improves carers’ quality of life.

Can we prevent dementia? This was considered by Tiia Ngandu, medical specialist, National Institute for Health and Welfare, Finland. Whilst there has been a dramatic improvement in the reduction of some risk factors (cholesterol and smoking) some areas have not improved (BMI and alcohol intake). Risk factors change over time and people who develop dementia today will have a different risk factor history than those who develop it in the future. Managing dementia is a lifelong commitment. It is a complex disease. Optimal intervention would focus on several risk and prevention factors. Tiia concluded that whilst we are not completely sure that we can prevent or delay dementia, we do know that it is important to keep vascular factors under check and remain active for the whole life span.

Armelle Leperre-Desplanques, Manager of the Department of Pilot Programmes, Haute Autorité de Santé, France, illustrated the useful tools resulting from the EU “ALCOVE” project. This project brought together 19 countries and 30 organisations to share knowledge and exchange best practices in five areas: (i) risk management, (ii) risk reduction programmes, (iii) timely diagnosis, (iv) ethical issues and (v) behaviour disorders and antipsychotics. The focus placed on raising awareness of the overuse of antipsychotics for people with dementia and the possibilities for other approaches has reaped particular benefits. Armelle explained that all the recommendations from this project are available on the website and structured in a way to help decision-makers to select the best approach.

Approaches to prevent carer burnout were proposed by Myrra Verhoij-Dassen, principal investigator, Radboud University Nijmegen Medical

*A positive perspective can be extremely powerful to help people cope with their challenges.*

*Myrra Verhoij-Dassen*
Center, Netherlands. She explained that whilst psychosocial intervention is a forerunner in the treatment of people with dementia, implementation is complex and requires sensitivity. The intervention should “fit like a shoe” if it is to be truly effective in empowering people to make choices. She highlighted the importance of “cognitive reframing”, saying that, in a supportive environment, a positive perspective can be extremely powerful to help people cope with their challenges.

Innovation and dementia

In 2012, the voice of people with dementia was given unprecedented exposure by the launch of the European Working Group of People with Dementia (EWGPWD). Nina Baláčková, Vice-chairperson of the EWGPWD talked of the importance which participation has for people with dementia. Consisting of people of different ages and with different forms and stages of dementia, this innovative group is vital in educating the general public about capabilities people with dementia have. Nina said, “we are often tired, we may appear simple, but we are friendly and sincere. Our life is shorter and our time is valuable.” She concluded by saying that she will fight dementia for as long as she can, reflecting that “we cannot stop what we have, but we can choose what we do with it.”

The development of Alzheimer’s disease drugs presents many challenges. Indeed, it has been a long time since the FDA approved a new drug (2003) and, historically, research has been highly fragmented. Alzheimer’s disease is often under-diagnosed and even if it is diagnosed the existing drugs only target some symptoms in some of the people. Further, the disease develops long before any symptoms manifest. Elisabetta Vaudano, coordinator of the Scientific Pillar, Innovative Medicines Initiative (IMI), Belgium, explained that the IMI is trying to address these issues by using innovative research tools, models and methodologies. She talked of two IMI projects, “PharmaCog” and “EMIF”, which will help to ensure that “the right drug is given to the right individual, at the right stage with the right dosage.”

David Mamo, Consultant Psychiatrist, University of Malta, gave a convincing argument for making changes in the way in which we respond to the behavioural and psychological symptoms of dementia (BPSD). As a major contributor to the cost of dementia, the current “knee-jerk” reactions to the problem are costly and inefficient. David asked delegates to reflect on whether it would be acceptable to give a two-year old child medication in response to certain behaviours and asked why it appears to be so for people with dementia. He proposed that costs could be reduced and care improved by the incorporation of neuropsychiatric care of people with dementia as a priority into all levels of care, by the development of flexible and well-coordinated service models and by research being carried out on the economic modelling of innovative community based pathways.

Assistive technologies have been at the cutting edge of innovative ways to help support people with dementia and their carers with the consequences of the disease. However, Franka Meiland, coordinator of knowledge transfer, Amsterdam Centre on Ageing, Netherlands, emphasised that the wishes and needs of people with dementia and their carers at an individual level must be listened to and incorporated if good quality care is to be promoted and maintained. This demands that an effective evaluation is carried out and that efforts are combined throughout Europe.
Dementia friendly society

A wonderful example of how careful planning in the areas of architecture, design, environment and technology can help people with dementia to remain at home for as long as possible was provided by Joost van Hoof, Head of Fontys EGT, Netherlands. Following a consultation process, a small Dutch house was constructed and opened in 2012. Many features including the use of lights and patterns, kitchen layout, safety and comfort and sightlines were adapted to address the specific needs of people with dementia and their carers. The house has been used to educate and train various professionals. Joost concluded with a quote: “We must be realistic. Alzheimer’s is a disease of the mind, not of the home. The environment is not a treatment, and it offers no cure. But many problems related to the disease can be lessened for the person with Alzheimer’s disease and especially for the caregiver by making changes in the home environment.”

Anthea Innes, Professor of Health and Social Care Research, Bournemouth University, UK, reflected how far dementia has travelled in the last 15 years and noted that the utopian idea of a dementia-friendly society had started in physical environments. She emphasised the need to move beyond the notion of dementia friendly “communities” to that of having a big society which is a dementia friendly experience for all. Anthea highlighted a ten-agency partnership (including supermarkets, banks, financial institutions, universities and fire services) which is currently being evaluated in Dorset, UK. Even though policy may be in place, it does not necessarily mean that dementia-friendly communities exist. Different ways in which to collaborate and integrate work need to be found. The first step is through engagement, ensuring people with dementia are given a voice. It is necessary to bring all stakeholders together to find out what they want and need.

Finally, Jim Pearson, Deputy Director of Policy for Alzheimer Scotland, invited all delegates to Glasgow – host city of the 24th Alzheimer Europe Conference in October 2014. The conference will run under the motto “Dignity and autonomy in dementia” and will be co-organised by Alzheimer Scotland and Alzheimer Europe.

Chairpersons Heike von Lützau-Hohlbein, Alzheimer Europe, and Stephen Abela, Malta Dementia Society, closed the conference by thanking all presenters, delegates and event staff for making the conference such an enormous success. In particular, they thanked people with dementia and their carers for their collective contribution. In turn, this has helped to engage both national and European policy makers in the debate and ensure dementia remains as a priority of the political agenda.

“Many problems related to the disease can be lessened for the person with Alzheimer’s disease and especially for the caregiver by making changes in the home environment.”

Joost van Hoof, quoting Warner

Carmelo Aquilina, Senior Staff Specialist and Clinical Director of Old Age Mental Health, St George’s Hospital, Sydney, Australia, lamented the fact that people with dementia are too often thought of as the “living dead”. He highlighted the fact that the individual “self” survives longer than expected in people with dementia and that if we want to provide respectful care of people with dementia it is necessary to give a clear acknowledgement that the self does exist. Carmelo closed by saying, “people with dementia are not the living dead. They are the dying who live and deserve our care and concern because of their continuing place as persons in the human world.”
Snapshots from Malta
Snapshots from Malta
“Nothing about us without us”: The European Working Group of People with Dementia

A particular highlight of the conference was the special symposium “Nothing about us without us” by the European Working Group of People with Dementia (EWGPWD).

The EWGPWD consists of 11 people with dementia from 11 different national Alzheimer associations. Chaired by Helga Rohra, this session was developed and moderated entirely by members of the EWGPWD. Interest was extremely high: indeed, some audience members had standing room only!

From little acorns: the Scottish Dementia Working Group

First to take the floor was Agnes Houston (Scotland, UK), Vice-chair of the EWGPWD and member of the Scottish Dementia Working Group (SDWG). Agnes explained that historically people with dementia were not given a voice, but this changed in 2002 when James McKillop set up a steering group in Scotland to address this. The result was the SDWG. Once a constitution was drafted the Group was able to focus on raising awareness of the issues surrounding dementia. In 2003, the decision was taken to be under the umbrella of Alzheimer Scotland. This support enabled the SDWG to concentrate on its work, not worry about financial issues yet maintain its independence. The working relationship between the SDWG and Alzheimer Scotland is, as James McKillop said, “a marriage made in heaven where parties can agree to disagree.”

The Group regularly meets with Scottish government representatives, successfully reminding the government of the importance of including people with dementia when drafting policy and strategy. Agnes was rightly proud of all of the pioneering work and achievements of the SDWG, not least because it had inspired Jean Georges, Executive Director of Alzheimer Europe, to create the European Working Group of People with Dementia.

Involving people with dementia at national level

The SDWG has also been a forerunner for other national dementia working groups, including those in Belgium, Finland and Ireland.

Although Jean-Pierre Frognet (Belgium) did not feel up to making his presentation himself, he nevertheless enlightened delegates about the group known as the “Fighters” in Belgium by asking Alex Teligadas, Communications Director, Alzheimer Europe, to read his presentation. At the time of his diagnosis, at the age of 55, Jean-Pierre sought help from the Belgian Alzheimer Association. A working group was being created of people who were diagnosed before the age of 60 known as the “Fighters”. The group wants to show that its members are fully involved in all aspects of living and dealing with the disease. The group is a close-knit community and has taken part in various conferences which has proved useful in showing that people with dementia are able to function and lead productive lives. Meetings consist of guest speakers and/or debates. He explained that the Fighter group is a tremendous source of friendship, encouragement and mutual support. It has also enabled him to remain active, teaching him how best to live with disease, rather than just suffer from it.

Raoul Grönqvist (Finland) explained how, for over
30 years he had worked as a researcher. He felt his life collapsed two years ago when he was diagnosed with Alzheimer’s disease as it robbed him of his work, workmates, driving licence and, most devastatingly, his will to live. This has changed. Although still frustrated by the disease, Raoul now belongs to a peer support group in Helsinki. In addition Finland has launched its own working group for people with dementia of which he is a member. He values being part of these groups and of being a member of the EWGPWD. He still enjoys walking his dog, playing his guitar and playing basketball. Raoul focuses on what is most important to him: his family.

In 2013, Ireland also created a working group for people with dementia. It has the support of the Alzheimer Society of Ireland. Dermod Slevin (Ireland) is a member of the Irish working group and has resulted in his participation in various forums on radio, TV and newspapers. The Irish group has contributed to the dementia strategy in Ireland. Dermod believes that membership of both the Irish working group and the EWGPWD has provided him with not only the opportunity to share experiences, find understanding and friendship, but it has had a profound impact on his self-esteem. He reminded the audience that it is important to enjoy life whilst you can.

Personal testimony

Stig Atle Aavik (Norway) also found a warm welcome when joining the EWGPWD. Moreover, he found solace in the fact that he was amongst people facing the same challenges. Diagnosed three years ago at the age of 51, Stig said that he was initially hesitant to talk to reporters about his experience. However, he was delighted that once he made the decision to be open, he has been able to raise awareness of this disease, not least with the Norwegian Health Minister and the King of Norway!

The unique role of the EWGPWD

Helga Rohra (Germany), Chairperson of the EWGPWD, described how the EWGPWD was launched in October 2012. She highlighted that Alzheimer Europe is unique in that no other European organisation has a working group of people affected by the disease. The EWGPWD works to raise awareness. She challenged the ‘old picture’ of people with dementia and highlighted the fact that the Group carries out pioneering work. Members of the Group participate in Alzheimer Europe’s work at every level. She asked delegates to remember not only the financial and social challenges which dementia presents, but also the human challenge.

Helga concluded the session by thanking all the presenters and invited delegates to make a point of meeting people with dementia at their stand or during the various presentations throughout the conference.

EWGPWD members: Stig Atle Aavik (Norway), Nina Baláčková (Czech Republic), Jean-Pierre Frognet (Belgium), Raoul Grönkvist (Finland), Agnes Houston (Scotland, UK), Dermod O’Slevin (Ireland), Ingegärd Poussard (Sweden), Helga Rohra (Germany), Rozel Snell (Jersey), Bojan Spanja (Slovenia) and Daphne Wallace (UK).
529 delegates from 44 countries attended Alzheimer Europe’s 23rd conference in Malta

Breakdown by country

Malta 105 / United Kingdom 173 / Romania 134 / Germany 129 / Italy 127 / Netherlands 124 / Finland 118 / France 118 / Belgium 116 / Turkey 113 / USA 113 / Ireland 112 / Sweden 112 / Switzerland 12 / Luxembourg 11 / Norway 11 / Australia 9 / Croatia 9 / Czech Republic 8 / Denmark 8 / Greece 8 / Monaco 7 / Hungary 6 / Slovenia 5 / Spain 5 / Austria 4 / Jersey 4 / Iceland 3 / Japan 3 / Poland 3 / Lebanon 2 / Lithuania 2 / Morocco 2 / Thailand 2 / Tunisia 2 / Canada 1 / Israel 1 / Liechtenstein 1 / Macedonia 1 / New Zealand 1 / Portugal 1 / Slovakia 1 / South Africa 1 / Taiwan 1

Breakdown by category

Malta 2013

Total: 529

Alzheimer association staff and volunteers 147
Academics/Researchers 140
Health or social care professionals 161
Industry representatives 38
Persons with dementia/carers 30
Policy makers/Civil servants 13

ALZHEIMER EUROPE RECEIVED FEEDBACK FROM 159 DELEGATES INDICATING THAT:

- Over 89% of delegates found all plenary sessions to be good/very good
- Over 90% of delegates found the topics chosen in parallel sessions to be good/very good
- Over 94% of delegates found the conference website to be good/very good
- Over 97% of delegates would recommend future Alzheimer Europe conferences to their colleagues
Tackling neurodegenerative diseases

Professor Adriana Maggi, University of Milan & Vice-Chair of the EU Joint Programme – Neurodegenerative Disease Research (JPND) Management Board, talks with Alzheimer Europe about the progress made to date, projects being supported by the JPND and the role of patient and carer organisations can play.

Alzheimer Europe: JPND is the largest global research initiative addressing the challenge of neurodegenerative diseases, particularly Alzheimer’s disease. What progress has been made in the last year?

Adriana Maggi (AM): JPND is a global initiative led by EU Member States, which is bringing countries together to align their common strategic goals in order to tackle neurodegenerative diseases – a problem which no country can address alone. JPND wants to tackle the growing burden of these diseases, so we have to support the full spectrum of research that is required (i.e. basic, clinical and healthcare/social research). JPND is also encouraging the development of national plans for neurodegenerative diseases, and is aligning national resources and initiatives in this area, with a focus on linkage, harmonisation and data sharing.

The past 12 months have seen JPND countries work together very effectively in a number of priority areas. Long-term, medium-to-large-scale programmatic initiatives are moving forward in parallel, creating the necessary trust and alignment between the 27 participating countries in order to implement our Strategic Research Agenda (SRA). Guided by our Phase One Implementation Plan (2012-2014), these actions include, but are not limited to:

• Annual Calls for Proposals – two calls are currently open in the areas of “Preventive strategies” and “Cross-disease analysis of pathways”.

• Alignment Actions to determine research needs and opportunities in areas such as Longitudinal Cohort studies, Animal and Cell Models and Assisted Living Technologies.

• Action Groups to promote engagement and partnership, including with the European Commission and other international organisations.

These JPND actions, among others, are bringing together leading scientific experts and funding bodies to investigate the key research questions and barriers to progress in these areas. It is likely that further actions (including calls for proposals) will be developed and launched during this phase, with more than EUR 100 million in total due to be made available. Importantly, this funding will be in addition to, not instead of, other neurodegenerative disease funding.

AE: Can you give us some specific examples of these Alignment Actions?

AM: All of the Alignment Actions are being chaired by JPND Management Board members, and are highlighted in the table below. Two of the most advanced actions are in the areas of Animal and Cell Models and Longitudinal Cohort Studies:

**Longitudinal Cohort Studies**

The JPND Action Group on Longitudinal Cohort studies has investigated potential actions for both disease-based and population-based longitudinal
cohort studies, looking at whether current member-led or EC-supported activities can be expanded or better exploited, or new activities identified. Action Group discussions during 2013 were focused on:

- Taking stock of current longitudinal cohort studies for both neurodegenerative disease-based and general population studies of relevance
- Determining how JPND adds value to existing cohort investments
- Identifying gaps and cases for new activity in areas of unmet need
- Scoping the emerging scientific opportunities

A copy of the report which was endorsed by JPND Management Board in October 2013 is available on the JPND website. The report brings together in one place for the first time the wealth of cohort opportunities for neurodegeneration research across JPND countries. It spans general population-based, targeted (preclinical) and disease-focused cohorts. Immediately available are the analyses presented in the report and listings of imaging studies and existing cohorts across Europe, with web references. Implementation plans will be announced later in 2014 once priorities for action have been decided. Recommendations span coordination, funding and policy areas.

**Animal and Cell Models**

A serious limitation of modern neuroscience is the frequent failure to translate information from preclinical research into new treatments, diagnostics and preventive strategies. This limitation is particularly critical in the field of neurodegenerative diseases where although studies conducted in experimental models provide invaluable physiopathological information, they do not point to a clear therapeutic pathway.

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<th>JPND Alignment Actions</th>
<th>JPND Chairperson</th>
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<tr>
<td>Investigating where current member state-led or EC-supported longitudinal cohort studies can be expanded or better exploited, or new activities identified</td>
<td>Rob Buckle</td>
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<td>United Kingdom</td>
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<td>Defining concrete approaches for alignment of national research initiatives and activities, focusing on areas with high potential for international cooperation and feasibility for alignment. The first area targeted has been neuroimaging.</td>
<td>Etienne Hirsch</td>
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<td>France</td>
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<td>Identifying new lines of intervention for Animal and Cell Models</td>
<td>Adriana Maggi</td>
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<td>Italy</td>
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<td>Working in a collaborative fashion with the Ambient Assisted Living Joint Programme (AAL JP) to meet user needs for neurodegenerative diseases</td>
<td>Jaqueline Hoogendam</td>
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<td></td>
<td>The Netherlands</td>
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<td>Increasing coordination of research into palliative care</td>
<td>Enda Connolly</td>
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<td>Ireland</td>
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<td>Promoting the involvement of patients and the public in neurodegenerative disease research</td>
<td>Mogens Horder</td>
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<td>Denmark</td>
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<td>Encouraging partnership with the European Commission and other relevant international initiatives</td>
<td>Philippe Amouyel</td>
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The aim of this Action Group is to open up a discussion on the models currently available for ND research and to devise strategies to overcome the current hiatus between the need to better understand the pathogenic mechanisms involved and the necessity to translate findings into diagnostic and therapeutic means.

Through the workings of the group, the most active European scientists in the field have joined forces to design a call for proposals which should stimulate more creative, multidisciplinary approaches for new experimental models which could identify markers of early prognosis and screen for potential therapeutic compounds. The call should also support the organization of interactive online workshops on experimental models for the study of neurodegeneration.

National Strategies

Since JPND began, several member countries are now processing strategic research agendas for neurodegenerative diseases (e.g. Denmark, Portugal). These national research strategies will both inform their countries’ participation in JPND, and will focus resources on tackling neurodegenerative diseases nationally, aligning with the European Research Strategy. Several new, related strategies (e.g. the Dutch Deltaplan for Dementia, the UK Prime Minister’s Challenge on Dementia) have also made specific references to JPND and are seen as the national vehicles for participation in JPND.

International Partnerships and Sustainability

JPND is also engaging in strategic partnerships both nationally and internationally, focusing on areas where expertise can be pooled and more progress can be made through collaborative efforts. JPND was repeatedly highlighted at the recent G8 Dementia Summit in London as an example of successful international cooperation in dementia research, and we look forward to working with the new global plans and initiatives emerging from the summit. JPND is actively discussing partnership with the European Commission and has organized a number of engagements with senior representatives to date. A meeting was also organised with the Office of Science and Technology Policy at the White House regarding future partnership with the USA. In addition, partnerships with industry, research funding agencies, and patient/carer organisations are being pursued in order to implement the JPND strategy in full.

The most important question for JPND in 2014 is how it is going to sustain the progress already being made. Our initial support from the European Commission ends later this year, so we are now preparing the sustainable management structure which will see JPND successes in transnational collaboration in neurodegenerative diseases continue into the long-term in order to tackle these chronic and complex diseases.

AE: When we last spoke with you, the first call for projects had gone out which focused on the use of biomarkers in the area of neurodegenerative disorders. What has been the result of that call?

AM: EUR 16 million in total was made available for that call (from all participating countries) and four projects began their work in 2012. These three-year projects are aiming to optimise biomarkers and harmonise their use in a number of neurodegenerative diseases including Alzheimer’s, Parkinson’s, motor neuron diseases, sporadic Creutzfeldt-Jakob disease (sCJD), and rapid progressive dementias in the young. Bengt Winblad of the Karolinska Institutet, Sweden is interviewed later in this article.
about the largest of these projects – BIOMARKAPD, which is focusing on both Alzheimer’s disease and Parkinson’s disease.

AE: What other projects are currently being supported by JPND?

AM: 11 new international research projects will begin in 2014, supported under the JPND Calls for European research projects for the “identification of genetic, epigenetic and environmental risk and protective factors” and “the evaluation of health care policies, strategies and interventions”. The successful projects, containing participants from 17 different countries span areas such as: risk factor assessment for genetics and environment in Parkinson’s disease; preclinical genotype-phenotype predictors of Alzheimer’s disease and other dementias; a programme for ALS care in Europe; research to access policies and strategies for dementia in the young. User-friendly fact sheets on all of these projects are available on the JPND website.

In addition, the Network of Centres of Excellence in Neurodegeneration (CoEN) initiative is funding five new innovative “pathfinder” projects under its second funding call. CoEN is aligned with JPND, although it operates as an independent entity. Under CoEN, EUR 3 m has been awarded for five innovative and creative proof-of-principle studies which, if successful, will provide a step change in neurodegeneration research. The awarded projects take a ‘high risk, high pay-off’ approach to identify and validate new potential drugs and develop innovative therapeutic approaches for Parkinson’s Disease, Alzheimer’s Disease and other dementias.

AE: What is the role that patient and carer organisations such as Alzheimer Europe play in the overall strategic research agenda and the specific projects?

AM: Patient and carer priorities are very important to JPND. A specific JPND consultation process identified patient/carer priorities in 2011 and these were translated into specific priorities within the JPND Research Strategy. Since the launch of the strategy in early 2012, JPND has expanded on that direct engagement by modifying the membership of its Scientific Advisory Board (SAB) to include scientific representatives from patient-led organisations and industry. Indeed, Alzheimer Europe’s current Honorary Secretary, Prof. Charles Scerri is now on our SAB! Having scientific representatives from patient organisations on our SAB will ensure that JPND continues to prioritize research areas such as improving the social care structures available to assist patients, their families, and health service providers so that patients can receive optimum care at all stages of their illness. The recently appointed new SAB members are:

- Charles Scerri (Alzheimer Europe)
- Brian Fiske (Michael J Fox Foundation for Parkinson’s Research)
- Eric Karran (Alzheimer Research UK)
- François Nicolas (GE Healthcare)
- Thomas Rooney (Sanofi)

JPND MB members have also determined that
patient and public involvement (PPI) in research should be an integrated part of SRA implementation, and a specific JPND Action Group has been working since 2012. The group is charged with “promoting public involvement in research in order to improve the way that neurodegenerative disease research is prioritized, commissioned, undertaken, communicated and used”. The Action Group is currently engaging with relevant external stakeholders, disseminating a plan for PPI, in order to obtain advice on implementation at the national and institutional levels. In addition, patient and carer organisations such as Alzheimer Europe will also continue to play a vital role in our engagement process to facilitate cooperation, two-way communication, knowledge transfer, as well as consultation on JPND plans and initiatives.

AE: JPND launched two Joint Transnational Calls in late 2013. What are the priorities for these calls and the expected results?

AM: The 2013 JPND Annual Calls for proposals are calling for European research projects in the areas of “Cross-Disease Analysis of Pathways related to Neurodegenerative Diseases” and “Pilot Studies on Preventive Strategies related to Neurodegenerative Diseases”. Both Calls were launched in December with a first-phase (pre-proposal submission) deadline of mid-February 2014. For both calls, JPND is piloting the use of a new online partnering tool. It is believed that this tool will especially benefit early-career researchers and research groups not normally included in established consortia.

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

By partnering with non-profit organisations, we can improve the health and education of those who need it most. Targeted, sustainable programs benefiting future generations in both the developing and developed world-helping them to do more, feel better and live longer.
After a decade of disappointing drug trials, European researchers are finding new ways to understand Alzheimer’s and Parkinson’s disease, just in time for the anticipated “tidal wave” of cases.

With worldwide cases expected to triple by 2050, it is widely accepted that early diagnosis of Alzheimer’s and Parkinson’s disease will be vital to tackling these neurodegenerative diseases. The goal of new clinical trials in this area will be to treat early-stage patients with drugs that inhibit the destructive process before too many neurons have been lost. However, as the clinical symptoms in these early stages may be very subtle, or even absent, the tools currently used to diagnose these diseases cannot be relied upon for these new trials.

According to Bengt Winblad of the Karolinska Institutet in Sweden “research tells us that instead of the current tools, we could use biomarkers to determine if someone has Alzheimer’s or Parkinson’s”. Ranked by the Journal of Alzheimer’s Disease as the world’s most prolific Alzheimer’s researcher, Winblad is coordinating one of the largest international collaborative projects ever undertaken in this area. The goal of the three-year “BIOMARKAPD” project is to standardize Alzheimer’s and Parkinson’s biomarker measurements across Europe. Supported by 19 different countries under the JPND initiative, the project results are predicted to transform the entire field of neurodegenerative disease research – leading to more definitive diagnosis, greater ability to measure disease progression and better assessment of new treatments.

“Nuts-and-bolts” science

Established biomarkers exist for early Alzheimer’s and promising candidates are underway for early Parkinson’s. However, a major problem today is the large variation that exists in biomarker measurements between different studies, centres and laboratories, which seriously jeopardizes their introduction into both clinical routines and clinical trials around the world. Standardizing biomarker measurements across Europe is a tricky business, and first requires standardized protocols on how to collect clinical samples from patients, how to perform the measurements and how to interpret the results. It is the veritable ‘nuts-and-bolts’ science – unglamorous but essential. However, such is the anticipated impact of the project results that world-leading laboratories from 21 countries (including Canada) are signed up to implement the BIOMARKAPD protocols.

Speaking at the project’s most recent general assembly in Barcelona, Winblad firmly believes that the resulting standards will have a major influence on clinical research and drug development for neurodegenerative conditions in general and for Alzheimer’s and Parkinson’s in particular. “The active involvement of all European JPND countries in the project not only provides enormous expertise, but also ensures that protocols developed can be applied by all the member states,” he says.

New Biomarkers

Whereas BIOMARKAPD is focusing on existing biomarkers in the spinal fluid of patients with Alzheimer’s or Parkinson’s disease, the project will also support the development of new promising biomarkers through its newly-created biobank, located in Luxembourg. The biobank will contain samples from Alzheimer’s and Parkinson’s patients, including patients in very early disease stages, as well as healthy controls. The project will look to make these samples available to the scientific community to conduct field-changing research such as developing new assays and testing new biomarker candidates.

Why has this not happened until now?

The development and standardization of biomarkers typically demands significant financial and intellectual resources, and for individual research groups it does not offer the short-term rewards and long-term competitive advantage often used to assess decisions to commit resources. “In light of the urgent need for optimized and standardized Alzheimer’s and Parkinson’s biomarkers and the ambitious goal of BIOMARKAPD to meet that need, it is fitting that multiple partners mobilize under the JPND umbrella, and through a coordinated effort, share the expense, risk and, ultimately, the benefits of the research,” says Winblad. “The JPND is well-positioned to lead the push and marshal the necessary resources to make projects like this a reality,” he said.

With Winblad at the helm, BIOMARKAPD seems to be well on its way to achieving its goals.
Michel Goldman, IMI Executive Director, highlights how projects within the IMI aim to address challenges in drug development.

Brain disorders, including dementia, have been a priority for the Innovative Medicines Initiative (IMI) since its launch in 2008. Today, IMI has three projects on Alzheimer’s disease and a fourth is in the pipeline. Between them, they are tackling some of the greatest challenges in drug development, including the need for better tests of drug efficacy, the identification of people at risk of dementia, the need to reclassify Alzheimer’s and Parkinson’s diseases, and a more efficient approach to clinical trial design.

Launched in 2008 with a EUR two billion budget, the Innovative Medicines Initiative (IMI) is the world’s largest public-private partnership in health. Through collaborative projects that unite experts from industry, academia, small and medium-sized enterprises (SMEs), patient groups, and regulators, IMI is developing tools and technologies to speed up the development of safer and better drugs for patients. The organisation’s budget comes from the EU, which contributes EUR one billion from the Seventh Framework Programme (FP7), and in kind contributions from member companies of the European Federation of Pharmaceutical Industries and Associations (EFPIA).

Brain disorders, including Alzheimer’s disease, have been a priority for IMI since its inception. The reasons for this are simple. Brain disorders places a huge burden on society, affecting one in three Europeans and costing the economy EUR 798 billion annually, according to the European Brain Council. Yet there is no cure for any brain disorder and treatments to alleviate symptoms or slow progression of the disease are not effective in all patients and may come with severe side effects. Furthermore, developing new treatments for brain disorders takes longer and costs more than for other diseases. A key challenge in drug development is the complex nature of the brain and our poor understanding of the underlying causes of many brain disorders.

IMI currently has three projects on Alzheimer’s disease, and a fourth is in the pipeline. Between them, they have a total budget of over EUR 150 million and cover issues as diverse as uncovering biological markers to test drug efficacy, the identification of people at risk of dementia, the reclassification of Alzheimer’s and Parkinson’s diseases, and new approaches to clinical trials.

**Pharma-Cog - Using the power of the matrix to develop Alzheimer’s treatments**

IMI’s Pharma-Cog project focuses on the need for better tests to determine the efficacy of new drugs. Tests based on just one physiological, functional, or biochemical marker are probably not sensitive enough to provide drug developers with sufficient information on whether or not a drug might be effective. Rather, a collection or ‘matrix’ of markers is necessary, and this is exactly what the Pharma-Cog team has developed.

The Pharma-Cog matrix represents a unique tool for the study of Alzheimer’s disease and potential treatments, as it can be applied to laboratory
models, human volunteers and patients alike. In 2013, the project completed the recruitment of 150 patients with mild cognitive impairment for a clinical trial of the Pharma-Cog matrix. The trial will help the team to test the value of the matrix as a tool for tracking disease progression in people with mild cognitive impairment.

**EMIF-AD - New results for Alzheimer’s from old data**

Although there are reams of data from countless Alzheimer’s studies in existence, most of this data is not linked together, making it hard to study. The aim of EMIF-AD, which was launched in 2013, is to link up data from a variety of sources such as patient health records, research cohorts, biobanks, registries, epidemiology studies and biomarker research, including drug and disease history, test results, and gene sequencing. It will then analyse this data to find links between genes, biomarkers, disease and outcome. For example, by delving into the EMIF-AD data, researchers hope to find biomarkers that identify people at risk of developing Alzheimer’s. These patients could be invited to join clinical trials to see if it is possible to prevent, or at least slow, the onset of the disease. By reusing existing data, rather than having to generate new information, the project will be able to move forward more quickly.

EMIF-AD is part the wider EMIF (European Medical Information Framework) project, which has access to 48 million patient records from seven countries. Due to the sensitive nature of the data, the project will ensure that all information is used responsibly and appropriately.

**AETIONOMY - Towards personalised medicine for neurodegenerative disease**

Today, diseases are defined largely on the basis of the patient’s symptoms and where they occur in the body. However, there is growing evidence that while two patients may be classified as having the same disease, the genetic or molecular causes of their symptoms may be very different. This means that a treatment that works in one patient may prove ineffective in another.

There is now broad recognition that the way diseases are classified needs to change, and the immense scale of the challenge means that only a large public-private partnership could take this on.

IMI’s AETIONOMY project, launched in early 2014, will embark on a new approach to disease classification, with a focus on neurodegenerative conditions, particularly Alzheimer’s and Parkinson’s diseases. There is still little agreement on how these diseases should be defined, and in fact most cases are classified as ‘idiopathic’, i.e. their causes are not known. The new project will deliver data, tools and recommendations that can be used by the biomedical community to develop new treatments and diagnostic tests.

**A new project to revolutionise clinical trials for Alzheimer’s drugs**

A new project that will pioneer a novel, more flexible approach to clinical trials of drugs designed to prevent was part of IMI’s 11th Call for proposals, which was launched in December 2013.
The project will focus on improving ‘proof of concept’ studies, early stage clinical trials in which researchers seek to determine if a candidate drug is safe and has an impact on the disease in humans. Currently, companies carry out these trials individually. Each trial costs a lot of money, lasts several years, and may require thousands of patients, half of whom are treated with a placebo.

The new project will test a new way of running proof of concept trials, in which several candidate drugs are simultaneously compared to a placebo. In this scenario, only about 20% of patients are in the placebo group, compared to 50% in conventional trials. Furthermore, this novel ‘adaptive’ trial design allows researchers to adapt the trial design in response to emerging results. For example, if a candidate medicine appears to be particularly effective in only certain categories of people, then that medicine can be preferentially directed to those people to confirm the finding. Similarly, new candidate drugs can be added to the trial and medicines that prove ineffective can be dropped. In addition, this design allows researchers to test both individual drugs and combinations of different medicines.

This innovative trial design has already been found to be effective for testing new treatments for breast cancer. This will be the first time such an approach will be used for Alzheimer’s disease.

A look to the future

The European Commission launched its proposal for IMI 2 in July 2013. The estimated budget of IMI2 is EUR 3.45 billion. Half of this will come from the EU (via Horizon 2020), and half will come from industry. Of the half that will be contributed by industry, most will come from EFPIA companies, but a small amount may come from other life science industries if they decide to join IMI 2 or its projects.

Neurodegenerative diseases feature prominently in the proposed IMI 2 Strategic Research Agenda (SRA). Key issues highlighted in the document include the need for a better understanding of the underlying mechanisms of disease, the need to identify new drug targets to prevent or slow progression of the disease, the adoption of innovative clinical trial designs, and the importance of tools to assess novel treatments. Finally, the SRA addresses the need to improve our understanding of the risk factors associated with neurodegenerative diseases.

“Neurodegenerative diseases feature prominently in the proposed IMI 2 Strategic Research Agenda.”

MICHEL GOLDMAN

Find out more

Website: www.imi.europa.eu
Twitter: @jIMI_JU
The view from Greece

Adonis Georgiades Spiridon, the Greek Minister of Health, considers the role of the EU in addressing dementia, the work carried out in Greece to help people with dementia and the need for a national dementia strategy.

According to the 2013 ADI report 200,000 people live with dementia in Greece and 400,000 family carers look after them. Due to the rising life expectancy worldwide and in Greece, this number could almost be tripled by 2050. This makes dementia one of the most important medical, social and economic future challenges in Greece.

The ageing of the population is one of the most topical issues in the sphere of health and well-being in any society. Changes in lifestyle and progress in the treatment of diseases which earlier had been the main causes of death have extended life expectancy and increased the prevalence of chronic health disorders, including mental diseases. The incidence of mental disorders among older people is very high.

The main reason of disability and of dependency among the elderly population is dementia. In 2010, 9.9 million residents of Europe were living with different subtypes of dementia with Alzheimer’s disease accounting for the largest share (World Alzheimer’s Report 2010).

The ratio of retired pensioners per one employed individual keeps growing and increases the socio-economic burden associated with neurodegenerative diseases. It is estimated that the cost borne by the 27 EU Member States of the treatment of Alzheimer’s disease and other dementias amounts to EUR 160 billion: 56% of this can be attributed to the costs of informal care of patients.

In the Fifth, Sixth and Seventh European Framework Programmes for Research, the subject of neurodegenerative diseases was addressed and in particular in the Alzheimer Europe project of the European Collaboration on Dementia (Euro-CoDe) and in the Era-net Neuron project competition.
The ALCOVE (ALzheimer COoperative Valuation in Europe) project implemented in 2010-2012, aimed at raising awareness regarding early diagnosis of Alzheimer’s disease, measuring resources in the European countries and developing guidelines for care and support to families. Greece participated in this project and has already started implementing ALCOVE’s recommendation for the restriction of psychotropic drugs in dementia patients. We strongly believe that it is important for Member States to ensure solidarity and to exchange good practices in order to avoid the wasting of resources and enable a multidisciplinary approach.

At the informal council of the Ministers of Health held by Greece prior to its taking over the presidency of the European Union, the agenda will include economic crisis and healthcare, immigration and public health, nutrition and physical activity.

Regarding healthcare, among the main issues to be discussed is mental health of elderly people. Dementia is a major social and medical problem that requires cooperation between the European Commission and EU countries, societies, industry, health and social care professionals and organisations. They should work hard for advancements in prevention and treatment of all forms of dementia and in the provision of education and support for carers.

In accordance with European and Global priorities, Greece started to organise and implement programmes about dementia in 2006. During the implementation of the PSYCHARGOS Programme (which was cofinanced by the European Structural Funds and the Greek state to establish mental health and psychosocial rehabilitation units) 13 Day Care Centers and three Respite Care Facilities were created under the responsibility of Alzheimer’s Associations in Athens, Thessaloniki and smaller towns in Greece with outstanding success. More than 5,000 people with dementia and their carers take advantage of these services. Additionally, the Alzheimer Associations in Greece are very active, organise awareness campaigns, seminars for health professionals, screening programs for the public, educational programs for the carers and scientific research with very limited funding.

As in most European countries and worldwide, Greece needs a dementia Action Plan and this has been earnestly pursued by all stake-holders for many years. Finally, the first step towards achieving this goal was taken recently. In November 2013, the Ministry of Health assigned a national committee to design, organise and implement such an ambitious programme. Professor M. Tsolaki, president of the Greek Alzheimer’s Confederation and Dr P. Sakka, president of the Athens Alzheimer’s Association are among its members. A comprehensive dementia Action Plan to address the unmet needs of people with dementia should propose mechanisms for:

- Promoting broad public awareness of Alzheimer’s and combating stigma
- Identifying dementia capable support services at all stages of the disease
- Assessing and improving the quality of health care, social care and long-term care support and services
- Assessing access to diagnostic services, pharmacological and non-pharmacological treatments and
- Public health efforts to conduct surveillance and promote brain health in general

Our vision is to improve older people’s lives, help them to contribute to society and consequently reduce pressure on health care systems.
G8 Summit makes dementia a global priority

AE Chair Heike von Lützau-Hohlbein reports on the G8 Dementia Summit which she attended on 11 December 2013.

The G8 Dementia Summit took place on 11 December at Lancaster House, near Buckingham Palace in London. Invited participants – in addition to the delegations of health ministers from the G8 countries (Canada, France, Germany, Italy, Japan, Russia, UK, USA) – were dementia researchers, representatives from national organisations from the healthcare sector, the pharmaceutical industry with a special interest in the area of dementia, the EU Commission and a number of different foundations.

As the Chairperson of Alzheimer Europe and the German Alzheimer’s Society, I was fortunate to represent the self-help movement alongside Marc Wortmann, Executive Director of Alzheimer’s Disease International (ADI). The 150 participants came not only from the G8 countries, but among others, also from China and New Zealand.

Peter Dunlop, an English physician who was diagnosed with Alzheimer’s disease at age 58, joined the participants for the day. He described his difficult path to diagnosis and emphasised how important it was for him. He has offered his services as an ambassador to Alzheimer’s Society for as long as he is capable to fulfil this role.

During the summit, it was repeatedly emphasised how important this day is. Moderator Vivienne Parry drew comparisons with the date in 1906 when Alois Alzheimer spoke publicly about this disease for the first time. The UK Health Minister Jeremy Hunt claimed that the G8 countries – as they did for AIDS in 2005 – have to come together and fight against dementia. If they do not, national healthcare systems will be bankrupted.

According to the latest research, the number of people with dementia is expected to triple by 2050. Scientists are still trying to understand the causes of the disease, and several speakers lamented the lack of therapies addressing the cause of the disease.

The Director-General of WHO, Margaret Chan, stressed that while dementia is certainly financially very costly, no other disease has such a high human cost in society. She pledged that the WHO will do everything possible to support the individual countries in their development of action plans.

On behalf of the OECD, Yves Leterme stated that the strategies for prioritisation in medical research would have to be modernised and that with recent technological advances in healthcare systems, much more emphasis should be placed on prevention.

The representatives of the G8 countries gave updates on what is happening in their countries. Federal Health Minister Daniel Bahr for Germany particularly highlighted the Alliance for people with dementia, which will bring out an action plan in spring 2014. He also mentioned the substantial improvements for people with dementia through
the last reform of long-term care in Germany. The DZNE, which deals specifically with the study of dementia, will be given funding of EUR 70 million this year.

All G8 leaders agreed to start joint activities and to get involved. The greatest and most urgent challenges lie in the use of the huge amount of scientific data available – bringing the data together, standardising and analysing it to make it accessible to researchers worldwide, while taking data protection issues into consideration. Also in the social sciences sector, cooperation and the development of international standards and norms is important.

There were valid contributions made on the subject of prevention – that is, reducing the risk factors of dementia – but in order to collect better evidence, multidimensional, long-term studies are needed.

In the area of pharmacological research, better cooperation of FDA and EMA and a wider involvement of patients were called for, in order to improve the regulatory systems.

To broaden the perspective, I reminded the audience that the global work of self-help organisations was essential and should be further encouraged, to give people with dementia and their families the support and protection they need. George Vradenburg, CEOI, reminded the audience about the importance of indicators to track progress. Marc Wortmann reminded leaders that dementia would also have to be on the agenda for developing countries and that they would need the help of the G8 countries.

In his closing speech, the UK Prime Minister David Cameron summed up: “We meet with realism about what we face but with determination to fight this and the real hope that one day that fight will be won.” He stressed that he wants the UK and UK research to play a leading role in this fight.

Jeremy Hunt closed the conference with a quote from Nelson Mandela: “It always seems impossible until it’s done”.

Four follow-up meetings were decided on for 2014, in which the topics discussed at the summit will be developed in more depth. These meetings will be held under the auspices of Japan, Canada/France, the United Kingdom and the United States.

Being now for more than a quarter of a century in the scene, I was overwhelmed at how things have changed in these years. In former times, we as family carers were trying to explain what dementia is like to our audience. Today, a person with dementia told his story publicly and the G8 health ministers – together with the WHO and the OECD – agreed to make the biggest effort yet against dementia.”

HEIKE VON LÜTZAU-HOHLENBEIN
Evaluating the French Alzheimer Plan

Professor Joël Ankri, Head of the Centre of Gerontology, Hopitaux Universitaires Paris, France, was charged with evaluating the French Alzheimer Plan 2008-12. He speaks with Alzheimer Europe about the major findings and resulting recommendations.

The French Alzheimer Plan (2008-2012) raised a lot of interest across Europe. France was one of the first countries to develop a specific well-structured and funded plan for this disease. This French third plan was ambitious; resulting in actions at all levels being implemented, from care to research, whilst respecting ethical considerations. It intended to improve the quality of care and to combine research efforts. Its governance at the highest level (Presidency of the French Republic) allowed coordinated actions between departments (health, social and research), hence avoiding classical obstacles related to a “silo” approach. The funding of EUR 1.6 billion corresponded to an unprecedented effort at national and international levels.

At the end of 2012, Prof Christine Van Broeckhoven and I were assigned with the evaluation of this plan at the request of the French Minister of Health, the Minister of Higher Education and Research and the Minister of Old People and Autonomy.

This evaluation has shown some improvements: the whole country now has specialised diagnosis and follow-up units and an effort has been made to ensure that each health district has its own memory unit.

Progress has been made in the implementation of integrated support services and care, allowing an efficient and flexible coordination of services according to the needs of the person with dementia or their caregivers. The reference centre for young patients conducted effective operations: to improve access to diagnosis, to develop research, and to produce and distribute standards for good practice. The increased knowledge about the disease in the field of research was particularly noteworthy in genetics and in young subjects.

New structures reinforcing home care by promoting the involvement of specialised personnel were created. A major effort was made to develop and strengthen structures of respite and caregiver training.

Behavioural disorders are a major problem in the management of some patients suffering from dementia. Specialised units were created within health care rehabilitation and follow-up departments for Alzheimer’s patients. These units offer specific care for both young and elderly patients, whether they live at home or in an institution. The aim is to enable them to return to their usual place of residence. With appropriate design and dedicated, specific care and support staff, and on the basis of a medical and psychosocial assessment, these units aim to stabilise behavioural problems.

This cognitive/behavioural specialisation in the treatment given to patients with Alzheimer’s and related diseases requires both the intervention of specific personnel (psychomotricity therapist, psychologist, occupational therapist, gerontological assistant, etc.) and access to psychiatric sessions.
Ethical guidelines were conducted under the guidance of the national centre acting as a catalyst. It has provided a model and brought together a series of thoughts and actions.

An excellent result in neurogenetics and GWAS (international leadership of a French team) has been achieved. Both the total number and the quality of French scientific publications have increased. The contribution of imaging, particularly MRI, to research into neurodegenerative diseases is considered as a way of finding out more about how they evolve. In light of this, some methodological advances have been performed during the last years with the development of guidelines applicable to any kind of centre and MRI machine.

Clinical research is better structured but has not yet been successful. A large cohort of patients was initiated and epidemiological research has received financial support for the extension of existing cohorts in the general population.

However, some weaknesses have been highlighted. In the medico-social field, the objectives have not been achieved. It’s probably due to a top-down approach. A lot of structures have not been created. In the research area, the development of studies dealing with the organisation of services is required. This “Health services research” should be multidisciplinary, involving health and medico-social professionals. It is needed to assess the impact of the provision of care and innovations, in order to identify the most effective ways to organise, manage, finance and deliver high quality care. Social science research focusing on the issues of health and disease should also be developed. Interface with clinical research networks and insertion in specific units seem essential. Priority must be given to the issues of social participation, restrictions in activity and autonomy, refusal of care, involvement of relatives (caregivers), social inequalities and economic aspects.

Faced with the burden of human and societal suffering caused by Alzheimer’s disease and other neurodegenerative diseases, we recommended the pursuit of public policy towards these degenerative and chronic brain diseases – particularly those affecting cognition. It has become necessary to include in the common law a number of measures that have contributed to the care of Alzheimer’s patients. These measures will be included in the roadmap of regional health agencies that will implement them according to their local needs and constraints. It also seems necessary to retain the framework of a plan for the most structural measures and maintain a centralised governance so the future plan mobilises all actors at all levels.

In September 2013, the three ministries established four working groups on neurodegenerative diseases which aim to:

• improve diagnosis, access to early treatment and delay the onset of the disease;
• meet the needs of people suffering from neurodegenerative diseases at every stage of the disease and all over the country;
• adapt society and cities to meet changing practices whilst respecting ethics, quality and welfare;
• develop and structure research.

We are waiting for our fourth new plan, in the interests of all the patients suffering from these diseases.

“An excellent result in neurogenetics and GWAS (international leadership of a French team) has been achieved.”

JOËL ANKRI
Portuguese national dementia plan

Dr Álvaro de Carvalho, Director of Portugal’s National Mental Health Programme, speaks to Alzheimer Europe about the progress of the country’s national dementia strategy.

Alzheimer Europe (AE): In October 2013, you gave an update on the progress of the Portuguese National Dementia Plan at Alzheimer Portugal’s 25th Anniversary Conference. What is the status of the plan and when do you expect it to be launched?

Director Carvalho (DC): The launch of a national dementia plan was one of the items in the 2013 action plan of the Directorate General of Health, which is a department of Portugal's Ministry of Health. It was determined that a nationwide epidemiological study would take too long and would be too costly; instead we are currently performing a needs assessment.

Based on the health primary care network, some pilot areas have been selected and people with probable dementia diagnoses are being identified by general practitioners. These diagnoses will be confirmed by health professionals with specific training, who will also provide an assessment of future needs. We expect this phase to be concluded by the end of the first semester of 2014.

AE: What are the key objectives of the National Plan?

DC: The main short-term objective is to offer a structured care network that will involve both public services (hospitals and local health centres) and social sector associations. Our aim is to develop a proper pathway to timely diagnosis and to health and social care, in step with the different stages of dementia and social and familial factors. This pathway will enable a dynamic flow between the different facilities and services available.

AE: At the same conference, you announced an agreement between the Health Ministry and Alzheimer Portugal, giving Alzheimer Portugal a mandate to train stakeholders as well as recognition as a partner in the creation and implementation of the Dementia National Plan. Can you expand on this?

DC: Training will certainly be a priority in the national dementia plan. We will focus on training family and professional carers who provide support to people with dementia living at home and in community facilities. It is clear that specialised facilities such as day care centres or residential homes have a growing need for professionally qualified staff members to look after the needs of people with dementia.

Training courses will be led by existing organisations that are recognised for following good prac-
Alzheimer Portugal will provide training to carers and also to new trainers, allowing the rapid spread of knowledge throughout the country.

Restoring the Tradition of European Medical Innovation

Over the past 200 years European scientists have been at the forefront of medical progress. Today, that proud tradition is under pressure from policies that devalue the role of innovation.

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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.

Janssen Pharmaceutica N.V.
Dementia in the news

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World Alzheimer’s Day 2013

Alzheimer Europe takes a look at how some national Alzheimer associations marked World Alzheimer’s Day. All shared the aim of raising awareness and understanding of dementia.

Belgium
The Belgian Ligue Nationale Alzheimer Ligue (LINAL) held a special Alzheimer Café Day in the centre of Brussels. This year, LINAL introduced art therapy as a new event. Two workshops, led by an art therapist, showed how people with dementia can express their creativity and increase their quality of life. There was also an exhibition of art produced by people with dementia.

Cyprus
The Cyprus Alzheimer Association opened the country’s first Day Care Centre for people with Alzheimer’s disease in Limassol. It was officially inaugurated by Mr Andreas Christou, mayor of Limassol while his Eminence Bishop of Limassol Mr Athanasios blessed the building. The Day Care Centre will offer services such as non-pharmaceutical interventions, group activities and support groups for caregivers and family members of people with dementia.

France
France Alzheimer presented 15 recommendations for the next “neurodegenerative diseases plan” that President Hollande has pledged to launch during his mandate. This new plan will pay specific attention to Alzheimer’s disease.

Greece
The Greek Association of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas) filled the month of September with events including an Awareness Week, a photo exhibition entitled “Memento”, an information stand, press interviews, a chess tournament to demonstrate that mind games may reduce the risk of dementia and a Memory Walk. All were open to the public and free of charge.

Ireland
The Alzheimer Society of Ireland ran a two-week brain health campaign called “Forget Me Not”. The campaign ran across radio and online, aiming to raise public awareness about how people could reduce their risk of developing Alzheimer’s disease and other forms of dementia in later life by looking after their brain, body and heart.

Italy
Federazione Alzheimer Italia held a conference entitled “Alzheimer’s disease: information about care, research and support” and also celebrated its 20th anniversary. Awards were presented to six young graduates for their outstanding theses relating to Alzheimer’s disease. Alzheimer Uniti also organised several events including a visit to an audience of Pope Francesco, its Annual Alzheimer Convention, an information stand with accompanying entertainment and the opening of its 5th Alzheimer Café in Rome.

Monaco
Monaco’s AMPA association organised a Memory Walk, a modern ballet performance about a man who develops dementia and a flash mob consisting of some 700 people who assumed the shape of a seahorse or hippocampus, which is AMPA’s symbol.

Netherlands
On 23 and 24 September, a new documentary entitled DementieEnDan (“Dementia, and then...”) aired on national Dutch television. This beautiful and moving work is about living with dementia, including all the barriers but also the possibilities. The film was produced by Ireen Ditshuyzen and follows five people with dementia and their partners.

Portugal
Alzheimer Portugal held Memory Walks in seven cities to celebrate World Alzheimer’s Day, under the motto “Remember Yourself”. Staff from Alzheimer Portugal were on hand to inform participants that...
timely diagnoses and specialised services for people with dementia are still scarce.

**Slovenia**

Slovenia’s Spominčica organised an Alzheimer Café meeting and Memory Walks. A large number of people joined on the walking tours in various Slovenian cities. In the capital, the walk was held under the patronage of the Mayor of Ljubljana. Along the way, members of the association provided information about dementia and also distributed the new issue of the Spominčica newsletter, which was recently relaunched.

**Spain**

CEAFA, the Spanish federation for Alzheimer’s disease and other dementias, held a press conference entitled “Alzheimer - A Matter of State” with government officials on 12 September. The main aims of the conference were to raise awareness of the status of people with Alzheimer’s disease in Spain and to put forward a four-pillar programme to deal with the challenges of dementia in the future. Mr Koldo Aulestia, President of CEAFA outlined why the country needs a sustainable and comprehensive national dementia plan.

**UK (Scotland)**

Alzheimer Scotland held a very successful Memory Walk on 21 September. Popular attractions on the day included a display of vintage cars from Ecosse Classic Wedding Cars, vintage hair and beauty make-overs by Boombarbers and Glam-candy, face painting, arts and crafts, a bouncy castle and a home baking stall.
Focus on Norway

The Norwegian annual telethon raised over EUR 27 million for the Norwegian Health Association’s work for people with dementia. Ingrid Fry, Communication Advisor of the Association, reports.

Each year the board of the Norwegian National Broadcaster (NRK) supports one cause through its ‘telethon’: this year the Norwegian Health Association was chosen for its work with people with dementia.

The eight-hour telethon was broadcast on Sunday 20 October 2013 and politicians, celebrities, people with dementia, carers and the Association all took part. It showed the Norwegian Health Association’s work with dementia and the challenges which people who are affected by dementia face. Some 100,000 volunteers visited 2.2 million homes all around Norway during two hours to collect money!

Dementia is a severe disease, both for the ones living with the disease and for their families and our goal is to combat dementia and cardiovascular disease and to make life better for everyone who is affected by dementia. We aim to do so through the funding of research, raising awareness of the role which preventative measures can play, the provision of information for all and by lobbying and informing policy makers. We are a voluntary, humanitarian organisation with volunteer-led health and dementia groups throughout Norway. We rely on voluntary donations. The money raised from the telethon is of great significance to us and it will enable us to help people with dementia and their carers by targeting three areas.

Three focus areas

Knowledge and understanding of the disease: a lack of openness and understanding adds an extra burden for people with dementia and their families. To encourage people to talk openly about dementia, they need to know that they will be met with understanding and respect. We also need to create a society more adapted for people with dementia. To address these issues, we will use part of the funds from the telethon to:

- increase the knowledge about dementia, so that more people who live with disease can be met with acceptance and understanding;
- establish meeting places for people with dementia and their families.
Participation: physical and mental activities can help delay the development of the disease, yet people with dementia might have problems participating in social activities. We will recruit and train volunteers to become ‘activity friends’. This is a programme that aims to give people with dementia fulfilling days and respite for the closest family. In particular, we will use part of the funds from the telethon to:

• offer activity friends both to people with dementia who live at home or in nursing homes;
• strengthen the continuing work creating meeting places for people with dementia and their families all over the country.

Research: over a hundred years after Alzheimer’s disease was described for the first time, the disease is still considered to be a riddle. One of the reasons for this is the lack of basic research. Through more research, progress can be made to understand the disease and find better treatment and prevention. To overcome the lack of research we will allocate part of the funds from the telethon to establish a long-term, coordinated research programme. The goal is to understand how the different forms of dementia occur, how they can be prevented and contribute to developing a more effective and curative treatment of dementia.

In terms of the numbers of participants and amount of money collected per capita, the telethon is the world’s largest fund raising event. During the broadcast on October 20, the focus on dementia not only collected the grand sum of EUR 27 million, it also created greater awareness about the cause.

“The money raised from the telethon is of great significance to us and it will enable us to help people with dementia and their carers.”

INGRID FRY
My name is Nina Baláčková. I am 55 years old. I was diagnosed with Alzheimer’s disease six years ago. My diagnosis took nine months.

Many things have changed for me since my diagnosis. Even though I was an accountant most of my working life, I am not able to count now. I can no longer smell and taste and I miss this. I have problems with organising, planning, cooking and I often forget things. However, I can still speak English and for this I am very grateful. This skill brought me the possibility to participate in Alzheimer Europe’s conferences.

Two years after getting a diagnosis of Alzheimer’s disease I organised discussions about my life with dementia. I gave an interview for various magazines and was also on TV. Through these activities I became a member of the European Working Group of People with Dementia (EWGPWD).

In the Spring of 2013, I participated in a special report on the radio dedicated to living with dementia. Over several months, I and others shared our own experiences. One reporter accompanied me on a visit to an old person with Alzheimer’s disease and his account of this won second place in the national competition “Report 2013”. I am proud of the cooperation we achieved and that this report resulted in people calling up the radio station to talk with myself and my husband about our experience of the disease. My husband is wonderful and supports me a lot. We used to do nearly everything together. We are blessed by a big family which, together with my friends, help me a lot.

I am training my brain all of the time through different means, including memory and cognitive training, crosswords, SUDOKU, puzzles, daily reading from a book aloud and singing songs. My husband and I are members of our church choir and it is there...
where I enjoy my favourite memory training which makes me remember words, melody and the arrangement.

I am sure that all my hobbies (daily exercise, traveling, hiking, listening to music and traveling), together with my strong hope, religion and support of my friends and family help me to keep happy. For me it is important to be useful and help others. It brings me satisfaction.

As we have three granddaughters, each of whom lives in another town, we travel a lot.

I also travel to EWGPWD meetings and Alzheimer Europe’s conferences. I made a presentation at the ADI conference in Taipei in April 2013. All of these meetings provide wonderful opportunities to meet many people, exchange opinions and hear about many useful developments. At the same time I am able to visit many different countries which I enjoy. My friend and very good carer, Eva Matějčková, helps me when I travel abroad and I am thankful for her help.
There are now 71 MEPs who are members of the European Alzheimer’s Alliance.
You can make a difference! Join today at www.alzheimer-europe.org
Our members are helping people with dementia and their carers in 33 countries

AUSTRIA – VIENNA
Alzheimer Austria

BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Ligue

BULGARIA – SOFIA
Alzheimer Bulgaria

BULGARIA – VARNA
Foundation Compassion Alzheimer

CROATIA – ZAGREB
Alzheimer Croatia

CYPRUS – LARNACA
Pancyprian Alzheimer Association

CZECH REPUBLIC – PRAGUE
Czech Alzheimer’s Society

DENMARK – HELLEURUP
Alzheimerforeningen

ESTONIA – TARTU
Estonia Association of Alzheimer’s Disease

FINLAND – HELSINKI
Muistiliitto

FRANCE – PARIS
Association France Alzheimer

GERMANY – BERLIN
Deutsche Alzheimer Gesellschaft e.V.

GREECE – THESSALONIKI
Greek Association of Alzheimer’s Disease and Related Disorders

ICELAND – REYKJAVIK
The Alzheimer’s Association of Iceland

IRELAND – DUBLIN
The Alzheimer Society of Ireland

ITALY – MILAN
Federazione Alzheimer Italia

ITALY – ROME
Alzheimer Uniti Onlus

JERSEY – ST HELETTER
Jersey Alzheimer’s Association

LUXEMBOURG – LUXEMBOURG
Association Luxembourg Alzheimer

MALTA – MSIDA
Malta Dementia Society

MONACO – MONTE-CARLO
AMPA - Association Monégasque pour la recherche sur la maladie d’Alzheimer

NETHERLANDS – AMERSFOORT
Alzheimer Nederland

NORWAY – OSLO
Nasjonalforsøkning Demensforbundet

POLAND – WARSAW
Polish Alzheimer’s Association

PORTUGAL – LISBON
Alzheimer Portugal

ROMANIA – BUCHAREST
Societatea Alzheimer

SLOVENIA – LUBLJANA
Association “Forget-me-not”

SLOVAKIA – BRATISLAVA
Slovak Alzheimer’s Society

SPAIN – PAMPLONA
C.E.A.F.A.

SPAIN – MADRID
Fundación Alzheimer España

SWEDEN – LUND
Alzheimerföreningen i Sverige

SWEDEN – STOCKHOLM
Demensförbundet

SWITZERLAND – YVERDON-LES-BAINS
Association Alzheimer Suisse

TURKEY – ISTANBUL
Alzheimer Vakfi

UNITED KINGDOM – EDINBURGH
Alzheimer Scotland

UNITED KINGDOM – LONDON
Alzheimer’s Society
24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014

Mark the dates!

www.alzheimer-europe.org/conferences