Ireland becomes a reality.

Kathleen Lynch, Minister of State with special responsibility for Disability, Equality and Health, talks about how the Irish Government is ensuring that the draft dementia plan in Ireland becomes a reality.

Alojz Peterle, MEP (Slovenia), discusses the situation for people with dementia in Slovenia.

Prof. Alexander Kurz presents recent clinical trials on dementia during a lunch debate in the European Parliament.

Dr Armelle Leperre-Desplanques, ALCOVE project leader, launches the results of the project in Paris.

Kathleen Lynch, Minister of State with special responsibility for Disability, Equality and Health, talks about how the Irish Government is ensuring that the draft dementia plan in Ireland becomes a reality.
There are now 70 MEPs who are members of the European Alzheimer's Alliance.
You can make a difference! Join today at www.alzheimer-europe.org
Welcome
By Helke von Lützau-Hohlbein, Chairperson of Alzheimer Europe

Prioritising Dementia

Facing dementia together:
Marina Yannakoudakis, MEP (UK), talks with Alzheimer Europe about her reasons for becoming Vice-Chair of the European Alzheimer’s Alliance.

Alliance in action:
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Alzheimer Europe projects 2013:
An update on some of the projects which Alzheimer Europe is involved in this year.

The European Working Group of People with Dementia (EWGPWD):
Alzheimer Europe reports on the third meeting of the EWGPWD.

Policy Watch

European action on dementia:
Alex Teligadas, Communications Officer, Alzheimer Europe, reports on the presentation of results and recommendations of ALCOVE, the European Joint Action on Alzheimer’s disease.

View from Slovenia:
Alojz Peterle, MEP (Slovenia) and member of the European Alzheimer’s Alliance, speaks about the challenges people with dementia and their carers face in Slovenia.

National Dementia Strategies in Ireland and Bulgaria:
Ms Kathleen Lynch, TD, Minister of State with special responsibility for Disability, Equality and Health, Ireland, discusses the steps taken towards a national dementia strategy and Irina Ilieva, Executive Secretary, Alzheimer Bulgaria, talks about the need for a national plan in Bulgaria.

Austerity measures:
Fanney Proppé Eiríksdóttir, Chairperson of the Alzheimer’s Association in Iceland, talks about the impact which austerity measures are having on people with dementia and their carers in Iceland. Also, Alzheimer Europe reports on the recent speech given by Corien Wortmann-Kool, MEP (Netherlands), on the “fiscal nightmare” of Alzheimer’s disease.

Policy roundup:
A look at recent national and European policy developments which may impact people with dementia and their carers.

Dementia in the news

National associations – Ireland:
Maurice O’Connell reflects on the achievements during his 14-year tenure as Chief Executive of the Alzheimer Society of Ireland.

Dementia in the arts:
Tatiana Nunes, Public Relations Officer, Alzheimer Portugal, talks about the successful “Spaces of Memory” project which brings together people with dementia and art students.

Spotlight on Finland:
Heidi Härö, specialist of early-onset memory diseases and Ella Okkonen, Executive Director of the Alzheimer Society of Finland, look back at the work carried out by Society as it celebrates its 25th birthday.

Living with dementia in Ireland:
Dermod Slevin shares his experience of living with dementia with Avril Dooley from the Alzheimer Society of Ireland, from the point of diagnosis to his involvement in speaking out about dementia.

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An exciting two-year project, the Joint Action on dementia “Alzheimer Cooperative Valuation in Europe (ALCOVE)” brought together 30 partners from 19 countries in order to improve our knowledge about the prevalence and diagnosis of dementia, the management of behavioural problems and the rights of people with dementia. We report on the results which were presented in Paris in March.

Working alongside people with dementia continues to be a key priority of Alzheimer Europe and I am proud that this issue includes an article on the progress achieved by our European Working Group of People with Dementia.

The European Presidency is currently held by Ireland and we are delighted to include three very different articles about life in Ireland for people with dementia. Dermod Slevin, talks about his life with the disease. Kathleen Lynch, TD, Minister for Disability, Equality, Mental Health and Older People, informs us about the Government’s plans to implement a national dementia strategy. Lastly, Maurice O’Connell reflects on the work of the Alzheimer Society of Ireland during his 14-year tenure as its Chief Executive.

The Alliance has supported each of Alzheimer Europe’s lunch debates in the European Parliament. We report on the 15th debate which was dedicated to clinical trials in Alzheimer’s disease and hosted by Sirpa Pietikäinen, MEP (Finland).

Iceland has been acutely affected by the current economic climate. I am grateful to Fanney Proppé for her contribution which highlights how austerity measures are impacting people with dementia and their carers in Iceland. It is important that the issue of austerity is also raised in the European Parliament and we are happy to cover a speech by Corien Wortmann-Kool, MEP (Netherlands) on the “fiscal nightmare” of Alzheimer’s disease.

National associations are working hard to highlight the needs of people with dementia. Irina Ilieva from Alzheimer Bulgaria tells us about the groundwork being carried out to develop a national dementia strategy. Tatiana Nunes from Alzheimer Portugal shares her experience of the “Spaces of Memory” project which brings together people with dementia and art students. Last but not least, Heidi Härmä and Eila Okkonen explain how the Alzheimer Society of Finland, ”Muistiliitto”, has grown over the last 25 years.

We are currently busy preparing for the 23rd Alzheimer Europe Conference, “Living well in a dementia-friendly society”, which will be held in Malta in October. I hope to meet many of you there!

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe
Prioritising Dementia

Marina Yannakoudakis, MEP (UK), explains why she decided to take on the role of Vice-Chair of the European Alzheimer’s Alliance.

Prof. Alexander Kurz presents recent clinical trials on dementia during a lunch debate in the European Parliament.

The European Working Group of People with Dementia holds its third meeting.

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The European Working Group of People with Dementia (EWGPWD):
Alzheimer Europe reports on the third meeting of the EWGPWD.
FACING DEMENTIA TOGETHER

Marina Yannakoudakis, MEP (UK), talks with Alzheimer Europe about her reasons for becoming Vice-Chair of the European Alzheimer’s Alliance and the role of the European Union in facing the challenge of dementia.

Alzheimer Europe (AE): Marina, thank you for accepting to become a Vice-Chair of the European Alzheimer’s Alliance in the European Parliament. What were the reasons why you decided to join the Alliance back in 2010?

Marina Yannakoudakis (MY): In the European Parliament’s Environment, Public Health and Food Safety committee I focus on the health portfolio. While focusing on health issues I have followed the issue of dementia, including Alzheimer’s disease, for some time. This is because in my London constituency alone, 68,000 people have developed dementia. And what is worse is that another 40,000 Londoners do not realise they have the condition. Currently fewer than 50% of cases of dementia are diagnosed in the UK. One of the issues which I would like to raise awareness of is early diagnosis of Alzheimer’s disease and we must encourage families to be alert for the signs of dementia in their relatives, especially as relatives get older.

AE: What do you hope to achieve in your role of Vice-Chair of the European Alzheimer’s Alliance?

MY: Dementia is the largest healthcare challenge which we shall face this century. We need a comprehensive, multinational approach and the European Alzheimer’s Alliance has an important role to play here. In my new role I would like to encourage the sharing of best practice on Alzheimer’s disease, especially on the four themes of prevention, diagnosis, treatment and cure. I hope that I can do the Alliance justice and live up to the expectations of the millions of people affected by Alzheimer’s disease in the EU as I take on my new role as Vice-Chair.

AE: What are the areas where you feel the European Union could do more to answer the dementia challenge?

MY: I think that the European Union works best when its sovereign Member States share best practice. For example, a recent survey showed that 28% of carers for people with dementia in France felt that the healthcare system ignored the wellbeing of older people. In Spain the figure is only 16%. Why is there a difference and how can French carers access the same level of support as their counterparts in Spain?

Until we have a cure we need to increase funding for scientific studies into the disease. Medication has come a long way and I hope that the revision to the Clinical Trials Directive on which I’m working in Parliament will make it easier to develop new Alzheimer’s disease treatments. Research – be it in the field of medical or technological innovation – is one of the few areas where I think EU funding should actually be increased. The European Commission’s Seventh Framework Programme has made over EUR 600 million available to study neurodegenerative diseases including Alzheimer’s disease. This should go hand-in-hand with national research such as the recent decision in the UK to invest EUR 22 million in 21 pioneering dementia research projects.
There are 70 Members of the European Parliament (MEPs) who have joined the European Alzheimer’s Alliance. Annette Dumas, EU Public Affairs Advisor, Alzheimer Europe, highlights some of the ways in which Alliance members have helped to raise awareness of dementia.

Ms Werthmann asked the Commission to list all research and development programmes, which have been running in Europe since the 2010 initiative as part of a European approach to combat Alzheimer’s and dementia.

Françoise Grossetête, MEP (France), Alliance Chair, received the EURORDIS MEP Award on 28 February 2013. This Award recognises her work in a series of EU legislations in the field of rare diseases, cross-border healthcare and the third EU public health framework programme (for which she is Rapporteur).

The EURORDIS Awards recognise excellence in the field of rare diseases. They promote leadership and achievement in the field of rare diseases. This year, the Awards acknowledge the outstanding contributions of patients’ advocacy groups, volunteers, scientists, companies, media, and policy makers toward reducing the impact of rare diseases on people’s lives.

The Awards were distributed on the occasion of the 6th Rare Disease Day.

Angelika Werthmann, MEP (Austria), sent two questions for written answers to the European Commission in March 2013 on the state of play of European actions on dementia. Responses from the Commission should be given before the summer break. The first question was on the spread of Alzheimer’s disease. While referring to the European Parliament (EP) Resolution of January 2011 on a European initiative on Alzheimer’s disease and other dementias, she wanted to hear to what extent the Council had acted on this call and what political strategies have been developed to combat the spread of the disease. She also wanted to hear if these strategies included education of the public.

Ms Werthmann’s second question dealt with research in dementia. She referred to the same EP Resolution, a recent article in the newspaper “Süddeutsche Zeitung” that said that Alzheimer’s disease was turning into an epidemic, and the “Deutsche Alzheimer Gesellschaft”, which says that the number of people with dementia will more than double by 2050.

Ms Werthmann asked the Commission to list all research and development programmes, which have been running in Europe since the 2010 initiative as part of a European approach to combat Alzheimer’s and dementia. She was also keen to hear how the Commission saw new ways and means of more effectively coordinating research in Europe, including cooperating with third world countries (the US or Asia), and improving communication. Finally, she wanted to hear which programmes, to combat Alzheimer’s and dementia, had been launched by the European Union since the start of 2011.
Elena Oana Antonescu, (Romania), could not be physically present at the conference but sent a video message. In this message, she stressed that Alzheimer’s disease was a challenge for the European health systems and that the ageing of the population impacts all EU countries, including Romania. Besides the lack of treatment for the disease, other major problems are the social integration of people with dementia and how to reduce pressures or constraints put on the family.

Ms Antonescu presented her work in the EP. On several occasions, she has called for European action in the field of dementia: she asked the European Commission to make the fight against Alzheimer’s a health priority and the Member States to develop national plans to tackle dementia. She also called for access to treatment to permanently remove inequalities that exist in Europe. European efforts must include consistent funding for research and treatment as well as more effective cooperation at European level and exchange of best practices.

Chronic conditions like Alzheimer’s disease directly affect a person’s lifestyle and social inclusion. Health authorities should take the experience of people with dementia and their families more into account to seriously address the social problems linked to this disease. This is particularly the case for Romania.

In its 20 years of existence, the Alzheimer’s Society of Romania has intensively contributed to increasing diagnosis and community care for people with Alzheimer’s disease and their families. Ms Antonescu was keen to thank the Society for all its work and reiterated her support to the Society and families.
Cristian Busoi, (Romania),

presented some of his on-going work in the EP that will impact the lives of people with dementia. In particular, he talked about how the EP was currently working on the revision of an EU Directive (the so-called “Transparency Directive”) that would require all European states to shorten to 90 days the period during which national agencies will agree on a price for original drugs and to 30 days for generic drugs.

Mr Busoi also mentioned that the EP was very keen to see more funds dedicated to research in health, with a requested budget of around EUR 9 billion.

Finally, Mr Busoi mentioned the revision of the Clinical Trials Directive. The aim of this Directive is to redress the clinical trials deficit that Europe is currently facing (25% decline in the number of clinical trials carried out in Europe over the past five years) and to improve the quality of the clinical trials conducted on European soil.

Daciana Sarbu, (Romania),

was happy to report that the EP had realised the urgency of tackling the dementia challenge in Europe and the increased importance of achieving a European dementia strategy, including Alzheimer’s disease. She acknowledged that Alzheimer’s disease was a public health problem, whose incidence increases with age. She called upon the European Commission to collaborate more with MEPs in order to find solutions to improve the lives of Alzheimer’s patients.

Ciprian Tanasescu, (Romania),

could not be physically present either but sent a message. In this message, he first set the scene by saying that between 50 and 70% of all people with dementia have Alzheimer’s disease. He added that by 2030, around 25% of the population will be over 65 years old and that some 10 million EU citizens will have Alzheimer’s disease. He added that the last few years have brought not only new technologies, but also the revision of specific terms. Even though Alzheimer’s is normally defined as a form of dementia, new voices aim for Alzheimer’s disease to be recognized as a disease by itself.

In the absence of any treatment, Mr Tanasescu said he supported active intervention as a solution to address Alzheimer’s disease. He expressed an interest in the use of specified memory tests and biomarkers that could make it possible to identify the disease before all symptoms have appeared. He sees the importance of capturing the early stages of the disease in order to take timely and tailored measures. To this end, Mr Tanasescu feels that investment in research remains a key element, together with coordination and exchange of best practices/knowledge between the Member States.
Prioritising Dementia

Alzheimer Europe would like to thank the following MEPs who have recently added their support to people with dementia and their carers by becoming members of the European Alzheimer’s Alliance:

- Martina Anderson (UK)
- Joseph Cuschieri (Malta)
- Mark Demesmaeker (Belgium)
- Rosa Estarás Ferragut (Spain)
- Arlene McCarthy (UK)
- Claudiu Ciprian Tănăsescu (Romania)

There are now 70 MEPs who are members of the European Alzheimer’s Alliance. You can make a difference! Join today at www.alzheimer-europe.org

Mario Mauro, MEP (Italy), steps down from the European Alzheimer’s Alliance.

Mario Mauro, a Member of the European Alzheimer’s Alliance since 2012, has left the European Parliament after being elected to the Italian Senate in February.

Alzheimer Europe would like to thank Mr Mauro for his support and wish him all the best in his new functions.
Alzheimer Europe’s 15th lunch debate was dedicated to clinical trials on Alzheimer’s disease and was held at the European Parliament on 26 February 2013. We report on some of the issues raised.

Ms Pietikäinen emphasised the importance which clinical trials have in addressing the challenge of dementia, the need for further EU research to be conducted and the importance ethical considerations have in research. Whilst introducing the speakers, she invited the audience to reflect on how vulnerable groups can be protected when clinical trials are carried out.

Medicines for Alzheimer’s disease

Prof. Alexander Kurz, Professor of Psychiatry and Head of the Centre for Cognitive Disorders at the Department of Psychiatry and Psychotherapy of Technische Universität, Munich, Germany, presented “New medicines for Alzheimer’s disease? Disappointing results and hopes for the future.”

A pathological cascade of events

Prof. Kurz explained the changes which occur in the brain of someone who has Alzheimer’s disease and illustrated the difference between the brain of a healthy individual and that of an individual with Alzheimer’s disease by highlighting the presence of beta amyloid (Aβ). Prof. Kurz explained that beta amyloid is accumulated in the brain when there is an imbalance between the production and clearance of the protein. This results in the aggregation of beta amyloid and, in turn, in the formation of plaques. The consequence of this is that a complex pathological cascade of events begins. The beta amyloid aggregation causes the aggregation of a second protein, tau, resulting in energy dysfunction and then in nerve cell dysfunction. If nerve cells die, some parts of the brain become atrophic and it is at this point that clinical symptoms become evident. Some components of this cascade are visible outside of the brain. For example, the levels of tau increase in the spinal fluid.

Approaches to tackling Alzheimer’s disease

Different approaches are currently researched to combat this process. They aim to target the aggregation of beta amyloid by inhibiting its production, enhancing its clearance, prohibiting its re-entry into the brain, inhibiting plaque...
Prof. Kurz said that some trials involving compounds which remove beta amyloid from the brain are proving to be promising. He explained that this removal can be achieved by using the brain’s own immunological machinery in one of two ways: (i) By active immunisation where beta amyloid fragments together with an immune stimulate are injected into the blood stream. The body responds by producing antibodies against beta amyloid which bind to them, flag them and stimulate cells known as “macrophages” in the brain (which recognise something is wrong) to eat up and degrade the flagged amyloid fragments. (ii) By passive immunisation where preformed synthetic antibodies against Aβ are injected. Some of these enter the brain, bind and flag beta amyloid and the macrophage eats it up.

Prof. Kurz highlighted a study (AN1792) in which an active immunisation treatment aimed to prevent the progression from mild dementia to advanced dementia. It showed that the biological effect was dramatic as beta amyloid had been cleared out of the brain. However, when cognitive ability and daily living abilities were compared to the placebo group there was no significant difference and there was no clinical effect. This led to the trial being stopped after an average of two injections. Even when individuals participated for longer and were followed for up to six to eight years, it did not prevent participants reaching the advanced stage of dementia.

He also presented a highly publicised passive immunisation trial using bapineuzumab. Prof. Kurz explained that this was the most expensive clinical trial ever conducted in Alzheimer’s disease. After 78 weeks of treatment it showed that the amyloid had gone from the brain. However, there were side effects. The discrepancy between the biological and clinical effects reflected the findings of the active immunisation trials in that there was no significant difference between the clinical results of the placebo group and the group receiving the passive immunisation.

However, another passive immunisation study which used solanezumab (LY20662430) has been more encouraging as it is the first time that a slowing of disease progression has been shown by the drug working.

**The way forward**

Prof. Kurz considered the reasons behind the dramatic discrepancy found between the biological and clinical effects of the drugs. He suggested that one reason may be that the treatments are administered too late in the disease process. At the moment, the diagnosis of dementia is made at a point when a large part of the brain is already damaged. In order to overcome this problem, Prof. Kurz emphasised the importance of making a diagnosis at an earlier stage. He explained that in the case of Alzheimer’s disease, there are biomarkers (such indicators of Aβ deposition e.g. PiB PET and CSF Aβ markers) in place to help us diagnose it earlier. Prof. Kurz said that another possible limitation is the fact that the focus is on...
beta amyloid. This is because many people believe that it is central to the process of Alzheimer’s disease. However, he reflected that the reality may be that beta amyloid is just one piece of a much bigger picture and suggested that we use a combination of pharmacological strategies to address not only beta amyloid aggregation but also the energy disruption, nerve cell loss and tau aggregation.

He concluded by saying that the development of new medications currently focuses on beta amyloid. Immunisation strategies to remove amyloid are the most advanced, have had impressive biological effects and recently have also had some clinical effects. However, the fact that treatment starts late in the disease lifecycle is a limitation as is the fact that beta amyloid may be one part of a far more complex scenario which we need to investigate further.

Charles Scerri and Heike von Lützau-Hohlbein, respectively Honorary Secretary and Chair of Alzheimer Europe asked for clarification regarding the progress of current anti-tau therapy. Prof. Kurz said that although some studies suggest it is not effective, there are some ongoing clinical trials which appear to suggest it is well tolerated. However, it is not possible to comment about clinical effects as the results are not due to be published until 2014.

The issue of screening was raised and Prof. Kurz said he believed that if there was a safe and effective drug available which could slow down Alzheimer’s disease, then screening would make sense. However, as we are not in a position to offer such a drug, he believed screening to be unreasonable in the current climate.

The proposal for an EU Regulation on Clinical Trials

Fabio D’Atri from the European Commission, Health and Consumers DG, Unit on Quality Safety and Efficacy of Medicinal products, presented an “Overview on the proposal for a Regulation on clinical trials”. He explained that the proposal for a Regulation was adopted by the European Commission in July 2012 and that it was now being discussed by the European Parliament and the Council. At this stage of the procedure interested parties willing to suggest changes to the Commission proposal would have to approach a Member of the Parliament or their Member State in order to do so. A plenary vote at the European Parliament may be scheduled for later this year.

Mr D’Atri said that a clinical trial is the “administering of a medicine on the basis of a protocol with the aim of exploring the characteristics of a medicine”. He also clarified that non-interventional trials (such as observational trials) and trials without medicinal products (such as a study on the best way to carry out surgery) will not be covered by the proposed Regulation.

To obtain an authorisation to carry out a clinical trial there must be a sponsor. The sponsor wanting to carry out a clinical trial must prepare a dossier. Mr D’Atri illustrated how under the current legal regime, a sponsor may carry out an international clinical trial. He or she will have to submit a different dossier to each of the Member States where he/she would like to conduct the trial. Currently, each Member State has different
requirements about how the dossier should be composed. Furthermore, now each Member State gives its decision independently, even if a trial has to be conducted in several Member States. This situation is highly complex and it often results in the same application leading to the authorisation of different protocols in the different Member States concerned by the trial.

**Assessment of clinical trials**

The Commission is proposing a new procedure so that a single set of common documents will need to be provided for assessment. A dedicated portal will be developed which will allow the sponsors to submit their dossier automatically to all Member States concerned by the trial. The new procedure defines issues which will be assessed jointly by the different Member States (part I) or assessed independently at national level (part II). Certain elements need to be already defined at the assessment stage such as a clear distinction on how a patient is recruited and the procedure for informed consent. In addition, a justification will be required if certain groups, such as older people or women, are excluded from a trial.

Mr D’Atri explained that there was much debate when discussing the current Directive back in 2001 on the issue of the protection of subjects involved in clinical trials. The new proposal broadly keeps the existing provisions. They have just been rearranged in order to make them clearer. Consent issues have been a big area of discussion and the Commission did not wish to modify the compromise agreement made back in 2001. Essentially, if a person is unable to give consent then consent must be gained by a legal representative. This has been strengthened through reference to the fact that incapacitated subjects should take part, as far as possible, in the consent procedure.

**Special provisions**

Special provisions are given for the assessment of clinical trials which concern people with incapacity. In this case it is required that the assessment include people with expertise in the relevant disease and the patient population concerned or that advice is taken on the clinical, ethical and psychosocial questions in the field of the relevant disease and patient population concerned. In addition to the general rules concerning the protection of subjects participating in a trial, additional requirements are stipulated for incapacitated subjects. A definition of what constitutes an incapacitated subject is included and the specific provisions on the procedure for requesting their consent are addressed.

Fabio D’Atri explained that a dedicated portal will be developed which will allow the sponsors to submit their dossier automatically to all Member States concerned by the trial.
A completely new section regarding emergency situations (which may concern also incapacitated people) has been added to the proposed Regulation. Mr D’Atri explained that this section refers to those situations when a person is not able to give consent, for example when someone has a stroke. It is very important to develop new medicines to treat these conditions yet in that moment, if no one from the family is present what can be done? A possibility to waive the informed consent requirement is suggested although consent will have to be sought as soon as possible. In addition, in emergency situations the clinical trial has to impose only a minimal risk and minimal burden on the subject. There is some debate over this issue and the minimal risk/burden requirement has been criticised for being too restrictive and not allowing clinical trials to be conducted in emergency situations.

Lastly, Mr D’Atri raised the issue of transparency. This is a big issue at the moment. Currently, applications are not available for public scrutiny and Member States do not necessarily disclose everything. The Commission has proposed to have a new portal where all submitted applications and all decisions by Member States are introduced, making them publically available. The Commission has proposed that a summary of the trial results must be submitted to the portal one year after the conclusion of the trial and consequently be made publicly available. The Commission has recently published guidelines on the structure and content of this summary. Raw data are not being demanded but safety concerns will highlighted in the submitted summary of results. A discussion is currently underway in the European Parliament on various options for transparency on clinical trials results. The burden that the various options may place on independent researchers is also the subject of discussions as well as the timing of the publication of results and if results should be publicly available or available only on justified request.

Margrete Auken, MEP (Denmark), remarked that clinical trials are for the good of society and humanity. Therefore, she believed it to be unacceptable that anything may be hidden. She emphasised that there is a duty to the public to have information which is both fully transparent and in electronic form. Mr D’Atri highlighted that the provisions which are being proposed are already a big step towards increasing the transparency of clinical trials results. Prof. Kurz added that there can be issues for the sponsors in that if a study protocol from a sponsor is received, it usually has information on the product which is strictly confidential. If we were to say that the portal will automatically publicise all information then there is a likelihood that this will result in the sponsor not sharing their information about their products so freely. To overcome this, a solution could be to prepare a guidance document to define commercially confidential information and personal information.

Clarification was sought regarding the requirement that the summary of results has to be submitted one year after the end of a trial. The end of a trial is defined, normally, as the last visit of the last patient. Mr D’Atri explained that if such summary is not provided within one year after the end of a trial it would be for Member States to take the appropriate legal action. The Commission will have to ensure that the proposed Regulation is correctly enforced by Member States.

“Special provisions are given for the assessment of clinical trials which concern people with incapacity.”
Fabio D’Atri
Helga Rohra, Chair of the European Working Group of People with Dementia (EWGPWD), asked why the view of only one patient should be taken into account and Sirpa Pietikäinen asked whether an association could be part of a procedure of representation of rights for those patients who do not have the capacity to protect themselves. Mr D’Atri explained that the proposal aimed at ensuring that at least one patient is involved in the assessment of a clinical trial application. Discussions ensued as to what constitutes a patient and what organisations may be able to represent them. It was felt that this would have to be assessed on a case by case basis.

Sirpa Pietikäinen thanked the speakers and delegates for an interesting and informative debate. Heike von Lützau-Hohlbein thanked everyone for supporting the lunch debates and was delighted that MEPs Anneli Jääteenmäki (Finland), Sirpa Pietikäinen (Finland) and Angelika Werthmann (Austria) had also given their support today. She closed the debate by emphasising the need to strike a balance between, on the one hand, enabling clinical trials to be done and, on the other, protecting the people who participate in them. She also highlighted the ethical aspects which need to be considered when conducting clinical trials in the field of dementia as people in the advanced stage of the disease are probably unable to give consent and this makes them vulnerable.
A snapshot of Alzheimer Europe’s 15th lunch debate in the European Parliament

1. Delegates at the lunch debate / 2. Jean Georges (Alzheimer Europe), Anne Arndal (Denmark) and Margete Auken, MEP (Denmark) / 3. Satu Glawe (Janssen) and Marco Blom (Netherlands) / 4. Annette Dumas (Alzheimer Europe) and Antoni Gelonch (Sanofi) / 5. Angelika Werthmann, MEP (Austria) / 6. Sabine Henry (Belgium) and Carolyn Bodnar (GE Healthcare) / 7. Heike von Lützau-Hohlbein (Germany) and Sirpa Pietikäinen, MEP (Finland) / 8. Charles Scerri (Malta) and Anneli Jääteenmäki, MEP (Finland) / 9. Laurene Souchet (EPF) and Elia Okkonen (Finland) / 10. Elisabeth Calov (Merz) and Ersi Grammatikou (Greece)
ALZHEIMER EUROPE PROJECTS 2013

An update on some of the projects which Alzheimer Europe is involved in.

EMIF (THE EUROPEAN MEDICAL INFORMATION FRAMEWORK, 2013-2018)

EMIF is a five-year project that aims to develop a common information framework for the reuse of patient-level data, with an initial focus on Alzheimer’s disease and obesity. By facilitating access to existing data sources, the project will ease the creation of links between sources and collect additional information wherever needed. To achieve this, the project partners will work within 15 work package groups to address such issues as data standards, interoperability, data privacy and ethical and legal issues. They will also cooperate to leverage “tranSMART”, an open source IT platform that allows access to multiple data sources. The project is the largest IMI project in terms of participants, with 57 partners and some 250 people from 14 countries. It has been allocated EUR 56 million.

Mr Bart Vannieuwenhuyse, overall Project Coordinator and Senior Director of Health Information Sciences at Janssen R&D, chaired the first General Assembly on 28 February - 1 March 2013. The meeting offered the 98 delegates the opportunity to find out more about:

- The aims of the project,
- Different aspects of the project through a series of breakout sessions,
- The relationship between diabetes and dementia,
- How the project management will work and
- The long-term “Grand Vision” of the project.

Alzheimer Europe is one of 21 partners in Work Package 10, which is entitled “Governance, Federation, DB Fingerprinting, Legal and Ethics”. The EMIF project has received support from EFPIA companies and the European Union (IMI JU).

THE EUROPEAN DEMENTIA MONITOR (2013)

Jean Georges, Executive Director of Alzheimer Europe, launched the new project “The European Dementia Monitor” at Alzheimer Europe’s company round table on 26 February. Representatives from nine pharmaceutical companies, 14 national Alzheimer associations, the European Working Group of People with Dementia together with the staff of Alzheimer Europe attended. Mr Georges explained that the monitor will be a benchmark of national dementia policies and will compare three key areas:

- Medical/scientific issues: prevalence, diagnosis and treatment,
- Care and social issues: social support, Alzheimer associations and care and
- Policy and legal issues: dementia strategies and research, guardianship.

By highlighting the strengths and weaknesses of access to care and treatment between countries, the European Dementia Monitor can become a powerful lobbying tool for change. Further, national associations will be able compare their own country to others. A data matrix form will be developed by Alzheimer Europe to facilitate further discussion with the group in June. It is hoped that first comparisons can start to be published as early as December 2013 and presented in the European Parliament.
GOOD INCONTINENCE CARE FOR PEOPLE WITH DEMENTIA (2013-2014)

Alzheimer Europe hosted the first meeting of the Good Incontinence Care for People with Dementia working group on 21 March 2013. The meeting was chaired by Dianne Gove, Information Officer for Alzheimer Europe and project leader. The participants included Jean Georges, Executive Director of Alzheimer Europe and Nicole Huige of SCA Global Hygiene via Skype. Also present were Vicky Morris, Daniela Hayder and Kai Leichsenring, independent experts and researchers in dementia, incontinence care and social and welfare policy.

The working group decided that the project should focus on good incontinence care for people with dementia living at home, provided by informal and professional carers. Issues such as data on the prevalence of incontinence and dementia in the home setting, access to incontinence care, the training of carers, ethical issues, assessment and diagnosis will be explored during this project. The project is fully funded by SCA Global Hygiene.

THE 2013 DEMENTIA IN EUROPE YEARBOOK: NATIONAL POLICIES RELATING TO CARE AND SOCIAL SUPPORT OF PEOPLE WITH DEMENTIA (2013)

Alzheimer Europe and representatives from its member associations met on 27 February 2013 to start work on the 2013 Dementia in Europe Yearbook, which is dedicated to national policies relating to the care and social support of people with dementia. During the meeting the group discussed how to best to develop the questionnaire which will serve as an instrument to collect data from Alzheimer Europe member associations. Questionnaires were sent out in April and currently the data is being collected.

In addition to the above, the 2013 yearbook will include the latest dementia prevalence figures in the EU counties and Iceland, Jersey, Norway, Switzerland and Turkey. These will be calculated for each five-year age group from age 30 onwards using population statistics from 2013. The yearbook will also have a directory of national Alzheimer’s associations, including the number of staff, budgets and types of services provided. This information will be ascertained from a survey. The yearbook will be published in December 2013.

DECIDE (THE DIAGNOSTIC ENHANCEMENT OF CONFIDENCE BY AN INTERNATIONAL DISTRIBUTED ENVIRONMENT, 2010–2013)

The aim of DECIDE was to design, implement and validate a GRID-based e-infrastruture. The service it provides assists in the earlier diagnosis of Alzheimer’s disease and other forms of dementia. Alzheimer Europe was one of 13 partners in the project, which was led by Consortium GARR in Rome. DECIDE was funded through the Seventh Framework Programme.

A final review of the project was held in Rome on 17 April 2013. Headed by Ms Athina Zampara, the review team saw a demonstration of the service and held discussions with project team leaders. The reviewers concluded that the project accomplished what it set out to do, with a specific citation for the scientific and technological excellence of the project. They also pointed out various areas for improvement; these will be addressed in the final report that will be delivered in the coming weeks.

Fortunately, the service will continue to operate after the end of the project life. This is mainly due to the Italian Ministry of Health, which has already approved funding for several follow-on projects involving DECIDE.

The project partners are also seeking a role for the service in various European FP7 projects. In addition, there has been a formal offer for the DECIDE diagnostic service for daily clinical practice to a group of leading European memory clinics. It is hoped that these efforts will ensure that the service will remain available for at least the next several years.
A brief report on the third meeting of the European Working Group of People with Dementia (EWGPWD).

**The European Working Group for People with Dementia**

Alzheimer Europe reports on the third meeting of the recently-formed European Working Group of People with Dementia.

The European Working Group of People with Dementia (EWGPWD) held its third meeting in Brussels on 12 April 2013. Ten members of the working group attended, together with eight carers and a representative from Alzheimer Europe as well as the Ligue Alzheimer Belgique. Helga Rohra chaired the meeting. The Group:

- Received an update on the work of the Alzheimer Europe Board by board member Helga,
- Exchanged information about Alzheimer Europe’s round table meeting with representatives from pharmaceutical companies and Alzheimer associations. Helga explained that she had highlighted the importance of showing that people with dementia are strong but that they also need support,
- Discussed the issue of end-of-life care and euthanasia and decided to propose to the Board that Alzheimer Europe’s ethics group address this issue,
- Elected Nina Baláčková as a new Vice-Chairperson,
- Began preparations for its participation at Alzheimer Europe’s 23rd annual conference to be held in Malta in October. Nina will be a keynote speaker. The Group discussed how it could disseminate information about its work,
- Discussed how people with dementia can be involved in society and how information about the Group can be disseminated. Members of the Group shared experiences of work in dementia within their respective countries:
  - **Belgium** – Jean-Pierre Frognet told the Group of a new “fighting group” which had been set up in Brussels. Issues can be discussed within this group alongside visiting specialists. Jean-Pierre explained that they had learned of tests for the evaluation of language which may be used during the diagnostic process.
  - **Czech Republic** – Nina Baláčková attends a small support group (of just four). She has organised a talk about her own life and been interviewed for a magazine. She will speak at two international conferences, one in Prague and the ADI conference in Taipei.
  - **Finland** – Raoul Grönqvist had participated in a Parliamentary seminar to launch the project “Valid”. A proposal has been put forward in Finland to set up a working group on how to deal with the situation whereby people struggle with the fact that no-one realises that a particular person has dementia. In addition, the Finnish Alzheimer Society will set up a working group of people with dementia and carers at the end of 2013. This will be the first of its kind in Finland.
  - **Germany** – Helga Rohra reported that a hotline for people with dementia, run by people with dementia, had been piloted. People with dementia and specialists had organised and run some workshops at a conference in Munich. Helga had attended the national conference on dementia in Romania and also an EFNA meeting in Brussels.
  - **Ireland** – Dermod Slevin had been invited by the President of Ireland, Michael D. Higgins, to commemorate 20 years of the Irish Alzheimer Society.
He explained that in February a national Irish working group of people with dementia had been established. Dermod will sit on a panel of experts at a Sonas (wellbeing) conference in Dublin. Lastly, Dermod explained how important the Alzheimer cafés are in helping people with dementia.

**Slovenia** – Bojan Spanja participates in meetings at Alzheimer cafés to help people to better understand the disease. Amazingly, 25 Alzheimer cafés have been set up in the space of one year and hopefully the awareness is increasing. There is great hope for the future, as a national programme for people with dementia has now been set up.

**Sweden** – Ingegärd Pousard, together with her husband, Rolf Pousard, have shared information about the work of the EWGPWDs during meetings at Alzheimer cafés. They enlightened the EWGPWD about the Swedish association’s theme nights which attract some 10,000 visitors.

**UK (England)** – In February, Daphne Wallace had attended a new board set up by the Alzheimer’s Society for user-involvement throughout the Society and all its activities. Daphne also informed other members of the EWGPWD about the “Dementia Action Alliance” which is a group of organisations who work together to see how they might improve things for people with dementia.

**UK (Scotland)** – Agnes Houston illustrated how the Scottish Dementia Working Group (SDWG) had produced a leaflet to help organisations overcome some challenges they face when organising conferences where people with dementia will attend. Agnes has also been involved in a study which looked at the emotional issues of people with dementia. It will be published soon. The SDWG is working alongside the Scottish Government on the development of the next National Dementia Strategy which will be launched in 2016. The work of the EWGPWD had been featured in the SDWG newsletter.

The EWGPWD will meet again in October.

**Participants at the EWGPWD meeting:**

Members of the EWGPWD - Stig Atle Aavik (Norway), Nina Baláčková, Vice-Chair (Czech Republic), Jean-Pierre Fрог.net, Vice-Chair (Belgium), Raoul Grönqvist (Finland), Agnes Houston, Vice-Chair (Scotland), Helga Rohra, Chair (Germany), Ingegärd Pousard (Sweden), Dermod Slevin (Ireland), Bojan Spanja (Slovenia) and Daphne Wallace (UK-Eng).

Other participants: Milja Ahola (Finland), Dianne Gove (Alzheimer Europe), Sabine Henry (Belgium), Ranveig Andrea Hoff (Norway), Donna Houston (UK-Scotland), Eva Matejkova (Czech Republic), Rolf Pousard (Sweden), Jean Scanlan (Ireland) Mihela Spanja (Slovenia) and Richard Wallace (UK).
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PROGRESS AGAINST ALZHEIMER’S DISEASE

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Experts present results of the European Joint Action “ALCOVE”.

24 European action on dementia:
Alex Teligadas, Communications Officer, Alzheimer Europe, reports on the presentation of results and recommendations of ALCOVE, the European Joint Action on Alzheimer’s disease.

View from Slovenia:
Alojz Peterle, MEP (Slovenia) and member of the European Alzheimer’s Alliance, speaks about the challenges people with dementia and their carers face in Slovenia.

National Dementia Strategies in Ireland and Bulgaria:
Ms Kathleen Lynch, TD. Minister of State with special responsibility for Disability, Equality and Health, Ireland, discusses the steps taken towards a national dementia strategy and Irina Ilieva, Executive Secretary, Alzheimer Bulgaria, talks about the need for a national plan in Bulgaria.

Austerity measures:
Fanney Proppé Eiríksdóttir, Chairperson of the Alzheimer’s Association in Iceland, talks about the impact which austerity measures are having on people with dementia and their carers in Iceland. Also, Alzheimer Europe reports on the recent speech given by Corien Wortmann-Kool, MEP (Netherlands), on the “fiscal nightmare” of Alzheimer’s disease.

38 Policy roundup:
A look at recent national and European policy developments which may impact people with dementia and their carers.

Kathleen Lynch, Minister of State with special responsibility for Disability, Equality and Health, Ireland, talks about how the Irish government is ensuring that the draft dementia plan in Ireland becomes a reality.

Alojz Peterle, MEP (Slovenia), discusses the situation for people with dementia in Slovenia.
EUROPEAN ACTION ON DEMENTIA

Alex Teligadas, Communications Officer, Alzheimer Europe, reports on the presentation of results and recommendations of ALCOVE, the European Joint Action on Alzheimer's disease.

The results of ALCOVE (ALzheimer COoperative Valuation in Europe) were presented in Paris on 28 March 2013. The two-year project was co-financed by the European Commission and built a network which includes 30 partners from 19 EU Member States.

The conference was opened by Jean-Paul Delevoye, President of France’s Economic, Social and Environmental Council and Dr Jean-Luc Harousseau, President of the French National Authority for Health. They welcomed the delegates and explained that efforts such as ALCOVE are invaluable, because dementia is a problem with social, economic and medical aspects – as well as a major challenge for public health policy. Dr Harousseau also expressed the hope that ALCOVE’s recommendations will be implemented in all EU countries – and called for a continuation of the excellent collaboration between Member States. They also introduced a panel of five dementia experts who were asked to provide comments on the project findings throughout the conference:

- Francesca Colombo, Health Policy Unit, OECD
- Jean Georges, Executive Director, Alzheimer Europe
- Joël Ménard, Alzheimer Foundation, France
- Véronique Roger, Chair of Health Sciences Research, Mayo Clinic
- Helga Rohra, Chair, European Working Group of People with Dementia

The next speaker was Michael Hübel, European Commission, DG Health and Consumers. He told the audience that the challenges of ageing and dementia in Europe are imposing changes to our public health policies. Mr Hübel cited ALCOVE as a model of the Commission’s strategy to strengthen cooperation between EU countries, adding that EUR 200 million has been allocated to dementia research. He also expects to see a follow-up to ALCOVE in the framework of the European Innovation Partnership on Active and Healthy Ageing.

The opening ceremony was concluded by Prof. Alistair Burns, National Clinical Director for Dementia in the UK and Dr Jean-Yves Graal, France’s National Chief Medical Officer and representative of the French Ministry of the Elderly and Autonomy. Prof. Burns highlighted three important ALCOVE elements that resonated in the UK: increasing dementia awareness, integrating health and social care and making a serious commitment to dementia by way of dementia-friendly communities.

The morning session began with Prof. Joël Ménard, Alzheimer Foundation, France, and one of the architects of the French Alzheimer Plan.
He gave an overview of the challenges of dementia and stressed that tackling dementia required a global approach such as ALCOVE. Despite the lack of a cure, Prof. Ménard explained that we have made significant progress in understanding the syndrome, particularly in genetics, imaging and biochemistry. For example, we can now detect abnormalities some ten years before an actual diagnosis of dementia is made. Nonetheless, Prof. Ménard said that dementia will keep growing as a demographic challenge, as the number of non-working age people continues to increase.

He was followed by Dr Armelle Lep erre-Desplanques, ALCOVE project leader and Manager of the Department of Pilot Programmes at the French Authority for Health. She explained that ALCOVE’s aims were to inform health professionals and policy makers about the specific health issues of dementia, propose care solutions and support to the carers and promote shared solutions between the participating countries. She also presented the four main pillars of the project:

- Epidemiological data on dementia: improving knowledge on dementia, including prevalence, available data and best practices for data collection.

- Early dementia diagnosis: exploring operational criteria in health care systems for timely dementia diagnosis in ambulatory and nursing home settings.

- Support systems for behavioural and psychological symptoms of dementia (BPSD): improving knowledge of the availability and efficacy of BPSD management at home, in hospitals and in care homes.

- Rights, autonomy and dignity of people living with dementia: improving the basic rights of people living with dementia, with a focus on advance declarations of will and competence assessments.

The project also explored ways to reduce the risks associated with excessive prescription of psychotropic drugs to people with dementia.

The remainder of the meeting was mainly devoted to the presentation of results from the four pillars of the project.

**Understanding prevalence**

The results of the Work Package on “Understanding prevalence & epidemiological data about dementia” were presented by Nicola Vanacore and Angela Giusti from Italy’s Istituto Superiore di Sanita along with Catherine Helmer of the French National Medical Research Institute. Their team conducted a review of some 30 epidemiological studies on dementia – including the EuroCoDe studies led by Alzheimer Europe – and used quality criteria to determine the most accurate result. Further analysis revealed differences of 22% in the prevalence rate of people with dementia compared to EuroCoDe and 12.2% compared to ALCOVE review estimates. Their final result is an estimated dementia prevalence rate of 7.23% of people over the age of 65 in Europe. Recommendations included the need to perform more studies on dementia prevalence, to carry out more studies to define the frequency of dementia in people under the age of 65 and to carry out studies in the same areas over different decades in order to detect possible changes in prevalence.
The team also looked at the exposure to psychotropic drugs in people with dementia. Prevalence is estimated at 10% in the general elderly population, but almost 36% in residents of nursing homes. This clearly indicates a need for a better understanding of the prescription and benefits of these drugs. It is interesting to note that countries with national dementia plans that address the use of antipsychotic drugs have experienced a reduction in their use.

Finally, they surveyed the status of 11 existing national dementia plans and five others that are close to launch. 27% of national programmes have been fully implemented, 54% partially implemented and 18% have not yet been implemented. Seven of the existing plans have a set of defined outcomes, standards and indicators that are measured on a regular basis, while eight countries have no national dementia plan.

**Timely diagnosis**

The findings of the Work Package on “Quality & timeliness of dementia diagnosis” were presented by Dawn Brooker, Association for Dementia Studies and Karim Saad, NHS West Midlands (both from the UK), along with Anders Wimo from Sweden’s Karolinska Institute. They analysed existing diagnostic systems in EU Member States.

Results show that most countries have conducted awareness campaigns for both professionals and the general public. They also have diagnostic guidelines for dementia and MCI. Despite this, only 40-60% of people with dementia have received an accurate diagnosis. The four professions that are mainly involved in these diagnoses are GPs, neurologists, geriatricians and psychiatrists. 70% of respondents said that their GPs have inadequate training in recognising the symptoms of dementia and diagnosing the disease. Information on post-diagnostic support and interventions also appears to be scarce. Legislation for people with dementia is varied: about one third of countries reported no legislation to protect people with dementia. Recommendations are in the form of specific strategies for timely detection and diagnosis.

**Behavioural and psychological symptoms of dementia**

The results of the Work Package on BPSD were presented by co-leaders Harriet Finne-Soveri, Institute for Health and Welfare, Finland and Pierre Krolak-Salmon, National Authority for Health, Lyon Hospitals, France. This team carried out a survey of national dementia plans to identify specific policies and interventions for BPSD. Currently, only three countries have specific BPSD guidelines in place.

Their presentation showed the types and origins of these symptoms and also the importance of taking them into account during treatment and care. BPSD symptoms are numerous, difficult to treat and constitute the main cause of institutionalisation of people with dementia. The researchers also showed a description of the structures and care organisations (SCO) for BPSD all along the patient pathway.

In the area of individualised patient and family carer interventions, the work focused on non-pharmacological and pharmacological therapies for people with BPSD and an overview of interventions for family carers, including psychological interventions. The main findings showed that multi-component information services were beneficial and that carer support reduced the incidence of depression. The latter was also recognised as an underutilised asset with the potential to reduce costs. Geronto-technology (assistive technology for older people) is also seen as positive and could be used to solve some safety issues.
The work on workforce and skills covered training and education for professionals, clinical guidelines and programmes for the reduction of antipsychotic use in Europe.

**Advance directives & competence assessment**

The results of this Work Package, entitled “Ethical & legal issues for advance directives & competence assessment in dementia”, were presented by Gerrit Rauws from the King Baudouin Foundation, Belgium and Herman Nys from the University of Leuven, Belgium and Dianne Gove from Alzheimer Europe. They addressed the issues of autonomy and dignity as they affect people living with dementia from an ethical and legal perspective.

This was done through a critical review of the medical-legal and bioethical literature regarding the concept and assessment of competence and national and international regulations on advance directives, a questionnaire survey regarding the legal regulation of advance directives in the EU Member States, and three workshops.

This Work Package dealt with competence assessment and advance directives in the context of strengthening the rights and protection of people with dementia. Dementia raises difficult ethical issues because it affects the cognitive and functional competencies of people with dementia. From an ethical perspective, it is crucial to strike the right balance between the autonomy of a person with dementia and the protection of that person, including his/her dignity and civic rights. However, striking the right balance is not only a question of care models and laws. The researchers investigated

Jean Georges added that dementia must remain a public health priority and that Alzheimer Europe is keen to see a follow-up to ALCOVE.
the legal status of advance directives in Europe and issued recommendations for their use. They also enumerated the benefits of planning for the future, both for people with dementia and their families and carers, but also for healthcare professionals. Attention was drawn to a few potential challenges such as the often lengthy duration of dementia and incapacity in certain domains, the historical association of advance directives with the end of life, and the stigma surrounding dementia.

The speakers emphasised the importance of considering advance directives within the broader context of advance care planning. This should involve a person-centred approach in which the diversity of personal wishes, social values and cultural backgrounds are taken into account and an on-going dialogue established between the person with dementia and healthcare professionals, but also informal carers, provided that the person with dementia so wishes. The need for national authorities to provide a legal framework for advance directives which is adapted to the needs and situation of people with dementia was also stressed. The possible advantages of combining advance directives with statements of values and the appointment of designated healthcare proxies were highlighted.

The ALCOVE toolbox for antipsychotics limitation in dementia

This was presented by Dr Martin Prince, Professor of Epidemiological Psychiatry at King’s College London and Dr Leperre-Desplanques. The overprescription of antipsychotics for behavioural disorders in dementia is a worldwide safety and ethical issue. It is well known today that chronic exposure to such drugs is non-effective and even deleterious for people with dementia: it can lead to an increased risk of mortality and certainly has a negative impact on their quality of life. The ALCOVE partners have created a common toolbox that provides alternatives such as non-pharmacological therapies and individual patient and carer interventions. The toolbox contains recommendations, key messages and case studies for all levels of care, including risk reduction programmes, timely diagnosis and prevention & management of BPSD.

After the Work Package presentations, the expert panellists were invited to give their remarks. Francesca Colombo suggested that the cost efficiency of new measures also need to be considered, along with the complications associated with comorbidity. Jean Georges pointed out that scientific developments are very important, but progress is also needed in legal and ethical issues. He added that dementia must remain a public health priority and that Alzheimer Europe is keen to see a follow-up to ALCOVE. Joël Ménard remarked that health inequalities within and between countries may make it difficult to implement the ALCOVE recommendations. He strongly suggests that these inequalities be addressed in any future work. Prof. Ménard also expressed support for new practical solutions, such as the nomination of health proxies. Helga Rohra suggested several new post-diagnostic guidelines for future recommendations. These guidelines would clarify the rights of people with dementia, including access to care, support and medication. She also highlighted the importance of directly consulting people with dementia: they are the best witnesses of the effects of any policy concerning dementia.
The symposium concluded with a presentation by Jürgen Scheftlein from the European Commission’s Directorate General for Health & Consumers. Mr Scheftlein expressed his appreciation to all of the project team members, saying that the Commission was very pleased with the results of the project. The ALCOVE recommendations and the questions that were raised during the discussions reflected the complexity of dementia. He recognised the new concepts that were being put forward in the area of early diagnosis and acknowledged the key role of people with dementia and their carers. Mr Scheftlein added that this work must continue and invited delegates to identify topics that could be included in a follow-on project to ALCOVE. In closing, Benoit Lavallard, Alzheimer Plan, France, congratulated all the participants of the project and hoped it will be possible to keep up the work in the future.

The final ALCOVE report presents specific proposals to improve care pathways and the quality of life for persons living with dementia and their carers:

- Improve knowledge about dementia prevalence, so as to better anticipate needs.
- Issue a diagnosis as soon as possible.
- Combine this diagnosis with a long-term care cycle for people with dementia and their caregivers.
- Design a public health strategy that deals with the behavioural and psychological symptoms of dementia (BPSD).
- Reduce caregiver burnout and allow people with dementia to stay at home for as long as possible.
- Improve the respect of the rights and dignity of people living with dementia by encouraging good practices in advance directives and competence assessment.

The final ALCOVE report, the list of recommendations and various videos can be found on the project’s website: www.alcove-project.eu

Attention was drawn to a few potential challenges such as the often lengthy duration of dementia and incapacity in certain domains, the historical association of advance directives with the end of life, and the stigma surrounding dementia.
We need to dedicate more resources to research to come up with appropriate medications and preventive methods as soon as possible.

Alojz Peterle, MEP (Slovenia) and member of the European Alzheimer’s Alliance, speaks with Alzheimer Europe about the challenges people with dementia and their carers face in Slovenia and discusses the development of a national Alzheimer’s plan.

“...We need to dedicate more resources to research to come up with appropriate medications and preventive methods as soon as possible.”

Alojz Peterle, MEP (Slovenia)

Alzheimer Europe (AE): what are the key challenges that people with dementia and their carers face in Slovenia?

Alojz Peterle (AP): In Slovenia, we have over 30,000 people with dementia and due to the increase of the ageing population we estimate the number could grow by 40 per cent in the next 10 years. Last year only about a quarter of people with dementia were medically treated. This is because in Slovenia there is still a widespread perception that memory related problems are common among the elderly and do not need treatment. On the other hand, it is also the result of an inadequate social response to this severe brain disease, because we do not have enough skilled health professionals for treating it. Consequently, people living with dementia are generally treated by neurologists and psychiatrists.

Due to the lack of trained medical staff, waiting periods for a medical examination last up to six months. Another problem we face in our country is late detection of the disease, however the situation is improving. Many people seek help only in the middle or even final stages of dementia, when they have already developed additional complications, so they need additional treatments as well. People with dementia and their families also face financial difficulties when coping with the disease, as the day care cost in non-specialised care homes for people with dementia is far more expensive than for regular inmates.

There is also a social issue, as people with dementia are often stigmatised. In Slovenia, raising awareness about the disease among the general public, relatives and health care professionals is poorly developed. The same accounts for adapted living environments for an improved way of life. Generally, people with advanced dementia not only need 24 hour assistance but also a lot of support from all of us. A wonderful case of social entrepreneurship is “Spominčica”, an association for helping people with dementia which was founded 15 years ago. This association, which is spread all over Slovenia, gathers enthusiasts and volunteers from all over the country for training, advising and supporting patients’ relatives at minimum costs.

AE: Governments across Europe are starting to pay more attention to the demographic changes in our societies and the resulting increase in the number of people with dementia in the future. Are there similar discussions in your country on a governmental or parliamentary level?

AP: In 2010, the Slovenian Ministry of Health established a working group for dementia. The working group issued a report on the situation of the disease and gave suggestions on how to regulate dementia in the professional field and on how to treat people with dementia and their families as well. Early this year, our previous Minister for Health appointed a new team (with professionals and associations from...
the field) to develop a national control program for dementia. I am pleased to hear that Slovenia will finally put dementia among its top priorities in public health.

AE: Do you believe that Slovenia will follow the example of France, Norway, the Netherlands, Scotland and England and create a National Alzheimer’s Plan?

AP: With the establishment of the working group for dementia in the Slovenian Ministry of Health, Slovenia is joining other countries with national plans to deal with dementia. But we need to dedicate more resources to research to come up with appropriate medications and preventive methods as soon as possible.

AE: What do you believe the three policy priorities should be for Slovenian policy makers to improve the lives of people with dementia and their careers in your country?

AP: The most important for me is early diagnosis, which is for the time being, set only by few specialists who mostly have very long waiting lists. The second one would be to raise public awareness about this disease thus contributing to the destigmatisation of this disease. It is important to stress that dementia is a physical disease of the brain. And finally, after being diagnosed, people with dementia should have access to good quality life conditions and their families should be offered support from the side of the social services.

AE: A last question on the need for a European response to the growing numbers of people with dementia. Would you support the development of a European Action Plan in this field and, if so, what should the priorities for such collaboration be?

AP: I can only express my strong support to a European action plan for people with dementia. In 2009, the European Parliament adopted a resolution on Joint Programming of research to combat neurodegenerative diseases, in particular the Alzheimer’s disease. It is believed that the instrument of joint programming could be very valuable in reducing the fragmentation of the research efforts, leading to a critical mass of skills, knowledge and financial resources. Neurodegenerative diseases such as Alzheimer’s and Parkinson’s diseases are one of Europe’s greatest challenges in mental health, affecting millions of citizens of the EU, a number that will probably double in the coming decades as a result of the ageing of the population. Therefore, the European Parliament takes the stance that the fight against Alzheimer’s and Parkinson’s diseases must respond to a dual challenge: provide care for an increasing number of people who live with dementia on a day-to-day basis and secure more resources so that the number of people living with dementia steadily decreases in the future. Also direct costs associated to the treatment of Alzheimer’s disease are increasing worryingly, which in 2013 are estimated at EUR 187 billion. Unnecessary hospital treatment due to dementia complications, too early moving of people with dementia to home care facilities and non-targeted medical examinations, represent a large part of this amount.

I would like to give my sincere thanks to “Forget-me-not”, the Alzheimer’s Disease and Related Disorders Association of Slovenia, established in 1997, which is a non-governmental organisation aimed at raising awareness of all forms of dementia and other mental disorders encountered in older ages.

“A Neurodegenerative diseases such as Alzheimer’s and Parkinson’s diseases are one of Europe’s greatest challenges in mental health, affecting millions of citizens of the EU.”

Alojz Peterle
ALZHEIMER’S DISEASE

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.

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NATIONAL DEMENTIA STRATEGIES: IRELAND

Kathleen Lynch, Minister of State with special responsibility for Disability, Equality and Health, Ireland, talks about how the Irish government is ensuring that the draft dementia plan in Ireland becomes a reality.

It is a simple fact that almost everyone knows someone who has dementia or whose life has been touched by it. With increases in the older population into the future, and particularly among the oldest old, the prevalence of dementia will only increase. We know that there are at least 41,000 people with dementia in Ireland now. This number is going to rise to between 141,000 and 147,000 by 2041.

We also know that dementia is one of the major causes of disability in older age and that, in economic terms, the overall cost of dementia in Ireland is around EUR1.69 billion per annum. While the numbers and costs are daunting, the economic cost of dementia is only a small part of the story.

The personal cost of dementia is overwhelming, not only for the people who have it but also for their caregivers and families. The impact on those with the illness and their carers is extreme – medically, psychologically and emotionally. I think that we all can agree that the time to act is now. The Government of which I am a member has given a commitment to develop a national Alzheimer’s and other dementias strategy by the end of 2013. It is our intention that the Strategy will increase awareness of dementia, ensure early diagnosis and intervention and development of enhanced community based services.

Many countries have developed dementia strategies, policies, plans and guidelines. We intend to learn from the many examples of good practice available around Europe so that the Irish Strategy will be a well-thought out plan for all future policies, programmes and services for people living with dementia in Ireland.

I believe that if we are willing to be innovative, if we promote co-operation among all sectors of society, and if we set out to properly plan for dementia by developing sound, evidence-based policy choices, we will successfully manage the economics of this issue, while at the same time, making our countries good places in which to grow older in the years ahead.

It is also important that we are consistent in our thinking on all of the issues which effect people with dementia. Last year, I launched a National Carers’ Strategy in recognition of the invaluable role and contribution of carers in Ireland. It places carers firmly on the
Kathleen Lynch

national agenda and sets the strategic direction for future policies, services and supports provided for Irish carers.

My colleague, the Minister for Health, recently published Healthy Ireland, a national Health and Wellbeing Framework and we are in the process of finalising a National Positive Ageing Strategy. These plans take a whole of Government approach to promoting health and wellbeing and recognise that quality of life is affected by a range of interconnected social, economic and environmental factors. The National Dementia Strategy will build on these initiatives and will ensure that recognition is given that for those with dementia, wellbeing is also affected by a range of interconnected factors that are broader than those that are just health-related. In order to build a better society for those with dementia a whole of government and whole of society approach is needed.

Last year, we launched “Creating Excellence in Dementia Care: A Research Review for Ireland’s National Dementia Strategy”. This research review gathered the evidence to inform the development of our Strategy and made a number of recommendations about key areas which should be focused on. We have also recently completed a public consultation process to ensure that everybody with an interest had an opportunity to inform the development of the Strategy. A report on these submissions was published earlier this year.

The key message which emerged from the consultation was the need to place the person with dementia, irrespective of settings, at the centre of service planning and in particular decision making processes about all aspects of

their lives. In this regard, a recurring theme throughout the submissions highlighted the need for increased awareness and enhanced training for health professionals in all settings.

My Department is currently setting up a working group which will include representatives from a broad range of stakeholders to help develop the Strategy. It is our intention to finalise the Strategy by the end of this year.

We are very conscious of the constraints imposed by the current budgetary situation but I recognise that our new dementia strategy must be visionary and creative and lead to changes in work practices, processes and realignment of resources to deliver real results for those who have dementia and for their families and carers.

We have an opportunity to ensure that the evidence which already exists is used to provide strategic direction to enhance dementia services that promote quality of life and quality of care for people with dementia, for their family, their carers, and their friends and community.


NATIONAL DEMENTIA STRATEGIES IN BULGARIA

Irina Ilieva, Executive Secretary of Alzheimer Bulgaria, speaks with Alzheimer Europe about the need for a national Alzheimer plan in Bulgaria and the role which Alzheimer Bulgaria has played in highlighting the needs of people with dementia.

Alzheimer Europe (AE): Ms Ilieva, what are the problems people with dementia and their carers face in Bulgaria?

Irina Ilieva (II): It is well-known that Bulgaria is the poorest country in the EU, having the lowest incomes and also the lowest public financial resources for health and social systems. The ageing population is one of the main issues identified in many official documents. Diseases which are related to this issue, such as dementia, are increasing, but the health and social systems are not prepared for them.

In Bulgaria there are 100,000 people with dementia of which 50,000 live with Alzheimer’s disease1. There is no information about how many of them are living with their families, where their relatives can take care of them and/or how many of them are living in social institutions. The problems encountered by the families and people with dementia are not raised during public debates, nor are they on the health or social policy agendas. The lack of discussion around the problems faced by family carers, together with a lack of a sustainable social support system were the main reasons the Alzheimer Bulgaria Association was formed in 2003.

AE: What role has Alzheimer Bulgaria played in highlighting the challenges faced by people with dementia and their carers in Bulgaria?

II: Alzheimer Bulgaria informs society and the authorities of the heavy burden faced by carers and the severe financial, social and emotional consequences of the disease. In two years, from 2010 until 2012, Alzheimer Bulgaria organised 13 round table meetings in several cities and towns throughout the country. Families of people with dementia came together with State representatives to share information. We looked at best practices in place in other European countries, we informed participants about European policies on dementia and we proposed changes to the Bulgarian legislation with the aim to relieve the financial and emotional burden experienced by families. During one of those meetings in Varna, in 2011, we invited Antonyia Parvanova, a Bulgarian Member of the European Parliament who is also a member of the European Alzheimer’s Alliance. Ms Parvanova’s experience and engagement in dementia at European level were extremely important to us. Thanks to our joint and determined efforts to highlight the plight of people with dementia, I am delighted to report the following progress:

1. Since 2013, there is partial reimbursement of the cost of dementia medication. This is a real success. People who were previously unable to have access to medication for financial reasons are now able to benefit from these treatments which may slow the development of the disease.

1 National Consensus statement on the early diagnosis and treatment of Alzheimer’s disease and other forms of dementia (2007)
The beginning of this process dates back to 2009, when Alzheimer Bulgaria put a complaint before the Commission against Discrimination. The Commission decided that because of the high medicine prices and the lack of reimbursement people with Alzheimer’s disease were discriminated against in Bulgaria. However, The Ministry of Health did not agree to change the legislation and appealed before Administrative Court. Nevertheless, on 5 December 2011, the Health Ministry was ordered again to change the legislation and include Alzheimer’s disease in the reimbursement list. The time frame within which the Ministry of Health had to obey the decision lapsed, yet still there were no changes. Alzheimer Bulgaria then asked for help from the Ombudsman of the Republic of Bulgaria, Mr. Konstantin Penchev. We explained the situation to Mr. Penchev, who in turn sent a letter to the then Minister of Health, Dr. Stefan Konstantinov, familiarising him with the case. Finally, in February 2012, the legislation was changed. Despite the fact that we had to wait until the beginning of 2013 for the necessary procedures and documents for the reimbursement of the medicines to be put in place, I am truly delighted with the outcome.

2. We have enjoyed tremendous support from many people, including the Ombudsman of Bulgaria. On 21 September 2012, during a celebration of World Alzheimer’s Day at a centre of dementia, Mr Penchev joined us and participated in our press-conference.

We continued to highlight the situation of people with dementia in Bulgaria and the need for action at national level throughout 2012. At the end of last year, we organised the first International Seminar for Dementia.

We named it ”Exchange of experience and of expertise on National Action Plan for dementia in this time of crisis”. We invited people with dementia and their relatives, doctors (general practitioners, neurologists, psychiatrists) and representatives from the Ministry of Health and Ministry of Labour and Social Policy. Representatives from the Czech Republic and Macedonia shared their experience of addressing dementia in their countries. Nina Balačková from the Czech Republic and a member of the European Working Group of People with Dementia (EWGPWD), demonstrated that medicine, as well as cognitive therapy and training, are all tools for a better quality of life. This meeting was like a dream come true for people with dementia and their carers in Bulgaria. Everybody agreed with the conclusion that it is a high time to develop and implement a National Action Plan on dementia in Bulgaria.

AE: What are the main issues you would like to see addressed by a national plan?

II: The National Plan for Dementia should cover:

- Support of early diagnosis,
- A launch of Day Care Centres: financed 30% by the state budget, 40% by the municipal budget and 30% by the sufferers’ families,
- The development of Rehabilitation Centres,
- The training of doctors, specialists and caregivers,
- The development of contemporary norms of care and acceptable legal protection (against legal abuse, i.e. theft of their real estate),
• The development and harmonisation of quality care standards,

• Support enabling respite for the carers,

• Groups for mutual support,

• Coordination between different systems (such as health and social systems and municipal and governmental departments) responsible for old people,

• Development of a consistent, long-term state policy to support research into dementia.

Alzheimer Bulgaria gathered signatures for the successful European Parliament Declaration 80/2008 and continues to gather support to ensure the principles of the Declaration are adopted within Bulgarian national policies.

Regrettably, in Bulgaria, ministers change very often and this lack of continuity makes our work very difficult. Nevertheless, we have proven that even in such an unstable environment we can make a difference. Although the changes are very slow and difficult to achieve, things are changing for better. This gives us strength to keep on talking and convincing both policy makers and the population of the need for action. We know that we are living in a European country and we have the power to remove barriers. We have already decided to create a National Plan in our Alzheimer Bulgaria Association program for 2014. We are working on that.

“Regrettably, in Bulgaria, ministers change very often and this lack of continuity makes our work very difficult.”

Irina Ilieva
“It seems that elderly people and people with dementia are easy targets when cutting costs.”

Fanney Proppé Eiríksdóttir

AUSTERTY MEASURES IN ICELAND

Fanney Proppé Eiríksdóttir, Chairperson of the Alzheimer’s Association in Iceland (FAAS), talks about the impact which austerity measures are having on people with dementia and their carers in Iceland.

The austerity measures put in place in Iceland since the bank crash in October 2008 are, year after year, taking more and more meat from the bone of health care. This is especially true with regards to the ageing population and people who live with dementia, as the budgets for activity centres, hospitals and nursing homes have been, and continue to be, cut dramatically.

Day activity centres provide services which aim to help people with dementia and their families to cope with the disease and postpone the need for people with dementia to be admitted into a nursing home. In spite of a significant increase in the number of people needing this solution, Government funds have been cut by more than 12% in the last four years. As the waiting list gets longer, people’s conditions worsen. Finally, when it is their turn, they are unable to make use of the memory and activity training, which the centres provide.

Before the austerity measures were implemented, people could stay in a day care centre for months; even up to two years or more and this really made a difference in their ability to live more productive, happier lives. Now, however, some people are only staying at an activity centre for a few weeks because, whilst waiting to attend, their condition has worsened and they require full nursing care instead. Unfortunately, the waiting list for nursing homes remains just as long. We need money for an increase in day activity centers as they have shown that a stay there does make a difference and costs less than full time care homes.

Budgets across the board are being cut back in hospitals, nursing homes and activity centers. Consequently, each of these manages on a reduced staff and the workload is enormous. One result is that over 300 nurses have handed in their notices at our biggest hospital, LSH. This represents a departure of about one fifth of the nursing staff. This will result in a lot more departments inside the hospital closing down, not only on a weekend basis – as has been the case since cost-cutting measures were first introduced – but there will be closures during the week too. The nurses cannot cope with the workload and low wages at a time when living costs are constantly on the increase. We have nurses flying between Norway and Iceland every third week or so, as they earn far higher wages over there and they say the workload there is “humane”.

It seems that elderly people and people with dementia are easy targets when cutting costs. This is because family caregivers will step in to do the only thing left to them: work harder, longer and depend on other family members and friends, often at a great cost to their own health and well-being. We at FAAS find that, increasingly, people contact us in order to get more understanding of what can be done and
Austerity Measures: The “Fiscal Nightmare” of Alzheimer’s Disease

Corien Wortmann-Kool, MEP (Netherlands), gave a speech at the “EU Science: Global Changes and Global Cooperation” conference, which was organised in the European Parliament by ISC Intelligence in Science, the Irish Council Presidency and Seán Kelly, MEP (Ireland), on 5 March 2013. The agenda included an “Alzheimer CEO Roundtable: Addressing the Global Challenge and the Role of European Leadership”.

In her speech, Ms Wortmann-Kool welcomed the CEO Initiative on Alzheimer’s disease and agreed that it was important for leading global corporations, non-profit and governmental organisations to join forces in the fight against Alzheimer’s disease. She stressed that it was essential to identify and advance activities related to prevention, care and cure of Alzheimer’s disease.

Ms Wortmann-Kool was invited to speak about the “fiscal nightmare” associated with Alzheimer’s disease, one of the future great threats for society and economy. Recent figures show that there are some 35.6 million people with dementia, including Alzheimer’s disease, worldwide. This number is projected to almost double every 20 years, increasing to 65.7 million in 2030 and 115.4 million in 2050. The ageing of the popula-
“The ageing of the population and its near-perfect correlation with the risk of developing Alzheimer’s disease beckons all actors to act in order to avoid epidemic proportions.” Corien Wortmann-Kool

tion and its near-perfect correlation with the risk of developing Alzheimer’s disease beckons all actors to act in order to avoid epidemic proportions. Ms Wortmann-Kool warned that if the status quo were maintained, Alzheimer’s disease would become a fiscal nightmare in the 21st century, overshadowing the other health and social challenges faced.

Ms Wortmann-Kool added that Alzheimer’s disease will also be a burden on economic growth, as the disease prevents millions from participating in the workforce, volunteering, mentoring, etc. She also recognised the burden the disease places on families, caregivers and friends. This is substantiated by research that shows that caregivers themselves often are at increased risk of depression and illness, especially if they do not receive adequate support from family, friends and the community.

To illustrate her points, Ms Wortmann-Kool presented some facts and figures:

- The informal care costs in Europe in 2008 were estimated at nearly EUR 90 billion (56% of the total costs), resulting from events such as productivity loss, adverse impacts on physical and mental health of carers, and out-of-pocket expenses.

- According to the World Health Organisation, much of this care is being provided informally by families in low and middle income countries; given this, global costs may be underestimated if informal care is not included in the estimation methodology.

- In 2010, the worldwide direct and indirect costs of dementia, including Alzheimer’s disease, were estimated to exceed 1% of global gross domestic product (GDP), at more than USD600 billion (EUR477 billion).

- In the EU 27 region, this cost was estimated at EUR160 billion (EUR22 000 per patient/year) in 2008.

- In some European countries, Alzheimer’s disease care takes approximately 10-25% of a family’s average net annual income.

In conclusion, Ms Wortmann-Kool reminded the audience that Alzheimer’s disease is a global challenge. It demands a global, cross-sector and cross-discipline solution and has implications for a wide range of government sectors: health, finance, social welfare, family and employment. She advocated that investing in Alzheimer’s now will have huge a payoff in the decades ahead.

In particular, she called for:

- Alzheimer’s disease to be recognised as a priority, notably in the area of Research and Innovation and more investments, better targeted and better coordinated, preferably at global level, at the least at EU level.

- Comprehensive plans to address the impact of Alzheimer’s disease both at national and European level.

- Health and social care services that better take into account the specific needs of Alzheimer’s patients.
POLICY ROUNDUP

A look at recent national and European policy developments which may impact people with dementia and their carers.

National dementia plans

Netherlands: The Dutch Ministry of Ministry of Health, Welfare and Sport announced on 4 April that it will allocate EUR 32.5 million to the fight against dementia over the next four years. This money is intended for the “Deltaplan Dementia”. This plan – analogous to the Dutch water works – is intended to limit the consequences of the foreseen explosive rise in people with dementia. The contribution of the government will be used to initiate a research program that concentrates on (1) rapidly improving the efficiency of healthcare, so today’s patients can benefit of the results and (2) fundamental research into the origins of dementia to improve diagnostics and find ways to prevent or cure dementia. The second objective will receive two thirds of the research budget and aims to improve the situation of tomorrow’s patients. The Deltaplan Dementia is a public-private partnership; a number of private partners have shown interest to support the financing of research projects and also the other two pillars of the plan. One of these is a registry that will monitor diagnosis and received care of Dutch patients, thereby contributing to a high national standard of care. The other pillar is an online portal that will help patients, cares and professionals to receive or provide the best possible care.

Luxembourg: Luxembourg’s Health and Family Ministries launched the country’s first national dementia plan on 14 May. The Ministry of Health will be responsible for the areas of prevention, diagnostic standards, medical reimbursement and education and the Family Ministry will develop a dedicated website and conduct an awareness campaign that includes a psycho-geriatric training course for health workers. Family Minister Marc Spautz likened awareness of dementia today to that of AIDS 20 years ago: the general public had little or no knowledge about it, so the disease was feared and its sufferers were stigmatised. Mr Spautz is confident that the campaign and the training course will help to eliminate these issues in Luxembourg.

Portugal: On 20-21 May, a group of some 40 dementia experts persuaded the Portuguese government that existing dementia prevalence figures are sufficiently accurate to allow the next phase of a national dementia plan to proceed right away. The original government plan called for a dedicated epidemiological study – an expensive and lengthy process. The group included psychiatrists, neurologists, general practitioners, researchers, members of the municipalities and representatives of Alzheimer Portugal. Their work was coordinated by Prof. Joël Ménard, one of the architects of the original French Alzheimer Plan. They put forward a prevalence figure of 160,000 people with dementia in Portugal. The next phase of the national plan is a study to determine the needs of people with dementia. This study is already prepared and can begin very quickly. It will begin in the north of Portugal and will return results within six to nine months. According to a government spokesperson, the rest of the country will follow in turn.
**Slovenia:** The Slovenian Minister of Health, Tomaž Gantar, officially approved the document that will be the basis of Slovenia’s national dementia plan on 5 March. This document will guide the activities of a new, dedicated Dementia Working Group within the Ministry. The working group consists of ten people, including Dr Aleš Kogoj (President of Alzheimer Slovenia - Spominica), Ms Štefanija Lukič Zlobec (Vice-President), Dr Gorazd Bernard Stokin and Dr Tatjana Cvetko.

**Dementia-friendly communities**

Welsh First Minister Carwyn Jones unveiled a programme on 23 April which he hopes will help to create dementia supportive communities in Wales. The aim of the programme – which is supported by the Alzheimer’s Society – is to make people in Wales more aware of dementia and how it affects the day to day lives of people living with the syndrome. The Alzheimer’s Society, the Welsh Government and the Older People’s Commissioner will work together on a number of initiatives to build awareness of dementia and build dementia supportive communities. Gwenda Thomas, Deputy Minister for Social Services, said that building dementia friendly communities is about much more than investing in health and social care services. She added: “While this is essential and something the Welsh government will continue to work to deliver, all of us – individuals, businesses, statutory services, the voluntary sector, and government at all levels – have a role to play.”

**Dementia Research**

**G8 to establish a new international approach to dementia research:** On 15 May, Prime Minister David Cameron announced that the UK will use its Presidency of the G8 to identify and agree on a new international approach on dementia research, in recognition that the condition is fast becoming the biggest pressure on care systems around the world. The Group of Eight (G8) is a forum for the governments of the world’s eight wealthiest countries: Canada, France, Germany, Italy, Japan, Russia, UK and USA. The EU is also part of the group. This year, the UK holds the Presidency and can therefore arrange summits. In September 2013, there will be a specific G8 dementia summit in London. This will bring together the members’ Science and Health Ministers, dementia experts and industry figures in an effort to secure more coordination and collaboration on dementia globally.

**European Month of the Brain:** Various events were held throughout May 2013 to mark the “European Month of the Brain” which aimed to make decision-makers, stakeholders, the media and the public aware of the successes achieved and the challenges still laying ahead for brain research. Brain-related disorders, including Alzheimer’s disease, will affect at least one in every three of us during our life and treating these disorders costs already now some EUR 800 billion in Europe every year. The European Commission organised two conferences: “European brain research – successes and next challenges” on 14 May in Brussels, Belgium, and “Healthy brain: Healthy Europe – a new horizon for brain research and health care” on 27-28 May in Dublin, Ireland. There were also other activities carried out by the European Parliament and in Member States.
**National associations - Ireland:**
Maurice O’Connell reflects on the achievements during his 14-year tenure as Chief Executive of the Alzheimer Society of Ireland.

**Dementia in the arts:**
Tatiana Nunes, Public Relations Officer, Alzheimer Portugal, talks about the successful “Spaces of Memory” project which brings together people with dementia and art students.

**Spotlight on Finland:**
Heidi Härämä, specialist of early-onset memory diseases and Ella Okkonen, Executive Director of the Alzheimer Society of Finland, look back at the work carried out by Society as it celebrates its 25th birthday.

**Living with dementia in Ireland:**
Dermod Slevin shares his experience of living with dementia with Avril Dooley from the Alzheimer Society of Ireland, from the point of diagnosis to his involvement in speaking out about dementia.
Maurice O’Connell reflects on the achievements during his 14-year tenure as Chief Executive of the Alzheimer Society of Ireland. He also considers the future challenges the Society faces and the role he played on the Board of Alzheimer Europe.

It’s not easy to reflect back over the last 14 years as CEO of the Alzheimer Society of Ireland (ASI), as this period in the history of dementia politics is so overwhelming, given the level and pace of change, the nature of the shifting discourse of dementia and the growth in interest and investment in cutting-edge dementia research. Being so embedded in the work, not just in Ireland but in Europe too, it is a challenge for me to sit back and begin to unpack all that has happened, in a more objective way. I have had the privilege of leading an amazing and dynamic organisation during this time and have seen it grow and develop in an unprecedented way. We have grown our service-delivery and expanded the range and types of services that we provide: over one million hours of care to over 3,400 people and their carers. We have developed a strong advocacy presence in the Irish political landscape. The public are now so much more aware of dementia and of our organisation. We have pushed the boundaries in terms of innovation in areas such as early intervention supports, telecare and assistive technology, awareness-raising, family carer training, and health and social research.

Coming into the dementia world it was hard not to compare. The pace of change felt much slower and more nuanced. And of course it is and it has to be. The nature of the condition, the need for multi-disciplinary inputs and a wide range of services and supports make the dementia world a very different one to what I had left behind. For me, probably the most significant change I have witnessed over my tenure as CEO, is the ongoing and strengthening voice of the person with dementia coming into the dementia discourse. Fourteen years ago it was not heard of to have people with dementia at the table. Now, it rightly permeates our organisation, our services and our projects. Indeed, the subtlety in the shift in the language is notable – we now readily talk about “living well”, “giving hope”, “living independently with support” and “the rights of the person”. We have moved away from “doing things for and to” to “doing things with” the person with dementia. If there is one legacy from my work as CEO that pleases me most it’s that of moving our organisation closer and closer to the point of having people with dementia at the centre of everything that we do.

Looking back, the 2005 Alzheimer Europe (AE) conference held in Ireland (in Killarney) was one of the “stand-out moments”. Standing in that hotel in Killarney on the most gorgeous of sunny June days (the only sun we got all year!), surrounded by hundreds of guests from
all over Europe, was both a thrilling and terrifying moment! It was, in fact, hard to believe that we had pulled off this event. It was cutting-edge in that it was one of the first AE conferences for which we had managed to engage not just one, but several people with dementia to address the delegates over the three days. In those times the host organisation played a significant role in organising the whole conference so it was a big undertaking with a year’s worth of planning needed to stage the event. But it was all worthwhile. If I were to pick out a “pivotal moment”, it would be the hosting of the AE conference. This marked a moment of change, a moment of renewal and a moment of knowing that we are absolutely on the right track.

Inspired by the work in Scotland and at a European level, we have now established the first Irish Working Group of People with Dementia. We have learnt from their expertise and experience and we have been motivated by their courage, commitment and energy to come out and speak and be part of the new landscape of dementia. They are now agents of change in their own right and with support, are playing a major role in how dementia is understood and responded to in social and public life. I am happy to have had a role in making it happen on a European level and now in Ireland.

The Paris Declaration was presented at the Alzheimer Europe conference in Paris 2006 and this further strengthened the movement which highlighted the main challenges for people with dementia and their carers. It stated the political priorities putting dementia at the centre of the debate on European and member country levels. Also, the Paris Declaration became the cornerstone for EU Member States and Alzheimer Europe’s members to develop strategic and political dementia plans. In Ireland it was the opportunity to state the European position, in order to influence making dementia a healthcare priority in Ireland. As Chair of Alzheimer Europe I supported Jean Georges, the Chief Executive, to establish a Public Affairs focus on a European level. After long conversations we restructured the small staff in the office to make room for the political direction of the organisation. This coincided with many countries taking the fight to the public and to Government. The establishment of the European Alzheimer’s Alliance in the European Parliament in 2007 began to influence the European institutions. This was further strengthened during the French EU Presidency as President Sarkozy embedded dementia as a priority.

The significant influence on all that is happening is the dedication of the Alzheimer Europe staff. The leadership, motivation, insight and passion are second to none. The mark of the man who has led Alzheimer Europe through its many phases comes from the place of “knowing” the experience of working with politically marginalised groups. Jean Georges has politicised dementia in Europe and has brought the person with dementia into the centre, in spite of all the pressures to engage in other subjects and follow different trends. The consistency of message has strengthened the cause and he has ensured that it has happened. It has been an honour and a privilege to have worked with Jean and his team.

At a broader level, the move towards early diagnosis and early interventions is really
Dementia in the News

Noteworthy. Those of us who work directly with people with dementia know first-hand the value of an early diagnosis. It is just taking us a little longer to convince others of the merits! Indeed, early intervention in Ireland is still in its infancy; we are still in crisis-driven mode; but the move to earlier diagnosis will compel us to do something meaningful for people in the early stages. There is plenty of evidence to say that early intervention prevents acute admissions and premature entry to long-term care and thus, saves money! But we still have a lot of work to do to shift the current outmoded thinking in this area.

In the 21st century, we now have dementia recognised as a major global challenge. The work of Professor Martin Prince is notable here. In Ireland, as I step back from the leadership, the Department of Health is starting the process of writing a national dementia strategy (NDS) promising to have it published by the end of this year. This NDS follows the best practice in many European countries where dementia strategies are part of their health and social service response to people living with dementia. We know from other countries’ experiences of strategies that they provide a meaningful framework for action and an opportunity to plan for services and support. We are advocating that the Irish strategy will be a transformative one that brings real change to the lives of people with dementia.

In Ireland there are two areas that I will watch with interest into the future. Firstly, ASI is leading a really exciting piece of work on developing dementia-friendly communities. Our plan is to work hard in the next three years to develop our towns, cities and neighbourhoods into meaningful places for people with dementia to live and engage in community life. Secondly, ASI has led a national conversation around the palliative needs of people with dementia, an area of life that many of us shy away from talking about. Our “Opening Conversations” report in 2008 led to a partnership with the Irish Hospice Foundation. Together, in 2012, we created a roadmap for the future of palliative care and end-of-life supports for people with dementia. This is an area of work I hope will grow and blossom and that Ireland will lead the way on.

Finally, if there is one thing that I could point to that has contributed to ASI’s success it is working in partnership and collaboration with numerous partners in the whole range of areas in which we work, including service-provision, advocacy, research, etc. We are so much stronger together and united. As I move to a new and hopefully another exciting chapter in my life I want to say thank you to all of the wonderful people I met on my 14-year journey. The strong bond of friendship will still remain. Your empathy and passion for this issue has enabled me to build my own resilience and sustain me on what has been a truly remarkable chapter in my life.
LOOKING BACK ON 14 YEARS OF MAJOR ORGANISATIONAL ACHIEVEMENTS

The past years have seen significant organisational growth:

• Doubling of hours of service delivery from 500,000 to 1,000,000 in 2011,
• Development of client base from 2,500 to 3,630 in last five years,
• Budget increase from EUR 13 million in 2006 to EUR 19 million in 2012,
• Trebling of staffing numbers from 300 staff in 2001 to 900 in 2011.

The Alzheimer Society of Ireland is now the key provider of dementia specific services, providing day care (43 locations), home care (38), social clubs for couples (9), overnight dementia respite care (2), carer support groups (19) and national family carer training programmes (19).

14 milestones in 14 years:

1. 1999/2000: EUR 1 million State funding for development of dementia specific services
2. 2005: Successful Alzheimer Europe Conference in Killarney attracting 500 European delegates
3. 2006: Launch of Paris Declaration stating the political priorities of the European Alzheimer movement
4. 2007: Launch of first ASI Dementia Manifesto marking the start of the association’s campaign to make dementia a national health priority
5. 2007: Investment in advocacy and awareness work by Atlantic Philanthropies to further politicise dementia
6. 2007 onwards: Increasing Government commitment to the development of a National Dementia Strategy
7. 2008: French EU Presidency Conference dedicated to the fight against Alzheimer’s disease
8. 2008: Move of national office to award-winning Blackrock campus with state of the art respite and day care centre
9. 2009: Development of educational and awareness programme on prevention
10. 2011-2012: Integrated awareness campaign on national radio and TV on early signs and symptoms of dementia to reduce stigma
12. 2012: 30 year anniversary celebrations marking the founding of the organisations in 1982 by a group of committed volunteers
13. 2012: Launch of volunteer strategy to ensure full participation by volunteers building on society’s commitment to grassroots volunteers throughout its history
14. 2013: Launch of first ever Irish Working Group of People with Dementia to show the society’s inclusive engagement with people with dementia
Tatiana Nunes, Public Relations Officer, Alzheimer Portugal, talks about the successful “Spaces of Memory” project which brings together people with dementia and art students.

The project “Spaces of Memory” resulted from a happy encounter between teachers of the Lyceum Maria Amalia and the staff of Alzheimer Portugal’s day care centre. Together, they had the idea of helping students gain a better understanding of dementia and finding the best way of relating to people who live with it. This will be achieved by a series of lectures, visits and art work. The motivation to facilitate this intergenerational exchange arose from the fact that, as dementia is predicted to grow exponentially, all of us might be carers in the future which means that there is an urgent need to educate younger people now. The students in this project were aged between 16 and 17.

In January 2013, the project was launched at the Lyceum with a lecture. The day care staff from Alzheimer Portugal shared information on the issues surrounding dementia and on the essential work that Alzheimer Portugal carries out. The interaction between people with dementia and the students began one week later, when those people with dementia who wished to participate in the project visited the Lyceum. They met with the students and were able to see first-hand some of the students’ work. Another meeting was arranged which enabled the students to visit Alzheimer Portugal’s day care centre. After being introduced to the facilities available at the centre, the students and people with dementia were able to develop their relationship further by exchanging life stories, discussing various issues and sharing their personal experiences. The project is unique as students are given an opportunity to learn in the dementia community itself as some of the lectures are carried out at the day care centre. This provides them with a greater depth of insight and understanding.

The students and people with dementia work together. In Alzheimer Portugal’s garden it is possible to see some of the work created: a mural painting, a vertical garden and an aromatic herb garden. In addition, various projects are being carried out inside the centre including:

- “The painting panel” – currently, this consists of silhouettes of people with dementia on large screens. As their life stories are shared, elements will be added to the screens.
- “The colour of foods” – small screens are being painted which are to be used in the dining room.
- “Museum of memories and objects” – in order to share the life stories a “museum” is being created. To facilitate this, all phases of the project are being recorded on a blog through the use of graphic diary, recordings and photographs. You can see this at: http://projetoespacosdereclamoria.blogspot.pt/

By combining information lectures, exchange of experiences and art, I believe that the project offers a therapeutic intervention for the participants, which respects a person-centred approach. It is having truly amazing results. By valuing the life story of each person, promoting their memories and encouraging people with dementia to express their feelings and desires, this is a pioneering project for Alzheimer Portugal and one which we hope to continue.
Reflections by people involved with the “Spaces of Memory” project

“During the first conversation I had with Mr J. S., he told me that he was born in 1951 and worked in passenger and cargo vessels. This professional activity is one that he is proud to speak of and to have done. Mr J.S. told me about some of his life by him and his colleagues. He says that Macao is a land with its own life, that he loves the beaches on the island of Madeira, where he has also visited and he especially enjoyed their vegetation. He loves to play dominoes and bingo. Painting is a discovery that we will do together. Probably we will paint the sea of his travels.”

A student

“The disciplines of art and drawing have been enhanced during the construction and development of the project, “Spaces of Memory”. This initiative was carried out within the framework of the project for the health of the Secondary School “Maria Amália Vaz de Carvalho”. In the context of a teaching-learning process, the design of this project has provided students to develop visual arts such as painting, drawing, design and sculpture. By working in partnership with Alzheimer Portugal, students and teachers have been given the opportunity to learn outside of the school context. The result is that a greater depth of skills has been achieved. At the same time, teamwork has been promoted and community integration facilitated.”

“A teacher

“From my perspective, this project is of great value to both parties involved. This is because, either through the exploration of techniques of artistic expression or through the intergenerational approach between the students, people with dementia, teachers and Alzheimer Portugal staff, the road travelled proved to be very productive, enjoyable and incredibly stimulating for all.”

“Teresa Varejao, Occupational therapist, Alzheimer Portugal

“This highly effective initiative made it possible to stimulate cognitive and motor skills, promote socialisation and relational skills, strengthen people’s identity and encourage memory recollection. These were all achieved whilst respecting and reinforcing the principle of a person-centred approach.”

“A teacher
The Alzheimer Society of Finland, “Muistiliitto”, celebrates its 25th birthday in 2013 with the theme “Take care!”. Heidi Härmä, Master of Social Services and specialist of early-onset memory diseases and Eila Okkonen, PhD, Executive Director, look back at the work carried out by the Society and talk about its current campaign.

The Alzheimer Society of Finland has, over 25 years, grown from a group of 15 “persons interested in dementia care” to a lively and influential society of 43 member associations with about 250 employees, over 400 active volunteers, almost 11,000 members and 13 employees in the headquarters of the Society.

The first chairperson, neurologist Raimo Sulkava, encouraged people who were actively involved in the field of dementia to establish and join new associations, and those associations to join the central society. From the beginning the mission of the society has been to provide assistance and support for its member associations, so that they can concentrate on their important work with people with memory disease and their family members. Distributing information and raising awareness in terms of making Finland a better place for people with memory disease has always been the priority. Currently, the Society is led by Executive Director, Dr Eila Okkonen.

The first big project of the Society was Leenankoti (“Leena’s home”) in 1989. This resulted in the first nursing home to be established which provided respite care for people with memory disease in Finland. A significant amount of groundwork to create this home was carried out by Mr. Harri Koivu, the husband of Leena Koivu who was the first resident of Leenankoti. Leenankoti represented a significant part of the Society and Finnish developmental work for people with memory disease and their family members until 2012, when it became privately owned and managed.

The Alzheimer Society of Finland functions mainly through the funding provided by Finland’s Slot Machine Association (RAY). This has enabled dozens of projects to be completed over the years and the funding allows us to continue with many ongoing projects. The Society has been an active and keen advocate for rehabilitation, the right for self-determination and equality for people with memory disease. As the Society changed its Finnish name to “Memory Society” in 2009, part of the focus has also been on the promotion of brain health and on brain disease prevention. Nevertheless, the most important person for the Society is every person with memory disease and every carer, family member and loved-one. Their well-being and quality of life is paramount. Peer support groups are thus an invaluable form of activity.

There has been a huge leap in public attitudes during recent years, as people with the disease and their family members have increasingly been prepared to be open about their condition and situation. The Society strongly encourages this, as it gives a face and a voice to this illness. We
professionals can never be as influential as one person with the disease who speaks out.

The Alzheimer Society of Finland has been a devoted pioneer with regard to the Finnish terminology concerning memory disease. We strongly feel that we should not be promoting misery. The Society completed an extensive survey in 2012 about the first year with a diagnosis of memory disease. To our delight, the results were very positive and encouraging: a diagnosis is not seen as the end of the world – there is still happiness and quality of life. We want to let the people choose their attitude towards the disease themselves, and not to choose misery and suffering for them.

Important milestones over the past 25 years have, among others, been:

- “Ten critical points to dementia care services”, a method to evaluate the quality of care in care facilities,
- Active regional work to provide support for member associations,
- Free peer-support helpline for carers,
- The provision of information and active development of self-determination and advance directives,
- An increase in the number of memory nurses/advisories across Finland from the Society’s member associations’ projects for continuous work within communities,
- Muistiluotsi (“memory pilot”): a strong network of third-sector memory professionals in every Finnish county (17). This has co-ordinated and strengthened the regional work of the associations and brought good practices together,
- Long-term developmental work towards better care and rehabilitation services and reducing the stigma attached to people with early-onset memory disease.

The Society celebrates its 25th birthday with the theme “Take care!”, which we hope will promote caring and purposeful interaction, everyday safety and the right for self-determination for people with memory disease. This campaign started from a sad but ever so common story: a person with memory disease walking across town in the middle of a freezing winter’s day in her night gown – and nobody stopping her or calling for help. She died in the hospital later that day. We want to raise awareness and encourage people to look out for other people. There are times when we really need each other, and people with memory disease may need more help than others.

The future challenges for the Society include more active involvement of the people with a diagnosis and their family members. We will form a working group which consists of people with memory disabling diseases. By having these genuine experts, who live with disease, to advise us, we will be able to better steer the work of the Society in the right direction.

The Finnish Memory Programme leads the Society to more concrete regional, national and international co-operation in terms of building a “dementia-friendly society by 2020”. The Society will become even more influential since it has now be linked with national policies and their implementation.

We look forward to another ever-more challenging, yet rewarding 25 years!

“We professionals can never be as influential as one person with the disease who speaks out can be.”

Eila Okkonen and Heidi Härmä

For further information please see:
www.muistiliitto.fi/eng
www.muistiliitto.fi/eng/memory_illnesses/advance_directive/

Dementia in The News
Overcoming everyday challenges in Alzheimer’s disease

At Lundbeck we are dedicated to overcome the challenges of Alzheimer’s disease. It is our goal to improve the quality of life for people living with the disease and for those who care for them.

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LIVING WITH DEMENTIA IN IRELAND

Dermod Slevin shares his experience of living with dementia with Avril Dooley from the Alzheimer Society of Ireland, from the point of diagnosis to his involvement in speaking out about dementia.

Dermod received a diagnosis of Lewy Body Dementia three years ago. Although, he had shown no signs or symptoms his general practitioner (GP) referred him to a specialist older person service for a more detailed health check. It was here that he received his diagnosis of dementia.

Dermod has described receiving this diagnosis as “a shock to the system.” He was told that he was to “go home, not to worry and forget about it”. He also took to Google to find out more about dementia – this is something he would not advise others to do “if you were to believe everything you read, it is too difficult to take it all in, I was overwhelmed.”

One of the main issues Dermod has as a result of his dementia is that his speech has been impacted – he now has a stammer and will sometimes struggle to recall words and names. He finds that particularly when he is under pressure or asked a question that his mind will go blank.

Initially he was very depressed. However things started to change for him when he attended an Alzheimer Café. This was the first time he had the opportunity to meet other people affected by dementia. Dermod describes the Alzheimer Café as a place of great “warmth and friendliness”. He enjoys the contact with people and talking about dementia with others that understand.

By the time he attended the Alzheimer Café, Dermod had also begun to tell other people about his diagnosis. He says “I tell everyone and people have stopped me on the street to congratulate me for speaking about it”.

Through the Alzheimer Society of Ireland, Dermod has been offered a number of opportunities for speaking out about living with dementia. Dermod was interviewed by various newspapers including the Irish Examiner and he says “It has opened new doors for me – I say I’m going to work. If I’m not doing something I’ll lie on the couch all day”.

He is part of the first European Working Group for People with Dementia representing Ireland. Dermod has said that this has given him “great opportunities to meet others and exchange ideas”.

At the meeting in Brussels Dermod also had the chance to discuss the issues he faces with Nessa Childers, MEP (Ireland). He met her in the European Parliament at the end of 2012 and spent forty minutes with her explaining the challenges of living with dementia and also outlining the opportunities that have been presented to him as a result of speaking openly about his diagnosis. Dermod was delighted that he had the opportunity to raise further awareness about the issues people with dementia face in Ireland with a key policy maker.

Last July the Government of Ireland called for submissions to Ireland’s first National Dementia Strategy. Along with four other people with
dementia and four carers, Dermod consulted with us about his views on diagnosis, information and services, maintaining yourself in your home and in your community, living well with dementia and residential care. The views we heard that day formed an important part of our submission to the National Dementia Strategy.

Dermod also spoke at the Alzheimer Society of Ireland’s National Conference in October 2012 where he received a standing ovation following his talk. He used this opportunity to describe what it means to him to be a voice for people with dementia. Dermod said “I hope that by speaking out about living with dementia this will help others and show that when given a voice at an early enough opportunity people with dementia have something very meaningful to offer.”

A highlight for Dermod was in December 2012, when he met with the President of Ireland Michael D Higgins at Aras an Uachtarain. The Alzheimer Society of Ireland had organised this volunteer recognition event to thank all those who have volunteered their time, energy and expertise over the past 30 years. Dermod said about the visit that “meeting the President was one of the greatest honours of my life and it brought tears to my eyes”.

Dermod is a founding participant of the first working group for people with dementia in Ireland. He emphasises the importance which this group has to him when he says that the working group “has given me an insight into other people’s experience and also a sense of purpose and confidence. You are talking to others who understand and who are going through the same experiences.”

From the perspective of the Alzheimer Society of Ireland it has been an honour and a privilege to work with Dermod over the past eighteen months. Through my role as Grassroots Coordinato and now as Project Leader for the Dementia Friendly Communities initiative, Dermod has been an intrinsic point of contact and advisor to me in my work.

He has enlightened all those that he has encountered in the organisation and beyond with his great humour and real modesty about his experience of living with dementia. He has been so willing to share his time and experiences, not only with the organisation, but also with other people living with dementia. He has played a huge role in enabling us to bring forward the voice of others living with dementia in Ireland.
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 29 COUNTRIES

AUSTRIA – VIENNA
Alzheimer Austria

BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Liége

BULGARIA – SOFIA
Alzheimer Bulgaria

BULGARIA – Varna
Foundation Compassion Alzheimer

CROATIA – ZAGREB
Alzheimer’s Disease Societies Croatia

CYPRUS – LARNACA
Pancyprian Alzheimer Association

UNITED KINGDOM – LONDON
Alzheimer’s Society

UNITED KINGDOM – EDINBURGH
Alzheimer Scotland

TURKEY – ISTANBUL
Alzheimer Vakfı

SWITZERLAND – YVERDON-LES-BAINS
Association Alzheimer Suisse

SWEDEN – STOCKHOLM
Demensförbundet

SWEDEN – LUND
Alzheimerföreningen i Sverige

SPAIN – MADRID
Fundación Alzheimer España

SPAIN – PAMPLONA
C.E.A.F.A.

SLOVAKIA – BRATISLAVA
Slovak Alzheimer Society

SLOVENIA – ŠENTJUR
Association “Forget-me-not”

ROMANIA – BUCHAREST
Societatea a Alzheimer

PORTUGAL – LISBON
APFADA

ALZHEIMER EUROPE MEMBERS

POLAND – WARSAW
Polish Alzheimer’s Association

NETHERLANDS – BUNNIK
Alzheimer Nederland

NORWAY – OSLO
Nasjonalforeningen Demensforbundet

MALTA – MSIDA
Malta Dementia Society

BULGARIA - VARNA
Foundation Compassion Alzheimer

CZECH REPUBLIC – PRAGUE
Czech Alzheimer Society

DENMARK – HELSINKI
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

IRELAND – DUBLIN
Alzheimer Society of Ireland

ITALY – ROME
Alzheimer Uniti Onlus

ITALY – MILAN
Federazione Alzheimer Italia

JERSEY – ST HELIER
Jersey Alzheimer’s Association

LUXEMBOURG – LUSSHELIA
Association Luxembourg Alzheimer
23rd Alzheimer Europe Conference
Living well in a dementia-friendly society
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www.alzheimer-europe.org/conferences