EU Commissioner, László Andor, explains how dementia is being addressed at the EU level.
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 30 COUNTRIES

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Alzheimer Angehörige

UNITED KINGDOM – LONDON
Alzheimer’s Society

UNITED KINGDOM – EDINBURGH
Alzheimer Scotland

TURKEY – ISTANBUL
Alzheimer Vakfı

SWITZERLAND – YVERDON-LES-BAINS
Association Alzheimer Suisse

SWEDEN – STOCKHOLM
Dementförbundet

SWEDEN – LUND
Alzheimerförbungen 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 Alzheimer

PORTUGAL – LISBON
APFADA

BELGIUM – BRUSSELS
Uigue Nationale Alzheimer Liga

BULGARIA – SOFIA
Alzheimer Bulgarıa

CROATIA – ZAGREB
Alzheimer’s Disease Societies Croatia

CYPRUS – LARNACA
Pancyprian Alzheimer Association

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
Istituto Onlus

ITALY – MILAN
Federazione Alzheimer Italia

LUXEMBOURG – LUXEMBOURG
Association Luxembourg Alzheimer

MALTA – MALTA
Malta Dementia Society

NETHERLANDS – BUNNIK
Alzheimer Nederland

NORWAY – OSLO
Nasjonalføringen Dementforbundet

POLAND – WARSAW
Polish Alzheimer’s Association
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By Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

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Debating dementia in the European Parliament
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Cooperation and collaboration between national and European organisations
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Facilitating neurodegenerative disease research across Europe
Prof. Olivier Blin and Dr Alexandra Auffret, coordinator and project manager, respectively, of the PharmaCog project, as well as Dr Elisabetta Vaudano, Principal Scientific Manager of the Innovative Medicines initiative, speak with Alzheimer Europe.

The role of the European Alzheimer’s Alliance in making dementia a European priority
Annette Dumas, EU Public Affairs Officer of Alzheimer Europe, reflects on how the European Alzheimer’s Alliance has worked to make dementia a European priority.

Policy Watch

The view from Italy
Patrizia Toia, MEP (Italy) and Member of the European Alzheimer’s Alliance talks about the situation in Italy for people with dementia and their carers.

Rising to the challenge: How the EU can help address dementia
European Commissioner László Andor talks about how dementia is being addressed at the EU level.

National Dementia Plans
Dr Paraskevi Sakka, Chairperson of the Athens Alzheimer’s Association and Vice-President of the Greek Alzheimer’s Federation, talks about the efforts to make dementia a public health priority in Greece. Sarah O’Callaghan from “The Alzheimer Society of Ireland” talks about how the Society has campaigned for a national plan for Ireland.

Out of pocket costs of dementia care: a high price for families
France Alzheimer reports on their recent study to evaluate the economic impact of dementia on people with dementia and their carers.

New insights into dementia: Highlights from the 2011 Romanian Alzheimer Conference
The Executive Director of the Romanian Alzheimer Society, Maria Moglan, reports on the Romanian conference held in Bucharest in February.

Policy developments
A brief look at some recent developments at European and national level which may impact people with dementia and their carers.

Dementia in the News

Members’ News
A snapshot of the recent activities carried out by some of Alzheimer Europe’s member organisations.

Living with dementia: Italy
Alzheimer Uniti, Italy, tells the story of Paola who was diagnosed with Alzheimer’s disease three years ago.

Dementia in Society
A look at how dementia is portrayed in the general media.

Science news
Highlights from recent scientific developments in the areas of prevention, diagnosis and treatment of dementia.
I believe we can better address dementia by working and learning together. This issue contains good examples of how collaboration can be mutually beneficial. In the article entitled “Cooperation and collaboration between national and European organisations”, our Finnish colleagues provide several examples where European collaboration had concrete outcomes in their country. PharmaCog is a Commission financed project in which 30 companies and organisations collaborate to overcome obstacles in Alzheimer’s disease research and speed up drug discovery. We also take a fresh look at the European Alzheimer’s Alliance and how Members of the European Parliament from different parties and countries have come together to make dementia a European priority.

In our interview with László Andor, the European Commissioner for Employment, Social Affairs and Inclusion, European collaboration on long-term care and active and healthy ageing are highlighted, both of which have the potential to improve the lives of people with dementia and their carers. We also focused on these issues in our recent European Parliament lunch debate hosted by Marina Yannakoudakis, MEP (United Kingdom). We report on this meeting.

Alzheimer associations around Europe work continuously to raise awareness of this disease. Thanks to the campaigns of our associations in Greece and in Ireland, national dementia plans are now being developed in those countries. Their work, at grassroots level, has clearly had an impact on policy makers. This, in turn, will hopefully result in legislative changes to improve the quality of life of all affected by dementia. We also report on a conference in Bucharest, Romania earlier this year. The Romanian Alzheimer’s association was able to raise invaluable media interest for their call for a national dementia strategy. I hope their efforts will be successful.

We are also able to gain some insight into what it’s like to live with dementia in Italy. In the first article, Patrizia Toia, MEP (Italy), explains the particular challenges which people face in Italy and what needs to be done to help people with dementia and their carers. In the second article, Alzheimer Uniti talks about how it has been able to offer support to Paola, who lives with dementia. Paola openly shares her experience of living with the disease. As always, our section on living with dementia should help all of us to better understand the challenges and problems which people with dementia face.

I very much look forward to meeting many of you at the 21st Alzheimer Europe Conference which will take place in Warsaw, Poland from 6 to 9 October. Organised under the motto “European Solidarity without borders”, the conference will provide a unique opportunity for networking, coming together and exchanging experiences and best practices.

I very much hope you are able to attend and support this event.

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Prioritising Dementia

DEBATING DEMENTIA IN THE EUROPEAN PARLIAMENT

On 15 March 2011, Marina Yannakoudakis, MEP (UK) and Member of the European Alzheimer’s Alliance, hosted Alzheimer Europe’s 9th lunch debate which was centred around “European activities on long-term care: What implications for people with dementia and their carers?”

Marina Yannakoudakis, MEP (ECR, UK), opened the lunch debate dedicated to long-term care issues by explaining that she had personal experience of dementia as her friend has dementia. She said that she wanted to affirm her support to people with dementia and their carers by hosting the debate.

The chairperson of Alzheimer Europe, Heike von Lützau-Hohlbein expressed her delight that so many people had taken the time to gather and she said she looked forward to learning how we can develop partnerships with Europe in order to help people with dementia and their carers.

Two representatives from the European Commission informed participants of the work on long-term care which has been, and will be, carried out at European level: Arnaud Senn, Policy Officer, Social Protection, Social Services, DG Employment, Social Affairs and Equal Opportunities and Wojciech Dziworski, Senior Economist and Political Analyst, Innovation and Health Ageing, DG Health and Consumers.

Long-term care: an EU priority

Mr Senn’s presentation, entitled "Long-term care: An EU priority” gave an overview of the common objectives between healthcare and long-term care since 2006, the recognition of long-term care on the EU agenda and the main policy challenges to be addressed in the field of long-term care. He explained that long-term care is a subject which concerns many European Commission DGs and Departments. Since 2006, the European Commission has worked hard to try to promote long-term healthcare which is accessible, of a high quality and both sustainable and affordable. Long-term care has been firmly placed on the EU agenda and European commitment was evident in 2008 when a reflection was launched which addressed a whole range of issues regarding care issues. In 2009, both the Swedish Presidency Conference on ageing issues and the Commission report “Access to healthcare and long-term care: Equal for women and men?” reinforced the EU’s commitment to long-term care. In 2010, the Voluntary Quality Framework for Social Services was...
adopted which aimed to provide guiding principles regarding the quality of social services across Europe. Finally, there is an overriding commitment to the 2020 Strategy, in which long-term care is evident within the aim for inclusive growth, which should be smart, sustainable and inclusive. “Issues surrounding long-term care,” said Mr Senn, “cannot be considered in isolation” and he gave the example of access to long-term care, which in turn raises the question of public funding. As such, this long-lasting reflection which has focused on long-term care has raised a whole range of issues, not only from a patient’s viewpoint, but also for Member States and EU institutions.

Mr Senn reiterated the key policy challenges in the field of long-term care which were highlighted during the Swedish Presidency Conference, namely:

- Better integration between health and long-term care
- Improved access to care for dependent old-age people
- Providing choice in public services
- Long-term care workforce policies
- The specificity of Alzheimer’s disease and other dementia
- Quality of services, quality of assessment/control/assurance
- Responsiveness, timeliness, delivery when needed
- Ageing in peace and grace, dignity, respect.

All long-term care issues are considered at EU level by the process of the Open Method of Coordination, which is a voluntary process for political cooperation, facilitating an exchange of good and best practices between Member States on specific subjects and includes the social protection committee.

Mr Senn emphasised that the EU commitment to long-term care has also been evident in other initiatives citing the Council conclusions “Promoting health and dignified ageing” of 2009, the EU 2012 Year of Active Ageing, the European Parliament Resolution of 2010 on long-term care for older people, the Social protection Committee’s 2010 voluntary quality framework on Social Services of General Interest (SSGI) and lastly, the recently launched European Commission Active and Healthy Ageing Innovation Partnership (AHAIP).

Expanding on the AHAIP, Mr Senn explained that the aim of the Partnership is to increase the average number of healthy life years (HLYs) by two by 2020. This can be achieved by improving the sustainability and efficiency of social and healthcare systems and by the creation of an EU and global market for innovative products and services with new opportunities for EU business.

The next step, he said, is for the Commission to write a Staff Working Paper which will map the needs across the EU and identify the challenges faced in different Member States. The Paper should focus both on the needs of the recipient of care and the contribution and role of the carer. This Paper should be issued by the end of 2011.

Marina Yannakoudakis asked whether the Commission would be including the findings from the European Parliament’s own initiative report on a European initiative on dementia and Mr Senn confirmed this would be the case as the Commission works closely with all EU Institutions and that having them involved and their support is very important.

Nis Peter Nissen, Director of the Danish Alzheimer Association, asked if the Commission had ideas regarding the structures which need to be in place so that better opportunities are really availa-
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ble for the elderly in terms of long-term care as this, he said, required special attention with regards to continuity. Mr Senn acknowledged that continuity had been identified as a problem in terms of the provision of long-term care.

The Chairperson of Alzheimer Europe and of the German Alzheimer Association, Heike von Lützau-Hohlbein, raised the issue of how society sees the ageing population and asked whether this could be something which the EU addresses. Mr Senn said one of the main issues was to change the image of elderly people but also that society has to be ready to consider how the elderly are included. Therefore, Mr Senn said, there needs to be a cultural shift to change the image of older people and further involve elderly people within society.

The Active and Healthy Ageing Innovation Partnership

Mr Dziworski explained how Alzheimer’s disease fits into the European Commission’s AHAIP and said that DG Sanco is very proud of this Partnership as it is a totally novel concept that involves many actors (from industry, business, research, health professionals and end-users sectors). The Partnership is a major instrument to achieve the EU 2020 Strategy goal, boost innovation and remove bottlenecks at EU level and ageing is seen as an opportunity. The Partnership will pool resources and expertise and build synergies between the different actors. One of the challenges the Partnership will address is that of the current unsustainable health systems within Europe and Mr Dziworski mentioned that aged-related spending is projected to increase by 4.75% points of GDP by the year 2060, whilst at the same time the workforce of the care sector is shrinking with a lack of health specialists being available.

Mr Dziworski reiterated that the Partnership has the overall aim of adding two healthy life years to the average life expectancy by 2020 which gives the project a nine-year timeframe. If this can be achieved, he said, there will be a triple win situation whereby the health status and quality of life of EU older citizens will be improved, the sustainability and efficiency of more integrated care services will be ensured and the elderly will be able to age actively and independently. This should boost EU competitiveness and, at the same time, decrease health costs. Therefore, by helping the individual, society also benefits. The Commission hopes this project will make a difference in a very practical way and one way this can be achieved is by recognising the importance of end-users’ involvement. At the moment, Mr Dziworski said, end-users involvement is insufficient. He added that the Partnership is not just about research (which will be continued), but about the identification and development of existing solutions in a coordinated and planned manner resulting in redeployment and prototypes. It will then also be necessary to identify gaps and address them.

The potential action areas of the Partnership which could be focused on with regard to Alzheimer’s disease are: Innovation in (a) support of people’s health and well being (e.g. prevention, early diagnosis, treatment etc.), (b) support of collaborative and integrated healthcare systems and services for older people (e.g. continuum of care, home and long-term care, training of workforce etc.) and (c) products and services for active and healthy ageing (e.g. reduction of unnecessary use of hospital services).

The action areas are extremely wide and will be developed by a Steering Group, which will consist of between 30 and 34 representatives. Whilst the Commission can contribute to the Steering Group’s work by offering guidance, the main advantage of working together is, he said, that a critical mass can be achieved. Consideration will be given to how we can build on projects which already exist. The final element will be to implement standards. In the case of dementia, Mr Dziworski said that it is important that a mapping exercise
takes place and that others realise what the growing number of people with dementia actually means to society. Targets can be set and the Partnership can then identify and develop actions in a given area. He gave the examples of Spain, Germany, the UK, France and Italy as all having already a list of projects on healthy ageing which could, once shared, discussed and adapted, be used by other countries.

Sirpa Pietikäinen, MEP (EPP, Finland) and Alzheimer Europe Board Member, asked whether the procedure could be made stronger by end-users participating in the whole planning process. Both Arnaud Senn and Wojciech Dziworski agreed that it had become clear during the consultation process which groups engage in civil society in an active way (e.g. in Denmark, the Netherlands and the UK). However, the idea was not to “see” the particular person but more to find solutions for the elderly which can be migrated and adapted to particular country’s situations. Such adaptation had been done at regional level and now it is hoped to do the same at national level. One way in which action can be effective is to link discussions on healthcare to discussions on reform.

Frieda Breopels, MEP (Greens/EFA Belgium) and European Alzheimer’s Alliance Vice-Chair, asked how the Commission will work to ensure that best practices enjoyed in one Member State can benefit all EU patients. Mr Dziworski said the identification and sharing of best practices is a very important part of the Commission’s role. He compared it to speed-dating where you find out the requirements then match up the people allowing a platform to be created where people can share information.

Ms Breopels also asked about the membership of the Steering Committee and Mr Dziworski highlighted the importance of including the input of Member States, especially as it is the Member States who are responsible for the provision of services. He said that it is also important for MEPs to be involved in the Steering Group and that the President of the Commission will be sending out invitations to participate in the Group.

Nis Pieter Nissen asked how the Commission includes end-users. He said that in Denmark they have a think tank which consists of people with dementia. Once a year they meet to discuss various matters which results in ideas, suggestions and proposals for the Danish Association to carry out. Some of these are taken up and developed into specific programmes. Mr Nissen invited delegates to also use this process.

Jean Georges, Executive Director of Alzheimer Europe, said that it was both refreshing and important to discuss long-term care not only as a challenge of the ageing population, but as an opportunity for EU economies in the context of increasing competitiveness for EU countries. On the subject of innovation, Mr Georges asked the Commission to consider ways in which higher value can be found for people who work in the area of long-term care, such as training and incentives.

Mr Dziworski acknowledged that this is an issue which needs to be addressed and can be challenging when many of the carers are not always health professionals. He raised the issue of migrants working in this area which is often not acknowledged in terms of the migrants receiving financial, legal or specific training.

Annette Dumas, EU Public Affairs Officer, Alzheimer Europe, reminded the two Commission representatives of the wealth of information which national Alzheimer associations have and suggested that the associations forward concrete examples of how to address long-term care to the Commission. Mr Dziworski said they would be grateful to receive such information and that first they need to identify best practices and then share them.

Heike von Lützau-Hohlbain thanked speakers for their presentations and the audience for their interest and participation. She closed the debate by affirming the important role which end-users have when acting as advocates and speaking on behalf of others.
COOPERATION AND COLLABORATION BETWEEN NATIONAL AND EUROPEAN ORGANISATIONS

In this article, Sirkkaliisa Heimonen, PhD (Psychology), RN, Line Manager, Age Institute, Finland and Anna Mäki-Petäjä-Leinonen, Doctor of Laws, Researcher, University of Helsinki, Finland, illustrate how cooperation and collaboration at national and European level can be mutually beneficial.

Cooperation at European level has gained momentum in all fields of society. The activities of the third sector should be no exception in this development because international collaboration reflects positively on national organisations and their activities. The active cooperation of memory associations at European level enhances the influence of national organisations, clarifies the national characteristics of associations and helps to direct development efforts.

On these grounds it is strategically necessary to invest in international collaboration at European level. Goal-oriented and sustained activities are essential. Concrete measures in this field are enabled by the operational activities of Alzheimer Europe.

European collaboration creates a strong basis for national influence by connecting it to a larger framework and offering empowerment and effectiveness. We must consider national and international dialogue so that we shall have a shared language for strategic measures and open channels for communication. We must see that new, international ideas will reach the local actors on national levels.

Organisational actors in various countries work with similar challenges however different the local environment or service structure may be. The common goals include the promotion of the quality of life and well-being of persons with dementia and their families, development of support and services, and changing the attitudes toward memory illnesses. Patient and family organisations in various countries have developed innovations for supporting people with memory illnesses and their families, and the dissemination and implementation of these innovations is a current issue. The annual conferences of Alzheimer Europe offer a wide range of good practices and a solid basis for disseminating knowledge and constructing networks.

Finnish expertise in several cooperation projects

In recent years, Finnish expertise concerning memory illnesses and dementia has been shown in many projects of Alzheimer Europe where data has been collected, good practices have been developed, and recommendations have been issued in various
countries. The projects have included Lawnet (1997-2000), the development of recommendations for advance directives (2004-2005), and EuroCoDe (2006-2008). All these have produced new networks and nationally useful materials.

**Lawnet – Recommendations for improving the legal protection of persons with dementia**

Alzheimer Europe formulated legal recommendations in order to improve the legal protection of people with dementia. The recommendations were prepared in cooperation with the member organisations of Alzheimer Europe and various other experts in a project funded by the EU. The aim was to ensure the legal rights of people with memory illnesses in all EU countries when the legislation concerning these people was reformed. In this regard, the legal status of people with dementia was not satisfactory. The recommendations cover three main areas: guardianship, involuntary placement, and bioethical issues.

The Alzheimer Society of Finland participated in Lawnet, published the results in its journal and used the material of the recommendations in its training and activities.

**Recommendations on advance directives**

With recommendations on advance directives, Alzheimer Europe and its member organisations participated in European discussion concerning advance directives. The result was the document entitled “Alzheimer Europe Report: The use of advance directives by people with dementia” which was based on the discussions of an interdisciplinary group including experts on psychiatry, neurology, psychology, ethics and law. According to Alzheimer Europe, previously expressed wishes and advance directives are an effective way of promoting the autonomy of people with dementia.

The Alzheimer Society of Finland participated in this project and published a form of advance directive based on the recommendations of Alzheimer Europe in 2004. Since then, the form has been revised twice, and it can be found on the Society’s website.

Based on these two projects, The Alzheimer Society of Finland, together with the University of Helsinki Department of Private Law, organised seminars where a large number of experts on social and health care as well as representatives of the third sector attended.

**EuroCoDe – An extensive network of collaboration**

An extensive, three-year project “European Collaboration on Dementia” (EuroCoDe) coordinated by Alzheimer Europe was established in 2006. The aim of the project was to develop a European network of all the players active in the area of dementia in order to jointly develop consensual indicators and to develop an ongoing dialogue between these actors to identify ways of developing synergies and a closer collaboration on a European level. The network included research centres, patients’ and family associations and other actors from more than 20 European countries. Finnish experts participated in projects concerning the risk factors and prevention of memory illnesses, assessment of the socio-economic effects of Alzheimer’s disease, and survey of the support actions and social benefits of people with dementia and their carers.

Collecting information was a key form of action. For example, an inventory of social support systems was carried out in various countries where service systems and legislation were examined concerning the services supporting people with memory illnesses and their families. The specific project collected recommendations for the organi-
sation and provision of support. It was important to note that these recommendations emphasised the significance of rehabilitation in various parts of the care path. The outcome of the recommendations was published in the Dementia in Europe Yearbook 2008.

**Dementia in Europe Yearbooks 2009 and 2010 – Practices in member countries**

The Alzheimer Society of Finland has produced materials for the Dementia in Europe Yearbooks. In 2009 the theme was health care decision making by people with dementia, including informed consent, advance directives, and end of life issues. In 2010 the theme was legal competence, including public guardianship.

**Finnish organisational and development activities presented in Alzheimer Europe conferences**

The role of Finnish organisational actors has changed from participant and observer to active collaborator. For more than 15 years the target has been to bring Finnish expertise in organisational action and strategically important themes to international conferences. The idea has been to challenge local organisations to present their development projects in conferences. The Finnish Dementia Association has been very active in this.

Rehabilitation is an example of one of the strategically important themes. Rehabilitation became a key theme in Finnish organisational activities in early 2000s, and the possibilities of rehabilitation in dementia have been presented at European conferences from various perspectives. In 2008, professor Tuula Pirttilä lectured about the role of rehabilitation at the Alzheimer Europe conference in Oslo. In the fall of 2010, this theme was again topical at the Alzheimer Europe conference in Luxembourg where professor Kaisu Pitkälä examined the significance of rehabilitation in the care of people with dementia.

Active collaboration in conferences means that already in plans of action we define the main themes that we want to bring to international venues. The main themes can be related to general themes of organisational activities or they can be results from development projects. At a national organisational level, participation in conferences opens a number of avenues if the available learning opportunities are utilised, new networks are created, and if we can find themes that serve the demands of national development activities. At their best, conferences work on many levels as arenas of new ideas and learning.

**Influence and decision making**

The Alzheimer Society of Finland has enjoyed great exposure to the European organisational activities with its representation in the board of Alzheimer Europe. This has enabled a significant link for national and European influence in this field. As member of the board of Alzheimer Europe, the former chairman of The Alzheimer Society of Finland, Pekka Laine, has done a remarkable job in the European organisational field and he has actively worked for open and strategic international connections. This effort will be maintained by the new member on the board of Alzheimer Europe, the vice-chair of the council of The Alzheimer Society of Finland, Sirpa Pietikäinen, MEP.

**Conclusion**

We can successfully confront the challenges presented by memory illnesses only by strengthening cooperation between various actors at national level and by building international forms of collaboration that promote influence and the exchange of knowledge. This will create synergy and two-way advantages because cooperation provides new resources for one’s own work and it can open venues for offering one’s own expertise to others. By strategic beneficial utilisation of the possibilities of international collaboration, great advantages can be reached in the fields of national influence, development and organisational activities.
FACILITATING NEURODEGENERATIVE DISEASE RESEARCH ACROSS EUROPE

The “Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development” (PharmaCog) is highly ambitious project which aims to tackle bottlenecks in Alzheimer’s disease research and drug discovery.

Dr Elisabetta Vaudano, Principal Scientific Manager of the Innovative Medicines Initiative, speaks with Alzheimer Europe about the Innovative Medicines Initiative and the PharmaCog project.

Alzheimer Europe (AE): Dr Vaudano, the Innovative Medicines Initiative (IMI) is a unique partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA). What are the aims of this important initiative?

Elisabetta Vaudano (EV): The IMI aims to boost innovation in healthcare in Europe by building collaborative networks in research and training projects. Major health issues like how to progress towards new treatments for Alzheimer’s disease are too complex for companies or universities alone to resolve. The IMI brings together partners from industry, academia, small and medium-sized companies, regulatory authorities and patient organisations, in multidisciplinary consortia that undertake collaborative projects. By supporting ambitious research projects, IMI aims to speed up the development of better and safer drugs.

AE: What can this initiative deliver for patients in general and for people with Alzheimer’s disease and other forms of dementia in particular?

EV: The main objective of IMI research is the development of tools and methods (for example new animal models, new biomarkers, new imaging methods…) to deliver better and safer drugs to patients. The lack of these tools is responsible for the failure to deliver really innovative treatments to needy patient populations. IMI is also committed in promoting and supporting information and education of patients both as part of its research projects and via specially targeted activities. In addition IMI aims to deliver a new “culture” of doing collaborative research where all stakeholders are involved including the patients. A clear example of this model is the PharmaCog project where Alzheimer’s Europe is a full partner of the consortium. PharmaCog research focusses on the development of a new translational strategy for developing drugs for Alzheimer’s disease, keeping the patient in the centre of the research approach.

AE: How does the IMI collaborate with other dementia initiatives on a European level such as the 7th Framework Programme or the Joint Programming Initiative?

EV: We are in constant contact with our colleagues at the European Commission and we are following with high interest the starting steps of the Joint Programming Initiative in order to create synergy and insure coordination among all these activities.
Prof. Olivier Blin, PharmaCog Coordinator, and Dr Alexandra Auffret, PharmaCog project manager, both from the Université de la Méditerranée, Marseille, France, speak with Alzheimer Europe about the aims, partners and early achievements of the project.

Alzheimer Europe (AE): PharmaCog is a project financed by the Innovative Medicines Initiative (IMI) to address current obstacles in the drug discovery process in the Alzheimer’s field. What are the aims of this EU project?

Prof. Olivier Blin (OB) and Dr Alexandra Auffret (AA): Directly in line with the main aims of IMI, the objective of PharmaCog is to develop methods and tools to improve the translation of pre-clinical findings and facilitate the evaluation of treatment response in early clinical development of drugs for the treatment of Alzheimer’s disease. Standard clinical trials for Alzheimer’s are time consuming, expensive and often uninformative. Unfortunately, most studies fail to yield sufficient evidence of the exposure-response relationship for efficacy and safety of novel compounds and thereby prevent go/no-go decisions early in the development process. Furthermore, current protocol designs and endpoints do not allow clear distinction between symptomatic and disease-modifying compounds. By focusing on the integration of data and on the predictive value of novel methods and tools, PharmaCog aims to improve decision making capacity during early clinical programmes, increasing the efficiency of the overall development process. The proposed approach is based on the use of an innovative multidimensional matrix that combines advanced statistical methods with systems biology, pharmacology, neuroanatomy, neurophysiology, biochemistry and neuropsychology. The success of this approach will be dependent upon harmonisation of protocols, optimisation of experimental design and on the systematic integration of data, as defined by the Matrix. This effectively represents a shift in the current paradigm for drug development, in which data from pharmacodynamic studies in pre-clinicals, healthy volunteers and selected patient cohorts will be evaluated in parallel, rather than in sequential, isolated manner. The research activities are structured around three key themes:

- The identification and validation of healthy subject models of cognitive impairment to support early proof-of-efficacy studies
- The development and validation of pharmacodynamic markers suitable to support the determination of efficacious dose ranges
- The identification of markers sensitive to early disease progression and development of pre-clinical models with greater predictive value.

AE: Who are the partners of the PharmaCog project?

OB and AA: PharmaCog consortium brings together leading scientists from 30 organisations comprising public institutions (12 Universities, Research Centres and Hospitals), corporate partners (5 Small and Medium Enterprises and 12 EFPIA members), and the patients’ association Alzheimer Europe, coming from 10 different EU Member States. PharmaCog will also work closely with the European Medicines Agency (EMA) with the objective of communicating project progress and discussing the implications of findings for drug development in the EU.

AE: The project has now been operating for over a year. What have been the key achievements and milestones of the first year?

OB and AA: During the first year of the project PharmaCog has largely focussed on several key actions:

- Maximising the opportunity of the diverse experience and background of the PharmaCog team to optimise clinical and pre-clinical study designs. Information was gathered from literature reviews, protocols and data from studies conducted by participating industry partners has been combined to optimise three clinical study designs and parallel pre-clinical research plans. Protocols have been finalised and enrolment of subjects will begin in June 2011.
Harmonisation and standardisation of endpoints across all participating pre-clinical and clinical research sites. Endpoints were selected on the basis of sensitivity to disease progression, pharmacological intervention and translatability between species. Protocols for each endpoint have been agreed and procedures have been harmonised and standardised across all EU participating sites.

Another example, researchers have already investigated the feasibility of sleep deprivation as a model of cognitive impairment in animals. Pilot studies have been completed demonstrating that robust cognitive impairment can be induced in a variety of preclinical models.

Experiments to understand the dynamic range for novel biomarkers in pre-clinical models of Alzheimer’s disease. A range of pilot studies have been conducted to investigate the magnitude of change in the novel biomarkers. The outcomes of this work will be presented in 5 posters at The Alzheimer’s Association 2011 International Conference on Alzheimer’s Disease (ICAD, to be held in Paris in July 2011).

Establishment of Standard Operating Procedures (SOPs) and guidance document for the governance of clinical trial preparation and management, data management, and publication policies in PharmaCog. Twenty-one SOPs were drafted and agreed by all partners to cover all key aspects of protocol development, human biological tissue sample management, data management and publication procedures.

The establishment of an ethics advisory board to oversee the ethical and scientific conduct of PharmaCog. An internal Ethics Advisory Board has been established to oversee and guide the project regarding ethical and safety aspects and scientific conduct of the study. Given the translational nature of PharmaCog, this committee focuses on both human ethics and preclinical models welfare.

OB and AA: PharmaCog partners have started to work closely with investigators in other major Alzheimer Initiatives across Europe and but also with the USA. PharmaCog PK/PD groups have started effective collaboration with Coalition Against Major Disease (CAMD) initiative. First effective meeting will be held in Brussels in the coming months (http://www.c-path.org/CAMD.cfm/). The PharmaCog investigators worked also closely with Alzheimer’s Disease Neuroimaging Initiative (ADNi) with the help of Prof Giovanni Frisoni in particular to develop one of the PharmaCog AD patient clinical trial.

In addition, PharmaCog scientists have set up a joint meeting with the AlzBioIndigo project (New Indigo FP7 project in collaboration with India) to share perspectives on AD biomarkers. The meeting will be held from 5 to 7 July in Bochum (Germany). Finally, PharmaCog actors interact with the NEURORESCUE project, an ambitious Coordination Action project (FP7, Region of Knowledge) aimed at stimulating cooperation in European fundamental, clinical and social researchers in mental health, in order to support Europe’s leading position in mental disorders, dementia or neurodegenerative diseases.

AE: How does the PharmaCog project collaborate with other EU projects in the field?

OB and AA: The first of Year 2 of the PharmaCog project will see the recruitment of patients into three major clinical studies. Pre-clinical work will continue extensively in parallel to allow the establishment of mathematical models to describe each model and the translational relationship with the clinic. By the end of the project, PharmaCog will help to validate the tools necessary to streamline Alzheimer’s disease drug discovery. All studies conducted are designed to improve our ability to identify successful new medicines as early as possible while stopping progression of those destined to fail. We hope that PharmaCog will improve the availability of models required to make drug discovery easier and accelerate effective medicine to patients.

AE: What do you hope will be the achievements of the PharmaCog project at the end of the project in 2014?

OB and AA: How does the PharmaCog project collaborate with other EU projects in the field?
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

You can make a difference. Join the European Alzheimer's Alliance today.
THE ROLE OF THE EUROPEAN ALZHEIMER’S ALLIANCE IN MAKING DEMENTIA A EUROPEAN PRIORITY

Annette Dumas, Public Affairs Officer of Alzheimer Europe, talks about the importance of the European Alzheimer’s Alliance in the dementia movement and the role its members can play.

Back in 2006, when Alzheimer Europe presented its political priorities embedded in the Paris Declaration to the Members of the European Parliament (MEPs), a good number of them eagerly agreed to support the Declaration. Soon after, the European Alzheimer’s Alliance was born, with the support of two founding members: Astrid Lulling (EPP, Luxembourg) and Brian Crowley (ALDE, Ireland).

The Alliance was created to broadly raise awareness about the challenges of dementia and trigger the necessary momentum needed to influence both the European and national public health, social and research agenda and thus respond to the Paris Declaration priorities.

Since the Alliance’s early days in 2007, all major European Parliament (EP) political groups and almost all 27 Member States have been represented in the Alliance. Not only did it soon become clear that dementia was indeed an urgent challenge to address now, thinking ahead and planning for the future were an obvious mission. The dementia community was most comforted to see that the interest of the MEPs remained intact after the last European elections in 2009 and that newly elected members agreed to join the Alliance. The Alliance currently gathers 54 MEPs and it is encouraging to see that the number of members continues to grow.

By working together with both the European Alzheimer’s Alliance members and its members at national level, Alzheimer Europe has brought the interests of the people with dementia and their carers to the European attention. Dementia is now clearly on the EU agenda and the four priorities of the Paris Declaration have been taken on board by various EU developments:

- In 2008, the French EU Presidency conference on the fight against Alzheimer’s disease led to a number of far-reaching Council Conclusions that were shortly followed by concrete outcomes: the 2009 European Commission’s Communication on a European Initiative on Alzheimer’s disease and Council recommendations for the joint programming of research into neurodegenerative diseases including dementia.

- To further improve the scope of the Commission’s initiatives, the EP greatly added to the Commission’s developments. Members of the Alliance were involved in the EP Written Declaration on the priorities in the fight of dementia (F. Grossetête), the two EP Resolutions on the Joint Programming of research to combat neurodegenerative diseases, in particular Alzheimer’s disease (E.O. Antonescu, N. Chountis, F. Grossetête, M. Matias, P. Toia) and on the Commission’s Communication on a European initiative on Alzheimer’s disease (M. Matias, E.O. Antonescu, N. Childers, F. Ries, M. Yannakoudakis).

The Alliance members have been extremely supportive in raising awareness, providing platforms to exchange ideas and influencing the European developments.

“"The European Alzheimer’s Alliance has played a key role alongside Alzheimer associations in putting the challenges of dementia to the forefront of the EU political agenda.”

Annette Dumas, EU Public Affairs Officer of Alzheimer Europe
Since 2006, the European Alzheimer’s Alliance members have presided over a number of awareness and information events in the EP: an exhibition to launch the Paris Declaration (A. Lulling), lunch debates on well-identified dementia topics with experts (F. Brepols, N. Childers, F. Grossetête, S. Pietikäinen, D. Roth-Bherendt, M. Yannakoudakis), launch of research carried out by Alzheimer Europe, be it within the context of EuroCoDe (European Collaboration on Dementia project financed under the Public Health Framework Programme) (F. Grossetête, C. Moraes) or Alzheimer Europe’s own-initiative reports.

Many Alliance members have provided articles (F. Brepols, B. Crowley, A. Lulling, L. McAvan, C. Moraes, E. Morin-Chartier, S. Pietikainen, D. Roth-Behrendt, C. Woortman-Kool, A. Zaborska), or participated in interviews for Alzheimer Europe’s policy magazine, Dementia in Europe Magazine (M. Cabrnoch, B. Crowley, M.E. Koppa, A. Lulling, S. Pietikäinen, P. Toia), thus sharing with a much wider audience their views and challenges of dementia.

At national level, Alliance members have participated in events organised by Alzheimer Europe’s members, thus stimulating their national governments to follow European recommendations and address dementia at national level too. Others have taken part in the shaping up of national Alzheimer plans.

It is undeniable that the European Alzheimer’s Alliance has played a key role alongside Alzheimer associations in putting the challenges of dementia to the forefront of the EU political agenda and, in some Member State, the national political agenda. The Alliance engagement rightly deserves recognition from the dementia community.

But this does not leave any room for complacency. Although more attention is being paid to our cause, the challenges of dementia are still high and need long-term attention.

Although we realise we can count on a large number of MEPs to support the work of the EP in the field of dementia, the number of MEPs effectively joining the Alliance will make a difference. This is why we would like all those who have an interest in people with dementia and their carers to come forward and join the Alliance. This would reinforce the weight and scope of this group. It would also give the people of dementia and their carers a clear signal that their MEPs are still working towards alleviating their plight.

We count on you!
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THE VIEW FROM ITALY

Patrizia Toia, MEP, Vice-chair of the Group of the Progressive Alliance of Socialists and Democrats (S&D) in the European Parliament and member of the European Alzheimer’s Alliance talks with Alzheimer Europe about the situation in Italy for people with dementia and their carers.

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

Patrizia Toia (PT): In Italy, as in some other countries, greater awareness about Alzheimer’s disease, age-related and neurodegenerative diseases has led to a series of concrete actions to tackle these diseases. If a few years ago the care of people suffering from these diseases fell onto the shoulders of the families, today we can report that research into these diseases has been encouraged, specialised support centres with highly trained professionals have been created for the people with dementia and their carers. We hope that further progress will be made to prevent or at least stop the development of these pathologies.

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?

PT: Inevitably, the ageing of the population calls for a series of changes in the field of health and treatment. But, overall, the level of well-being has increased. The training of general practitioners, the possibility to have access to early diagnosis and access to care have been important measures. This can be explained by the major steps forward made by our country in the field of information and awareness about Alzheimer’s disease. A lot of work has been carried out in this field by the associations which take care for these people. They all deserve a big thank you. However, Italy is certainly lagging behind on legal matters and there is still a long way to go before we see results.

AE: Do you believe that Italy will follow the example set by France, Norway, the Netherlands and England to create a National Alzheimer’s Plan?

PT: It is difficult to predict the future. All recommendations from health professionals go towards the setting up of a national programme or outline laws in order to coordinate the various projects and programmes that prove to be efficient in some regions and, above all, clearly inform the citizens about what resources are available. Today, the challenges of dementia are not exclusively an Italian issue: we would need a European body to give guidelines and engage all countries in tackling dementia. This seems to be the way to go.

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

PT: The objectives of Federazione Alzheimer Italia are to provide information and raise awareness amongst the public and policy mak-
ers about dementia, promote medical and scientific research, provide support to and represent the people with dementia and their carers, contribute to the development of public health and social policies. The aim is to respect the dignity of all people affected by disease, inform them about their disease so they can make enlightened decisions about the care and support they want to receive, including access to social and medical services. They should have the right to choose the type of services that are available.

Policy makers have always to act in the best interest of the citizens and be at their service. In health matters, and more specifically in the case of diseases that call for continuous assistance, psychological support for the family carers and access to tailored care are needed. But family carers have to face the costs linked to the various forms care of the person with dementia. Specialised and highly qualified professionals are needed. On this front, we can be thankful to the non-governmental organisations for the work they are doing. Thanks to them many steps forward have been made.

AE: Would you support the development of a European Action Plan and if so, what do you believe the priorities should be?

PT: The European Union is certainly a driver: it shapes our future and the choices we will make at European level will affect all of us. It is most important that all decisions taken at European level be embraced and implemented at national level by as many Member States as possible. Our priorities must always put the interests of the citizens on the front line, especially those citizens affected by a debilitating, care and support demanding diseases. Their carers must be supported too and be certain that they will not have to face alone situations labelled as dramatic on their own. The European Union must work together on this front.

“Now, more than ever, we need to address the availability and accessibility to financial resources while offering the best treatments and care.”

N.B. Prevalence figures for 30-59 age group from EURO DEM (Hofman et al) and for 60+ age group from EuroCaDe (Reynish et al).
The proliferation of counterfeit medicines poses a real and growing threat to patients around the world.

Over a two month period in 2008 customs from the EU Member States seized more than 34 million* illegal medicines.

* Brussels, 16 December 2008 IP/08/1980 Customs: Millions of illegal medicines stopped by “MEDI-FAKE” action

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Do more, feel better, live longer.

The medicine her doctor prescribes should be the medicine she receives.
RISING TO THE CHALLENGE: HOW THE EU CAN HELP TO ADDRESS DEMENTIA

László Andor, European Commissioner for Employment, Social Affairs and Inclusion, talks with Alzheimer Europe about how dementia is being addressed at the EU level.

Alzheimer Europe (AE): Dementia is a disease that may lead to complete dependency of the person with dementia and involves both formal and informal carers during the disease development. However, service provision to cover long-term care needs is currently very diverse across the EU Member States. What are the aims of the Open Method of Coordination in this area?

László Andor (LA): Population ageing is an EU trend. At the same time, dementia raises great challenges, both in clinical and organisational terms. It is clear that ensuring affordable access to good quality long-term care, in the context of financially sustainable systems, will be a complex task for all Member States.

The Open Method of Coordination in this area aims at ”Working together and working better” in close connection with the Member States. The purpose is to improve access, quality and sustainability of these systems.

Under the social Open Method of Coordination, long-term care (LTC) is the one area which differs most across the EU. Countries are at very different stages in their efforts to address the need for help and care of vulnerable older people. Generosity in funding, organisation models, as well as cultural perceptions of LTC vary greatly across Member States. As well as this, there are other challenges like the expected workforce shortage in the field of LTC (as well as in the health sector), the lack of a commonly agreed framework and also the informal natures of much LTC delivery. When LTC is delivered by informal carers (either family members or other informal carers), it is clear that quality standards are not always guaranteed.

This is why the Commission is currently drafting a working paper on long-term care to be published at the end of 2011. This will map existing long-term care systems and will look at how closer policy coordination at EU level can add real value to the efforts of Member States.

AE: Dementia is a costly disease with a financial burden on families and long-term care has been identified by the European Parliament as a priority the EU should tackle as a matter of priority. Do you think the Open Method of Coordination can be extended to the financing of long term care?

LA: Among the challenges mentioned above, it is clear that quality, funding and the organisation of long-term care are key issues, especially in the current climate of budgetary constraints. These areas are the responsibility of Member States, but the Open Method of Coordination will help countries learn from each other and improve common experience sharing on these complex subjects. In our work, we will consider both the user’s and the carer’s perspective, including working conditions.
There is also the recent initiative, the Voluntary European Quality Framework for Social Services which can be applied to LTC. The Commission supported the work on this framework which covers quality principles and methodological elements in the field of social services. What is interesting is that it is flexible enough to be applied in the national, regional and local context in all the EU Member States and to a wide range of social services.

AE: The EU 2020 strategy flagship “An agenda for New Skills and Jobs” will bring concrete solutions to the challenges and specific needs of an ageing, increasingly dependent population. How will these two flagships articulate around the Active and Healthy Ageing Innovation Partnership and identify new skills and specific trainings for the care of people with dementia?

LA: The EU employs about 22 million health and services workers. In fact, healthcare constitutes one of the most significant sectors of the EU economy, providing employment for one in ten of the EU workforce, and approximately 70% of the healthcare budgets are allocated to salaries and other charges related directly to employment of the health workforce. The workforce in health and social services is dominated by women and workers are relatively young (under 40 years).

However, studies suggest a shortage of health workforce in the EU by 2020. According to Commission internal estimates, we will be short of around 1 million health workers (physicians/nurses/dentists/pharmacists/physiotherapists). This means that almost 15% of the necessary care will not be covered. The figure of 1 million will double if long-term care and ancillary health professions are also taken into account.

This shortage of health workforce results from the combined effect of increased healthcare needs among an ageing population and the ageing of the health workforce itself, with the “baby boomers” set to retire over the next decade.

In November 2010, the Commission presented, as part of its Europe 2020 strategy, its initiative “An agenda for new skills and jobs”. This sets out plans, in cooperation with Member States, to develop by 2012 an action plan to address the gap in the supply of health workers. The preparation of the action plan will start in April 2011, providing a platform for cooperation between Member States under the Health Programme on forecasting health workforce needs and workforce planning.

The objective is to improve workforce planning and to work on skills. It is also about helping Member States equip the health workforce with the right skills, improve retention and recruitment of health personnel, implement the World Health Organisation’s code on international recruitment of health personnel and collect high quality and comparable data.

AE: The recent Commission’s Green Paper on pensions pays very little attention to the situation of carers who often need to stop a paid activity to look after a person with dementia. Are there any plans to address this specific situation?

LA: The Public Consultation Green Paper highlighted the issue of carers as part of “Addressing Pension Adequacy”. It says that the “lack of compensatory crediting for periods of unemployment,
sickness or caring duties can also lead to gaps”. The paper refers to the need to consider carers linked to gender issues, given that women tend to take on caring roles more than men. For instance, it underlines that “to strengthen social cohesion, a number of Member States may want to address outstanding issues such as minimum pensions, coverage of atypical workers and crediting of some involuntary employment breaks, for example when caring for frail dependents.”

Whilst Member States remain largely responsible for the design of pension systems, the EU level – through the Open Method of Coordination – will continue to encourage Member States to consider the position of carers as they reform their pension systems.

The pensions White Paper, due in September 2011, will outline the next steps on the EU level work on pensions, taking account of the outcome of the consultation launched last year. This will include considering developing the Open Method of Coordination and continuing work to encourage Member States to look at the impact on pension adequacy of involuntary labour market absences – including those due to caring responsibilities – and how to mitigate these impacts.

AE: 2012 has been identified as the European Year for Active Ageing. How do you plan to work with other Commission DGs and stakeholders to reconcile a productive and healthy working life, the supply of tailored and timely services for the people with dementia and their carers, training and evaluation of a health workforce dedicated to the people with dementia?

LA: We need to create conditions that allow people to stay active as they grow older. Active ageing is also about helping older people to remain longer in the labour market, to contribute to society as volunteers and carers and to remain as autonomous as possible for longer.

We need to take steps to remove all obstacles that prevent people from fully using their potential as they grow older.

This means involving many different stakeholders: national, regional and local authorities, employers and trade unions, civil society organisations. And it calls for action in many different areas: employment, social protection, education and training, health and social services, as well as housing and public infrastructures.

The proposed European Year for Active Ageing will frame actions to raise awareness, to identify and disseminate good practice and, more importantly, encourage policy makers and stakeholders at all levels to promote active ageing. The aim is to invite these players to commit to specific action and goals in the run-up year 2011 so that tangible results can be presented during the European Year itself in 2012.

The EU has already taken initiatives to promote active ageing in the areas of employment strategy, adult education, public health and the information society. These activities should benefit from an enhanced visibility in the context of the European Year. Many of the existing policies and instruments can be geared towards the goals of the European Year so that projects with an active ageing dimension can get some financial support from the EU (research, conferences, seminars, exchange of experience).
Alzheimer Europe (AE): Your organisation has been actively campaigning for the development of a Greek Dementia Action Plan. What should be the key elements of such an Action Plan?

Dr Paraskevi Sakka (PS): Alzheimer Associations in Greece have been campaigning relentlessly over the last years to make dementia a public health priority in order to meet complex health and social care needs of people with dementia. We have identified the following action areas:

• Increase of public awareness of the disease
• Eradication of any stigma and misconceptions
• Development of support, medical and social services
• Training of health professionals
• Legal and ethical issues
• Support of dementia research.

We believe that the first step is to organise the action plan. For the plan to be effective it is necessary that we (a) obtain epidemiological data regarding dementia in the Greek population. This information is missing at present, (b) promote general public awareness of the disease and (c) increase the allocation of public funding. A major problem is that Greece, and Europe in general, faces an economic crisis and this has resulted in both a lack of effort and a lack of money being made available to fund the dementia action plan.

AE: What were the key elements of your campaign to make dementia a priority and what successes have you had so far?

PS: The key elements of our campaign were the following:

• We involved a large majority of the stakeholders
• We publicised the campaign through the media
• We found sponsors
• We offered memory screening free of charge on various days including World Alzheimer’s Day
• We organised annual Memory Walks (in 2008, 2009 and 2010) in many cities for the first time in Greece
• We increased membership
• We organised a web-based petition which was presented by people with dementia to the former Minister of Health during a ceremony on the 2009 World Alzheimer’s Day.

AE: During the 2010 World Alzheimer’s Day activities, you presented the Greek Minister of Health with 15,000 signatures from people who supported your campaign. What was the reaction of the Health Minister and what are the next steps now towards the establishment of a Greek strategy?

PS: During the 2010 World Alzheimer’s Day activities, we presented the Mayor of Athens and other representatives from the Ministry of Health with 15,000 signatures from people who supported our campaign. As you can see, all the above elements were successful but no real change has been implemented due to the fact that the present Minister of Health is unobtainable!! Our effort continues!
Prioritising Dementia in Europe

Alzheimer Europe (AE): Why is there a need for a national dementia plan in Ireland?

Sarah O’Callaghan (SO’C): In Ireland, dementia has long been an under recognised public health issue with massive social, political and economic implications. Traditionally one of the “younger” EU states, our rapidly ageing older population suggests that the number of Irish people affected by Alzheimer’s and dementia is expected to rise from 44,000 currently to 104,000 by 2036.

Regardless of its potential impact, dementia is a relatively new area of policy focus in Ireland and it continues to receive inadequate funding attention. In 1999, Professor Eamon O’Shea authored “An Action Plan For Dementia”, pioneering the concept of the development of a strategic national policy response to the issue but it has remained largely unimplemented. As a result there now are:

- substantial gaps in the systemic knowledge base regarding dementia care and prevalence;
- meagre and uneven policy response and planning;
- no clear care pathway for the lifespan of the condition;
- enormous gaps in and fragmentation of health service provision;
- inadequate investment in dementia education and research;
- and a total lack of clarity about how much is spent on dementia-specific services by the state;
- an over-dependence on under supported family caregivers.

The impact on individuals and families is significant as evidenced in a recent national care survey, which identified the major challenges they face as:

- inequitable access to a timely diagnosis – 1 in 5 people had to wait between 2 and 4 years to get their diagnosis – compared to an average of 9 months in Germany and 13 months in Italy;
- a lack of information & carer training – 15% respondents received no information at diagnosis and 77% carers received no carer training with four in five of this group wanting it;
- a dearth of flexible dementia-specific service options through the continuum of the condition – two thirds of carers are caring alone for their loved one for more than 12 hours per day; 3 in 10 carers rarely or never receive respite from caring; 62% of carers experience increased stress due to the lack of support services; and
- isolation & barriers to having their voice heard – 62% carers feel they are not valued by the State for their role in caring.

There is an urgent need for more quality-driven dementia care services, improved access to medical care, better information and education etc. And the sooner, and more effectively, these issues are addressed the better the quality of life people can enjoy both now and in the future.

Ireland: As Ireland begins to draft its first-ever national dementia strategy, Sarah O’Callaghan, Head of Public Affairs and Communications at The Alzheimer Society of Ireland, talks with Alzheimer Europe about the role which the organisation has played in bringing dementia to the fore.

Alzheimer Europe (AE): How has Alzheimer Europe played a role in bringing dementia to the fore?

Sarah O’Callaghan: One of the “tipping points” in our success in shifting public opinion regarding dementia was an investigative programme on dementia in Ireland which aired on our national TV station in May 2010.
AE: What part has the Alzheimer Society of Ireland played in ensuring dementia is on the political agenda?

SO'C: The Alzheimer Society of Ireland has, since its formation, lobbied and campaigned on behalf of people with dementia and their carers to improve the lives of all those affected by dementia. Since 2007 the Society has been calling for dementia to be recognised as a national health priority and for the development of a national dementia strategy. It has been a long and challenging journey but I’m delighted to say that in February 2011, our newly elected government’s Programme for Government contained both of our objectives; dementia has gained recognition as an health priority area AND there is a commitment to the development of a National Dementia Strategy by 2013.

The Alzheimer Society of Ireland has been a major player in making this progress happen, I’ve no doubt in my mind about that. And, I think that the reasons we have been successful are that we set ourselves clear objectives and a realistic timeframe within which we could achieve them. In addition, because this level of policy change doesn’t happen quickly or on a whim, we developed an integrated campaign using 4 complimentary strategies: lobbying; strategic communications; alliance building; and grassroots activation.

Lobbying: Policy analysis, research and evidence-based positions formed the foundation of our lobbying and advocacy work. Building on existing activities – including our annual Pre-Budget Process, policy submissions and expert working groups etc. – we increased and strengthened our programme of face-to-face meetings and briefings with politicians and decision makers, at national and local level.

As a new initiative, we have established a cross-party network of parliamentarians – “Friends of Dementia” – modelled on the effective Alzheimer Europe initiative. To date we have almost 40 members – including 10 senior government figures – whom we brief and communicate with on a regular basis.

Strategic communication: i.e. publications, public events and campaigns, media advocacy and outreach activities, plays a critical role in broadening the understanding and support for our issues and in achieving our objectives. In addition to our annual programme of media activity, briefings and public meetings, including our World Alzheimer’s Day activities, we developed a number of new communications initiatives that have proven to be fruitful.

One of the “tipping points” in our success in shifting public opinion regarding dementia was an investigative programme on dementia in Ireland which aired on our national TV station in May 2010. The programme unveiled the harsh reality of many people living with dementia in Ireland and the lack of services and planning here. It received much media and political attention and it seemed to move the general public deeply.

Online advocacy offers a new channel of stakeholder communication and is an effective method of extending reach and mobilising agents of change. We have made some advancements in this area as part of our General Election 2011
campaign and we plan to overhaul the current website to harness a wider support base.

**Grassroots Activation:** In Ireland all politics is local! Mobilising our passionate, motivated and knowledgeable grassroots network – clients, carers, families, branches, volunteers, staff and supporters etc. – for lobbying and campaigning activities within their local areas has been central to our ability to influence political and policy change. To support them and build capacity for the future, we have provided coaching, training and toolkit materials where necessary.

**Alliance Building:** In order to broaden our support base we have been conscious of the need to collaborate with key stakeholders and to build a platform of support for the development of a National Dementia Strategy. Key allies include: GPs & allied healthcare professionals; academic & research community; dementia strategy experts (national and international); and Age Sector & other NGOs. We have also developed a network of celebrity and expert “Dementia Ambassadors” to help us champion the issues of dementia.

These four strategies are really ingredients which we measured out and combined in a way that was successful for getting dementia onto the public and political agenda in Ireland. However, we cannot underestimate the lessons we have learned from our partners in Alzheimer Europe who succeeded in getting a national strategy in their countries before us.

AE: What do you believe are the key issues which should be addressed in a dementia plan for Ireland?

SO'C: Now that we have secured a commitment to develop a National Dementia Strategy by 2013, what is it that we really want and need addressed in it?

Notwithstanding the current economic situation in Ireland, a national dementia strategy would enable the formulation of a strategic and fully coordinated response to meet the needs of people with dementia and their carers.

The Alzheimer Society believes that the dementia strategy should include a detailed implementation plan with dedicated funding, close links to other policy initiatives, in-built evaluation mechanisms and clear lines of accountability – at both a political and statutory level.

Taking an integrated dementia care-pathway approach to dementia care, the strategy should incorporate the following key priorities: (1) early intervention, education, risk reduction and training; (2) enhanced and flexible community based services for people with dementia and their carers through the continuum of the condition; (3) increased emphasis on research; (4) a person-centred and quality standards approach to care; and (5) a joined up, multi-disciplinary approach to service provision.

Preparatory work for the dementia strategy has already begun and The Society is an active member of that work. Development of the strategy is on schedule to begin before the end of 2011. In many ways this story is just beginning.
Enabling a person with Alzheimer’s disease to live at home can result in a significant financial and physical cost both to the person with dementia and their carer. These are the findings of a socio-economic study carried out by France Alzheimer between September 2009 and November 2010 involving close to 500 carers.

This study was carried out in two ways: individual interviews with 88 carers in 5 departments, and an on-line survey with the participation of 378 carers. “Above all, our goal was to collect accurate and credible data to highlight a worrying situation where economic difficulties and the burden of the informal carers of people with dementia are combined. From a financial perspective, France Alzheimer wanted to evaluate the specific personal financial costs incumbent to the carer and the person being cared for after considering the range of goods and services used, the support received and the activities performed by the informal carer”, explained Marie-Odile Desana, President of France Alzheimer.

Results:

- The out-of-pocket costs are on average around EUR 1,000 per month, although this amount can vary by a factor of one to four depending on whether the patient is living at home (EUR 570) or in a care home (EUR 2,300).

- The main costs mentioned by the interviewees are: costs linked to the home help (“auxiliaire de vie”), day care or temporary care; costs linked to incontinence; those linked to keeping the house clean; transport; home modifications; night carers. These costs are to be put in perspective with the French pension levels (EUR 1,100) and with the average co-payment received by the families (EUR 411 per month). “This is, in short, well below the families’ real needs”, regrets Marie-Odile Desana. As a matter of fact, the people with the disease can only benefit from the “allocation de perte d’autonomie” – APA (dependence social allowance) linked to the loss of autonomy), and there is no specific and tailored support for the people suffering from this degenerative disease.

- The informal carers’ daily activity spans on average 6 ½ hours (for some of them, it is 24 hours a day). This does not take into account the time when the carer is looking after the sick person and cannot go out or reduce their attention.
The financial value given to this daily activity is estimated to be EUR 3,000 per month (based on the gross salary of a home care professional at EUR 16 an hour).

“The cost of human care, be it performed by professionals such as home helps or by informal carers, is by far the heaviest and reflects one of the consequences of the very specific needs linked to care for people with Alzheimer’s disease or another form of dementia”, says France Alzheimer’s President. These data emphasise, even if it were not necessary, the importance and the scope of the debate started in France on the reform of dependence. In this respect, France Alzheimer reinforces the organisation’s calls for:

- a decrease in the out-of-pocket costs incumbent to the family;
- funding by reforming national solidarity measures notably by an increase of the CSG (General Social Contribution);
- no taxation of the estate of dependent persons;
- creation of a universal right to autonomy support;
- a personalised support plan for all.

In France, over 800,000 people have Alzheimer’s disease and only one in two people receives a formal diagnosis. Therefore, the socio-economic costs found in France Alzheimer’s report are only the tip of the iceberg. It is essential that the initiatives called for by France Alzheimer are acted upon if carers of people with dementia are to continue providing their invaluable support.

The socio-economic costs found in France Alzheimer’s report are only a tip of the iceberg.

There were 974,391 People with Dementia in France in 2006

N.B. Prevalence figures for 30-59 age group from EuroDEM (Hofman et al) and for 60+ age group from EuroCoDe (Reynish et al).
NEW INSIGHTS INTO DEMENTIA:
HIGHLIGHTS FROM THE 2011 ROMANIAN ALZHEIMER CONFERENCE

The annual Romanian Alzheimer conference took place in Bucharest on 18-20 February 2011. Maria Moglan, Executive Director of the Romanian Alzheimer Society, reports on the event.

About 350 participants attended the Romanian Alzheimer Conference organised by Alzheimer Europe’s member, Societatea Romana Alzheimer, including, among others, people with dementia, carers, local and national policy makers, representatives of regional branches, specialists and general practitioners (GPs).

The Conference theme was “New Insights Into Dementia” and the topics discussed covered all stages of the management and care of dementia – recognition of the early symptoms, diagnostic criteria, early detection possibilities and alternatives for differentiating the type of dementia in usual clinical conditions, ethiopathogenic mechanisms, pharmacological and non-pharmacological therapeutic interventions, available care services and ethical and legislative aspects.

The focus of the first day’s plenary session was to improve the lives of people with dementia and their carers. Commencing with the presentation “From a Taboo Diagnosis to the Memory Centre: Alzheimer Disease in Romania”, Dr Catalina Tudose highlighted advances that have been achieved by Romanian Alzheimer Society. Then, Annette Dumas presented the role the European Union can play to tackle Alzheimer’s disease. Dr Carmen Manu talked about the main challenges and opportunities of the long-term care systems in Romania and scientific presentations were given by professors: Michael Davidson (Director Stuckinski Centre for Alzheimer’s Disease Care and Research), Ovidiu Băjenaru and Bogdan Popescu (Carol Davilla University of Medicine and Pharmacy, Bucharest).

Opening the conference, Dr Catalina Tudose, President of the Romanian Alzheimer Society, highlighted the importance of making Alzheimer’s disease and other forms of dementia a national public health priority. Romanian policy makers (Mircea Savu, Director of the Bucharest Municipality, Mrs Crina Girleanu, General Directorate for the Protection of Persons with Disabilities, Razvan Chivu, Counsellor of Minister for Health, Mrs Carmen Manu, General Directorate in the Minister for Labor and Social Protection) also participated at the opening ceremony, calling for intensive collaboration. Representatives of Alzheimer Europe, Annette Dumas (EU Public Affairs Officer) and Dianne Gove (Information Officer) participated in the conference along with Helga Rohra, Vice-President of the Alzheimer München Association (Germany) whose speech “Living with dementia” was one of the conference highlights.

“The focus has to be the people with dementia and their carers, as they are the ones who are facing dementia together.”
Bucharest). Dianne Gove presented Alzheimer Europe’s work on the legal and ethical issues in relation to people with dementia and dementia care.

Throughout the two days, the delegates had a wide range of parallel sessions from which to choose. There were sessions on risk factors, prevention, preclinical dementia, diagnosis, drug development, future treatment strategies, pharmacological treatment, disease management and legal and ethical issues.

In the parallel sessions, three workshops were held with people with dementia and their carers. These workshops covered the needs of family members, the stress of carers, the relationship between GPs and patients and their carers. Ms Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, was quoted as saying: “dementia is often an extremely difficult disease to live with and it can be overwhelming”. However, the impact of this disease can be reduced if the needs of the people with dementia and their carers are met. The focus has to be the people with dementia and their carers, as they are the ones who are facing dementia together at a very personal level.

In the afternoon, a course on the neuropsychological evaluation of the elderly took place and 25 psychologists learned about early diagnosis.

In the last day of the conference, Professor Constantin Bogdan spoke about “Abuse of People with Alzheimer’s Dementia: Ethical and Legal Protection”, then Professor Florin Tudose presented “The Liaison – Consultation Psychiatry and Alzheimer’s Disease”. A lot of information was provided by Professor Sorin Paveliu through his “Pilot Study Concerning the Economic and Social Cost of Dementia in Romania”. Other financial aspects were presented by Ilan Gonen (TGD Chief Executive Officer).

At the end of the conference, the Romanian Alzheimer Society Vice President, Letitia Dobranici, explained the Medical comorbidity of Alzheimer’s disease. The neuroimaging course for specialists was held into a parallel session.

This Alzheimer conference raised a lot of interest among the Romanian policy makers and benefitted from huge media coverage. Building on the conference presentations and discussions and following the advice of Razvan Chivu (Councellor for the Health Minister), the Romanian Alzheimer Society issued a Manifesto. This Manifesto calls upon the Romanian Government to recognise dementia as a social and public health priority and to propose a National Plan for Dementia.

In Romania, there is a huge need to develop a national strategy on dementia and to include, in a coherent way, the main measures that will ensure decent medical and social assistance for people with dementia and their families, at least with the minimum resources available.

The conference was highly appreciated by attendants with many of them declaring that they found the programme highly interesting and thought-provoking, with interesting and comprehensive presentations, stimulating workshops, attractive and useful courses.

Indeed, some delegates found they were spoilt to be in the situation to choose between parallel sessions as they said they would have liked to have been able to attend all of them!
POLICY DEVELOPMENTS

Here we report on recent developments at the European and national level which may impact people with dementia and/or their carers.

National plans

Wales: The document “Dementia Vision for Wales” outlines a roadmap to transform the care of thousands of people with dementia and carers in Wales and was launched in February 2011. GBP 1.5 million annually has been allocated to the training of the dementia care workforce and to the creation of patient information packs and new roles in dementia within local health boards. The document was launched by the Welsh Assembly Government in partnership with Alzheimer’s Society.

France: On the occasion of the 3rd anniversary of the French Alzheimer Plan, a roundtable was organised in Bordeaux (France) on 22 February 2011 and presided over by French President, Nicolas Sarkozy.

On the research priority of the Plan, Valérie Pécresse (Minister for Higher Education and Research) reported that under the Plan, in 2010 twenty international publications reported advances in animal experimentation. Two genes showing a predictability to develop the disease were discovered in 2009 and another two in 2010. The French Alzheimer research team (set up within the framework of the plan) has recruited 96 new researchers, 509 practitioners have been trained in clinical epidemiology and 104 fundamental research projects in therapeutics and human and social sciences have been launched. An international consortium gathering all existing projects on genotype has been set up and France is leading the Joint Programming of Neurodegenerative Diseases (JPND) research.

Nora Bera, Secretary of State, Work, Employment and Health Ministry, presented the progress made in the priority dealing with the improvement of the quality of life of the person with dementia and said that early diagnosis has been improved through the new 65 memory clinics that have been set up since the beginning of the Plan and will be reinforced with 507 new diagnostic centres. The reduction in the use of anti-psychotic drugs as a priority of the Plan has borne fruit: in 2007, 16.9% of people with dementia received an anti-psychotic whereas in 2009, 15.7% of them did.

Roselyne Bachelot, Minister for Solidarities and Social Cohesion, presented the medico-social solutions offered by the Plan. On respite care, the Plan’s website now offers a database of the respite care available across the French territory. The number of respite care facilities has not increased as planned. In 2011, a mapping of how the respite care facilities are used will be carried to support further action in this domain.

The professionals who were invited to express their views recognised the Plan had yielded tangible and important results, more so in the field of research. Some professionals regretted that implementation on the ground was not optimal in that coordination between all different actors was not always obvious.

Switzerland: In Switzerland, two motions on the need for a dementia plan were unanimously accepted by the Conseil National. The next stage is for the second chamber (Conseil des États) to
vote on the motions. Should they be accepted, the government will have to develop a national Alzheimer’s plan. The Swiss Alzheimer Association has played a pivotal role in these developments, most notably by generating over 34,000 signatures to their dementia manifesto and by contacting members of Parliament directly.

**Care and treatment of people with dementia**

**Report published:** The report “Dementia: Decisions for Dignity” has been published by the Mental Welfare Commission for Scotland. The Mental Welfare Commission also had concerns which were listed as key messages in the report. These included the fact that: (a) some admissions to hospital could have been avoided if more flexible and responsive care services for people with dementia had been available, (b) general hospital staff did not always obtain and record information about people with dementia or involve close ones in their care, (c) legal safeguards for people who lack capacity to consent medical treatment are not being applied, (d) general hospital staff should be made more aware of human rights and incapacity legislation, (e) more could be done to make environments dementia friendly, (f) a return home should be the starting point when discharging a person with dementia from hospital rather than to a care home.

**New guidelines published:** In April the German healthcare cost-effective agency, IQWIG, updated its guideline on cost-effectiveness of the drug memantine (which is used to treat the symptoms of Alzheimer’s disease), saying that it does provide a benefit. This contrasts with its earlier recommendation in 2009, when the agency recommended that memantine should no longer be reimbursed by health insurers. This change was as a result of the manufacturer, Merz, providing additional data. A similar decision was made in Britain earlier this year by the agency National Institute for Health and Clinical Excellence (NICE), which also updated its 2007 guidelines to allow certain drugs (Ariment, Exelon and Reminyl) for people in the early and moderate stages of Alzheimer’s disease: Ebixa to be made available for people in the late stages of the disease) to be available on prescription by June.

**Research**

**European-wide neurodegenerative research mapping:** A web-based survey was launched in February to map the current research and resources supporting research into neurodegeneration across 23 Member States. This survey is part of the three-year JUMPAHEAD project, which is a coordination action in support of the implementation of the new collaborative approach to European health research (JPND): the Joint programming of neurodegenerative diseases research. The project is funded by the Seventh Framework Programme.

**European Commission allocates EUR 6 million to clinical trials for Alzheimer’s disease:** Within the context of the Seventh Framework Programme (FP7), in May, the European Commission awarded EUR 6 million to an international research consortium known as NILVAD. The aim of the consortium is to develop a new Alzheimer’s disease treatment. NILVAD is comprised of 18 European universities, hospitals and pharmaceutical companies and includes Alzheimer Europe. It is led by Trinity College, Dublin, Ireland. It will conduct clinical trials of NILVADIPINE to determine whether it can improve memory and slow the rate of progression of Alzheimer’s disease. It is currently used to treat high blood pressure and has been shown to decrease the risk of developing dementia. The study will be conducted on around 500 people over an 18 month period.
Restoring the Tradition of European Medical Innovation

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

Innovation takes many forms: from the ground-breaking treatments and cures that emerge from our laboratories, to new solutions for today’s and tomorrow’s major health challenges. An ageing population, access to the best treatments and the availability of credible health information are issues of concern for both policy makers and society as a whole.

We believe that partnerships between governments, public institutions and the research-based pharmaceutical industry are essential to meet public demand for medical excellence, while revitalizing Europe’s spirit of innovation and competitive position in the global marketplace.

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Pilot art programme for people with dementia launched in Portugal

Annie Girardot died with Alzheimer’s disease

Film launched about the life of Pasqual Maragall

Members’ News
A snapshot of the recent activities carried out by some of Alzheimer Europe’s member organisations.

Living with dementia
Alzheimer Uniti, Italy, tells the story of Paola who was diagnosed with Alzheimer’s disease three years ago.

Dementia in Society
A look at how dementia is portrayed in the general media.

Science News
Highlights from recent scientific developments in the areas of prevention, diagnosis and treatment of dementia.
MEMBERS’ NEWS

Below are some of the activities carried out recently by national Alzheimer associations

**Belgium: “Dementia Friendly Cities’ Charter” drafted**

In March, the Belgian French-speaking Alzheimer association, La Ligue Alzheimer and its partners, wrote the final version of the “Dementia Friendly Cities Charter”. Set up on the basis of the World Health Organisation’s (WHO’s) Age-friendly cities, the initiative’s objective is to encourage the integration of people with dementia within the city. Each activity must contribute to the improvement of the quality of life of people with dementia and their carers and this objective is stated on the March 2011 Charter.

**Bulgaria: Socioeconomic rights of people with dementia and their carers discussed**

In Bulgaria a round table meeting on the socioeconomic rights of people with dementia and their carers was organised by Alzheimer Bulgaria, with the support of Compassion Alzheimer Foundation on 15 April 2011. The meeting was organised within the framework of an advocacy campaign on socioeconomic rights and Alzheimer’s disease called “There is no time to lose”. Dr Antonia Parvanova, MEP (Bulgaria) and member of the European Alzheimer’s Alliance, supported the event.

**Germany: German Alzheimer Association publishes manual and DVD to help teach children about dementia and also information about stress and carers of people with dementia**

The German Association has released “Dementia – a practical manual for teaching”. It is aimed to help school teachers (of children and adolescents) introduce and discuss dementia during school activities. Also, in April, the German Alzheimer Society published information on the issue of stress and carers of people with dementia. It highlights that stress is both a major concern and a constant companion for carers of people with dementia whether at home or in a residential care setting.

**Finland: Alzheimer Society of Finland launches a book about memory and early-onset dementia**

This year the main focus of Muistiliitto, the Alzheimer Society of Finland, is people of working age. To celebrate this, in March, the Society brought out a 400-page book about the memory of the working population and early-onset dementia entitled “Työi- käsien muisti ja muistisairaudet” (“The memory and memory related diseases of working-aged people”).

**Greece: In-house theatre programme for people with dementia launched**

The Greek Association of Alzheimer’s Disease, within its efforts to improve people with dementia and their caregivers’ quality of life, is collaborating with the National Theatre of Northern Greece (NTNG), offering “in-house” theatrical performances. The first patient – an 80-year-old woman – had the chance to make a trip down memory lane, back to her childhood through the mini theatrical performance that was held in her home.
Italy: Alzheimer Uniti launches GPS project to help people with dementia

In May, Alzheimer Uniti launched the “Progetto Diogene” (The Diogenes Project) which is providing global positioning system (GPS) devices to people with dementia who are at risk, on an experimental basis. The device, in the form of a wristwatch or a pendant worn around the neck, continuously monitors the whereabouts of a person each time that they wander out of their usual established perimeter. The trial is in its first 3-month phase and involves twenty people with dementia. With the exception of two people, who are in nursing homes, all are living at home.

Portugal: Alzheimer Portugal raises awareness of dementia via Facebook and promotes music, art therapy and volunteering

During March and April Alzheimer Portugal was busy raising awareness and helping people with dementia by promoting: (a) The use of Facebook: Alzheimer Portugal’s Facebook page now has 5,000 followers. Alzheimer Portugal set up a cause on the Facebook page entitled ”Alzheimer Portugal – No memory of a cause like that” to which 44,000 people have joined, (b) Music therapy: music therapy intervention sessions were carried out which aim to increase communication, socialisation, cognitive and physical functioning and reduce the anxiety and agitation, to improve the quality of life with people with dementia and (c) Art Therapy: The Northern Delegation of the Alzheimer Portugal Association promoted Art Therapy sessions under the theme of “Shape Memory” which had the aim of stimulating the person with Alzheimer’s disease and also to promote contact between carers and families. Alzheimer Portugal, together with the Calouste Gulbenkian Foundation, also developed a pilot project of art for people with dementia. The ultimate goal is to make art accessible to people with Alzheimer’s disease, providing them moments of cognitive stimulation and well-being.

Romania: Romanian Alzheimer Society campaigns to secure support from policy makers for a National Dementia Plan

In June, the Romanian Alzheimer Society, Societatea Română Alzheimer, campaigned to get support to develop a national dementia by contacting various policy makers including the President, Prime Minister, the Minister for Health, the Minister for Labour, Family and Social Protection, the Minister of Education, Research, Youth and Sports as well as the Agency for the Protection of People with Disabilities and the Mental Health Centre. The society also contacted several Romanian MEPs to encourage them to support the European Alzheimer’s Alliance (EAA).

UK: Organisations combine to raise awareness of dementia and low diagnosis rates

The Alzheimer’s Society, Alzheimer Scotland and supermarket Tesco have combined forces to raise GBP 5 million to help people with dementia and to help raise diagnosis levels by 2014. Following a study on the prevalence and diagnosis of dementia a dementia map has been launched which reveals diagnosis rates vary hugely around the UK and predicts that over a million people will have dementia by 2021. The Tesco Charity of the Year partnership aims to help fund new research, provision of professionals to help people with dementia and a dementia community road show that will travel around the UK to raise awareness of the disease and also to encourage people who are worried about their memory to go to their GP.
In each issue of the magazine a person with dementia and/or their carer shares their experience of living with dementia. In this article Alzheimer Uniti tells Paola’s story.

The Story of Paola

This is the story of Paola. Three years ago, at the age of 63, she was diagnosed with Alzheimer’s disease. She found her way, alone, to Alzheimer Uniti Italy’s offices in Rome to ask for help.

“They say that I have Alzheimer’s Disease and I don’t know what to do. My husband does not even know that I am here in your offices today. I read about your organization in a magazine. Can you help me?”

Because of the unusual way that Paola came in, the Association contacted her daughter (who also did not know about her mother’s diagnosis). Together, they arranged for Paola to attend the Day Center. Paola has been attending the Day Center now for 3 years.

“I love coming to the Centre. It cheers me up. I tell everyone that I am coming to school. I try not to miss even a day. The bus picks me up in the morning and drops me home at the end of the day. I even enjoy the bus ride and like to help my fellow passengers on and off the bus, reminding them of their stops.”

The Day Centre provides physical, occupational and cognitive therapy through different activities such as art projects and music sessions.

“I enjoy all the activities. We do art projects and dancing sessions. One of my favorites is music since I particularly love to sing – especially pop Italian songs from the San Remo Festival.”

“We have had three months of violin lessons too. I really loved those lessons – holding the violin, learning to hold a bow and playing along with the music teacher. I tried to remember the names of the parts of the violin and would write them down on little pieces of paper, put them in my pocket, and look at them again and again, to try to memorise the names. I never thought that with this disease I would ever be able to learn something new again!”

“Recently I had to have a small surgical procedure but I made sure that I could return to the Centre as soon as possible. I did not want to miss even a day.”

Paola has become a leader in the group. She is protective of other patients who are in a more advanced stage of the disease. She helps them in physical activities and also speaks on their behalf when they have trouble finding the right words or expressions.

“I have written three letters to the doctors, therapists and staff of the Day Centre, expressing my appreciation. I have written the letters myself, on the computer.”

Paola’s husband is her main caregiver but has some trouble accepting his wife’s condition.

“My husband is very kind and he showers me with gifts, especially clothes and perfume. He likes me to look elegant and fine. I get my hair done regularly at the hairdresser and like to wear cheerful and bright colours. Dressing nicely and looking good cheers me up! My husband does not come to
the Day Centre and he does not want me to be photographed. I feel sad about that because I would like to be photographed and video-taped when we do special projects that I am proud of. They even call me “super Paola”. But my husband is a good man and I respect his wishes. He is a good husband.”

Paola’s daughter is now quite involved with the Alzheimer Association and Day Centre, regularly attending the support sessions for family members. It was Paola herself who brought in the membership money and signed her daughter up as a member of the Association. Her daughter had originally been upset with the way that her mother was informed that she had Alzheimer’s disease.

“It was a cruel way to tell someone that they have Alzheimer disease. He told my mother that she had the disease and then just sent her on her way, with that diagnosis. The doctor did not even offer her any suggestions of treatment or support. Thank goodness that she found this Day Centre!”

Paola talks readily about the disease.

“I think that we should spread the word about Alzheimer’s disease since people should know about it. They think that something is wrong with us, that we are fools, but they do not understand that this is a disease, like other diseases.”

“I like to go to events such as the annual World Alzheimer Day Convention in Rome to give my support by my presence there. I have been to each convention for the last three years. But I do not like to speak in public. I go with my sister or with my daughter.”

“I read the newspapers, looking for articles about the Disease. There was one recently in the newspaper La Repubblica which was great. They need to raise awareness but I also hope that they find a cure. And I hope that they will let me know as soon as they do!”

When asked about life at home, she says,

“I no longer cook nor tidy up the house like I used to. And I am no longer comfortable taking my grandchildren to school since I am worried that I might get lost. I find that I prefer to stay home more and more. It’s sad but I feel that I can’t lose heart and that I must simply carry on as best as I can.”

Alzheimer Uniti Onlus

Alzheimer Uniti Onlus consists of 22 associated organisations throughout Italy. The Association provides the following services:
- Regular support meetings
- Training of caregivers
- Free legal assistance
- Call centre
- Quarterly newsletter
- Courses for doctors, nurses, therapists, pharmacists, graduate students. Café Alzheimer.

In addition, Alzheimer Uniti participates in congresses, meetings, radio & TV programs, film work. The organization also participates in numerous innovative projects to help people with the disease.
Dementia in Society

In this section we report on how dementia is portrayed by the general media (for example, on television and in films).

7 February 2011: Film launched about Alzheimer’s disease “Bicicleta, cullera, poma”

The film entitled “Bicicleta, cullera, poma” was shown on 7 February 2011 during the 18th cinema festival of the Catalan-Luxembourgish Centre of Luxembourg. The film focuses on the life of Pasqual Maragall (who was Mayor of Barcelona from 1982 to 1997 and President of the Catalan government from 2003 to 2006) starting shortly after his diagnosis in 2007 up to the present day. His family explain how their lives have been affected by Alzheimer’s disease and his doctors are also interviewed.

The film is full of humanity, sincerity and humour as well as sadness. (Bicicleta, cullera, poma)

The film is a moving account of Maragall’s personal experience. It is full of humanity, sincerity and humour as well as sadness. It addresses important issues such as research into a cure and prevention, autonomy and the right of the person with dementia to personal freedom. Whilst the main language spoken was Catalan, parts of the documentary were filmed in India, the United States and the Netherlands (with English subtitles throughout). This highlights the fact that Alzheimer’s disease affects people all over the world and shows how people from very different cultural and social backgrounds experience Alzheimer’s disease and try to deal with it from medical, scientific and personal perspectives.

The film was directed by Carles Bosch, lasts 106 minutes and the main language is Catalan with subtitles in English.

11 February 2011: Play opens about dementia

“Dementia Diaries” is a play which explores “the troubled relationships within a family struggling to cope with dementia”. It is presented through the monologues of an Anglo-Polish family and their Polish carer. Maria Jastrzebska, the writer, explains “I wrote the monologues for the five characters in Dementia Diaries to represent the way family members can sometimes speak without listening to each other. I also wanted to explore responses to and preconceptions about dementia and its impact on families and to look at Polish immigrants of different generations – those established here and those recently arriving.”

Dementia Diaries opened in the Nuffield theatre, Southampton and during 2011 will tour the UK, starting in London.

28 February 2011: French actress Annie Girardot dies with Alzheimer’s disease

French actress Annie Girardot died on 28 February 2011, at the age of 79. She had been suffering from Alzheimer’s disease for 10 years. Her daughter, Giulia Salvatori, had made the disease public in 2006 to stop degrading rumours about her mother.

Two books have been published about Annie Girardot and her disease: in 2007, Giulia Salvatori published “La mémoire de ma mère” (My mother’s memory) and in 2009, Léo Brandon, Ms Girardot’s personal secretary published “Annie, te souviens-tu...” (Annie, do you remember...).
In September 2008, French TV TF1 broadcast a documentary on Annie Girardot – Annie Girardot, ainsi va la vie (Annie Girardot, as life goes by...). In this documentary that followed the actress during 8 months, Annie Girardot spoke about her past and the impact the disease had on her life.

**30 March 2011: Asian DVD on dementia launched**

Meri Yaadain (my memories) is an educational DVD which has been launched in Punjabi, Hindi and Urdu (with English subtitles). It shares the life stories of carers of people with dementia and their loved ones. The Meri Yaadain Dementia Project was “set up three years ago to look at the growing needs of South Asian older people suffering from dementia. The project works with older people and their carers through a variety of means which include home visits, a newsletter, a monthly support group, leaflets, radio programmes and workshops.”

For more information please contact the Meri Yaadain Dementia Team, Communications, Bradford Council, 5th Floor, Olicana House, Chapel Street, Little Germany, Bradford, BDI 5RE, UK or e-mail: akhlak.rauf@bradford.gov.uk

**8 May 2011: Günter Sachs death raises questions about the stigma which surrounds dementia**

It has been suggested that former German businessman Günter Sachs took his life on 7 May 2011 due to the fear of Alzheimer’s disease. The German Alzheimer Association has issued a press release in response to this. It states: “Germany is home to some 1.2 million people with dementia, of which about two-thirds have Alzheimer's disease. Most of them are cared for devotedly by family members, living for a long time in the home environment. Even with dementia, a life worth living is possible. This is reported by, amongst others, the participants who share experiences for groups for people with dementia in an early phase of the disease. “The group is full of potential,” said one participant. Although some capabilities will be lost, often enough abilities remain resources to enjoy being active. This was the conclusion of nearly all of the forty people present.

“Of course, the diagnosis of Alzheimer's disease at first a shock and the progressive loss of control over one's life causes deep anxiety,” said Heike von Lützau-Hohlbein the chairperson of the national Alzheimer's Association. “The death of Günter Sachs also shows us that we need to do much to break the taboo of this disease and to give support.”

Günter Sachs was a German documentary filmmaker, photographer author and industrialist.
Diagnosis of dementia

Pathological changes may occur 20 years before symptoms of certain types of dementia appear: The first findings of the Dominantly Inherited Alzheimer Network (DIAN) study have found that the pathologic changes of Alzheimer’s disease may begin as early as 20 years before the expected onset of the disease, at least in people whose families carry a high-risk gene. DIAN is an ‘an international research partnership of leading scientists determined to understand a rare form of Alzheimer’s disease that is caused by a gene mutation’ (March 2011).

Gene variants identified as possible risk factors for Alzheimer’s disease: Previous studies had identified the gene variants APOE-e4, CR1, CLU and PICALM as possible risk factors for late-on-set Alzheimer’s disease but two new studies have identified additional gene variants. The studies were part of the genome-wide association study (GWAS) in which DNA samples were studied from more than 56,000 study participants. The first study identified a fifth gene variant, BIN1 and also EPHA1, MS4A, CD2AP and CD33. A second team identified an additional gene known as ABCA7 which may be a risk factor. The first study was coordinated by the Alzheimer’s Disease Genetics Consortium (ADGC). The second team was led by Julie Williams, Cardiff University School of Medicine, Wales and included investigators from the USA and Europe (Belgium, Finland, France, Germany, Greece, Iceland, Ireland, Italy, the Netherlands, Norway, Poland, Spain and the UK) (April 2011).

Potential biomarkers for Alzheimer’s disease identified: A pilot study has shown that an immune gene which clears amyloid beta (which is associated with Alzheimer’s disease), is expressed differently in different people with Alzheimer’s disease. The gene identified is known as mannosyl (beta 1,4) glycoprotein beta 1,4,N acetylglucosaminyltransferase (MGAT3). The study was reported in the Journal of Alzheimer’s disease and carried out by researchers from the University of California, Los Angeles (UCLA), USA (March 2011).

In another study, researchers who monitored specific areas of the brain (the cortical regions) known to be affected in Alzheimer’s disease have concluded that “subtle but reliable atrophy is identifiable in asymptomatic individuals nearly a decade before dementia.” The research was conducted by BC Dickerson and colleagues from the General Hospital and Harvard Medical School, Rush University Medical Center, Brigham and Women’s Hospital and the John Hopkins University School of Medicine, USA. It was published in the journal Neurology (April 2011).

New criteria and guidelines for the diagnosis of Alzheimer’s disease published: The National Institute on Aging/Alzheimer’s Association Diagnostic Guidelines for Alzheimer’s disease have been published online by Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association. They include an update of the 1984 diagnostic criteria, a refinement to guidelines for diagnosing mild cognitive impairment, an expansion of the conceptual framework for thinking about Alzheimer’s disease to include a “preclinical stage” and the establish-
ment of a framework for adding biomarker benchmarks to the diagnosis of Alzheimer’s disease (April 2011).

Prevention and risk factors

International consortium launched to discover and map Alzheimer’s disease genes: The International Genomics of Alzheimer’s Project (IGAP) has been launched which will create a shared resource data base including genetic data for more than 40,000 individuals. The formation of IGAP is supported by the French Alzheimer’s Association and the Fondation Plan Alzheimer (February 2011).

Study examines relationship between ADHD and dementia: A study found “a higher risk of Lewy Body Dementia in patients with preceding adult attention-deficit and hyperactivity disorder (ADHD) symptoms.” No clear explanation for this association was found. Researchers from Argentina, led by Dr Golimstock, Neurology Department, Hospital Italiano Buenos Aires, Argentina, carried out the study which was published in the European Journal of Neurology (February 2011).

Mouse study examines the effect of vehicle pollution on the brain: A mouse study found that short term exposure to toxins resulting from a mix of tiny particles from the burning of fossil fuel and weathering car parts and pavement may cause changes in the brain associated with premature ageing and Alzheimer’s disease. The study was reported on the Medical News Today website (April 2011).

Study examines the role of stress hormone in memory impairment: A mouse study has found that high levels of the stress hormone cortisol in aged mice resulted in their being less able to remember how to navigate a maze. The study was carried out by researchers at the University of Edinburgh and published in the Journal of Neuroscience (April 2011).

Treatment of dementia

Worm study examines role of dye in ageing process: A study suggests that a dye [basic yellow 1 or Thioflavin T (ThT)] used to detect damaged protein in Alzheimer’s disease may, in small doses, extend the lifespan of healthy nematode worms and slow the progression of Alzheimer’s disease in genetically modified worms. The study was led by Gordon Lithgow with researchers from the Buck Institute for Research on Aging, Novato, California, USA and published in the journal Nature (March 2011).

Animal study examines light treatment and Alzheimer’s disease: A flexible patch has been developed which works by emitting light through the skin, resulting in nitric oxide being produced may potentially be used to treat Alzheimer’s disease (by helping to address reduced cerebral blood flow in the brain) in a non-invasive way. The patch has been developed by Clairmedix Inc and was presented during the International Conference of the Alzheimer’s disease/Parkinson’s disease Conference in Barcelona (March 2011).

Study examines the effect of lithium treatment on people with mild cognitive impairment: Researchers explored the effect of long-term lithium treatment (in terms of cognitive and biological outcomes) on people with amnestic mild cognitive impairment (aMCI). Their findings suggest that “lithium has disease-modifying properties with potential clinical implications in the prevention of Alzheimer’s disease”. The research was led by Dr Orestes Forlenza, Faculty of Medicine, University of São Paulo, Brazil and published in the British Journal of Psychiatry (April 2011).
ALZHEIMER EUROPE PUBLICATIONS

Dementia in Europe Yearbooks [Cost: EUR 10 (plus EUR 8 handling and postage)]

Our Yearbooks present the findings from various Alzheimer Europe projects, each year focusing on different issues linked to dementia. The Yearbook for:

- 2010 focuses on the topic of proxy decision making and various forms of legal capacity.

- 2009 is dedicated to a comparison of national laws in Europe with regard to healthcare decision making by people with dementia.

- 2008 contains the outcome from four of the workgroups on the European Collaboration on Dementia (EuroCoDe) project.

- 2007 highlights the findings of a survey on social support systems amongst Alzheimer Europe’s member organisations.

- 2006 provides a European overview of the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the provision of home care.

The annual accounts are contained at the back of each Yearbook.

Alzheimer Europe Reports [Cost: EUR 5 (plus EUR 4.20 handling and postage)]

The Alzheimer Europe Reports focus on specific aspects of dementia. Topics covered include end-of-life care, advance directives, the state of dementia care in Europe, ethical issues and assistive technology.

Each Alzheimer Europe Report focuses on specific aspects of dementia.

- “The ethical issues linked to the use of assistive technology (AT) in dementia care” (2010): This publication examines the ethical issues linked to the use of AT for/by people with dementia. It highlights various ethical issues linked to the use of AT and addresses not only possible disadvantages but also looks at the positive implications of the use of AT and how it can contribute towards respecting certain ethical principles with regard to people with dementia.

- “End-of-life care for people with dementia” (2008): This practical guide is for all those involved in this delicate and demanding stage of dementia and is available in English and German.

- “The use of advance directives by people with dementia” (2006): This includes Alzheimer Europe’s position on advance directives as well as giving background information (legal, ethical, medical, personal and practical issues) in the case of dementia.

- Alzheimer Europe Survey “Who cares? The state of dementia care in Europe” (2006): This presents the results of a survey carried out by Alzheimer Europe which revealed a shocking picture of the level of commitment by carers, a significant lack of information for carers at the time of diagnosis, a lack of basic support services as well as the need of carers to contribute financially to existing services.
Care Manual [Cost: Please see website for details of costs, supplier and language versions.]

Written for carers, the Care Manual provides general information on Alzheimer’s disease, as well as specific information on symptoms and how to cope. It is published in several languages.

Children’s book [Cost: Please see website for details of costs, supplier and language versions.]

Written as a story through the eyes of a child, this book aims to help children gain awareness of Alzheimer’s disease and is available in several language versions.

Dementia in Europe Magazine

The Dementia in Europe Magazine is dedicated to covering dementia policy. Developments at both the European and national level are reported on as well as interviews with key policy makers.

• Issue 7 (March 2011): Highlights of this issue are reports on Alzheimer Europe’s 20th Annual conference in Luxembourg, the Belgian EU Presidency Conference dedicated to dementia as well as updates on the progress of national dementia strategies in Denmark, England, Finland and Portugal.

• Issue 6 (October 2010): This issue includes interviews with the EU Commissioner John Dalli and Astrid Lulling, MEP (Luxembourg) as well as information on the national dementia strategies in France, Germany and Scotland. Issue 6 also has a supplement dedicated to Alzheimer Europe’s 20th anniversary.

• Issue 5 (April 2010): Professor Philippe Amouyel gives an in-depth interview about the Joint Programming Initiative on Neurodegenerative diseases and updates are given the status of national dementia plans in Malta, Cyprus and Portugal.

• Issue 4 (December 2009): Highlights include the European Parliamentary lunch debate on European action on dementia, the 19th Annual Alzheimer Europe Conference in Belgium, the Dutch national dementia plan.

• Issue 3 (May 2009): This issue carries interviews the European Health Commissioner, Androulla Vassiliou, the Czech Health Minister, Daniela Filipová and MEP for Greece, Maria Eleni Koppa. There is also a special section dedicated to the achievements of the 2004-2009 European Parliament in regard to helping people with dementia and their carers.

• Issue 2 (December 2008): The French Presidency Conference on Alzheimer’s disease is covered, as is the EuroCoDe project and the European Ethics network.

• Issue 1 (June 2008): out of print – can be downloaded from our website.

Details of our publications and how to order them are available on our website (www.alzheimer-europe.org)
21st Alzheimer Europe Conference
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Mark the dates!

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