Editorial

February was a busy month in Luxembourg and it appears that this pace will continue during the whole year. We are working on the 2014 Conference and also our annual publications. We have also attended various meetings — and have received an astonishing number of proposals to participate in new IMI and Horizon 2020 projects.

Our first event of the year was a lunch debate hosted by MEP Françoise Grossetête. The debate focused on the current and future activities of IMI, presented by Executive Director Michel Goldman. This was followed by two meetings that covered corporate and public affairs; we are very grateful for the high turnout and are pleased that so many of our partners and member associations are willing to participate in AE’s 2014 projects.

The next lunch debate will take place in the new European Parliament in December 2014. In the meantime, we invite our readers to encourage their candidate MEPs to sign our European Dementia Pledge.

In EU news, the Parliament has approved the new EU Health Plan and a group of MEPs launched a new Written Declaration for the rights of people with disabilities. Meanwhile, the Council of Europe continues its quest to guarantee the rights and freedoms of older people.

In the science world, IMI has named new experts to head its Scientific Committee and AstraZeneca and Merck both announced Phase 3 trials of their respective BACE inhibitors.

February also saw the launch of issue 16 of the Dementia in Europe magazine: EC President José Manuel Barroso discusses the EU’s role in helping people with dementia and a remarkable group of MEPs speak out on how they are making dementia a priority in their work. There is also an evaluation of the third French Alzheimer Plan and an insider’s view of the forthcoming national dementia strategy in Portugal. We look back at World Alzheimer’s Day and our conference in Malta — including the hugely popular sessions organised by the European Working Group of People with Dementia. We have already booked a larger room for the Group in Glasgow.

We have also opened the call for abstracts for the 2014 Conference and this will remain open until the end of April. The Programme Committee is in place and looks forward to receiving numerous proposals that will reflect this year’s theme of dignity and autonomy in dementia.

Jean Georges
Executive Director
Alzheimer Europe

30 January: Heike von Lützau-Hohlbein presents the views of people with dementia and their carers

On 30 January, Heike von Lützau-Hohlbein, Chair of Alzheimer Europe, was a speaker at a debate entitled “Impact of Aging on Mental Health and Well-being” in Barcelona. Her presentation focused on the view of people with dementia and their carers:

Respect for autonomy and dignity: People with dementia must be able to exercise their right to self-determination. Advance statements and directives can effectively preserve the autonomy of people with dementia and also reflect their human dignity.

Healthcare and decision making: Informed consent must be obtained for every decision, not once and for all. People with dementia must be able to appoint a healthcare proxy in advance of incapacity and must also have the right to be informed of diagnosis.

Guardianship and legal capacity: Guardianship measures should be proportionate to needs and legal capacity should not be unnecessarily restricted. People with dementia should be involved and kept informed when decisions are being made on their behalf.

Social support: Support for people with dementia and carers is often unavailable or inappropriate. There is a lack of trained professional carers and service providers, along with an often inflexible approach to service provision. These are all barriers that prevent people from accessing the services and support they need.

End-of-life care: The dignity of people with dementia must always be respected. If needed, palliative care should be provided before the situation becomes unmanageable. Legislation covering access to palliative care should take into account the nature of dementia and the progression of the disease.

Ms von Lützau-Hohlbein’s presentation was particularly well-received as she was able to share many personal insights; she was the main carer for her mother and her mother-in-law, who both lived with dementia.

This debate was co-organised by B.DEBATE, an initiative of Biocat with support from “la Caixa” Foundation, the Parc Sanitari Sant Joan de Déu and the Sant Joan de Déu Research Foundation.

4 February: Jean Georges attends meeting of EU governmental experts on dementia

On 4-5 February, Jean Georges, Executive Director of Alzheimer Europe, attended a meeting organised by the European Commission in Luxembourg which brought together government experts on dementia. The meeting was opened by John F. Ryan, the Commission’s Acting Director for “Public health” who presented the Commission rationale for the development of its European initiative on Alzheimer’s disease and other dementias which was adopted in 2009.

The meeting also served to evaluate the various activities undertaken as part of this European initiative and to discuss the implementation report which the Commission will have to address to the European Parliament and Council later in 2014.

An initial tour de table provided an opportunity for the invited government experts to present the latest developments in the development, implementation or evaluation of their national dementia strategies. Updates were provided by the representatives of the Czech Republic, Finland, France, Hungary, Latvia, Luxembourg, Malta, Norway, Portugal, Slovakia, Slovenia, Spain, Switzerland and the UK (England), while Greece and Italy provided written contributions.

Additional presentations on European initiatives were given by Armelle Leperre-Desplanques and Pierre Krolak-Salmon (ALCOVE), Jean Georges, Philippe Amouyel (JPND) and Eibhilin Manning (European Innovation Partnership on Active and Healthy Ageing).

17 February: Alzheimer Europe holds first 2014 Board meeting

Nine Board members attended the Alzheimer Europe Board meeting on 17-18 February in Brussels. Apart from financial and administrative matters, the agenda also covered AE’s activities following the G8 Dementia Summit and during the upcoming EU elections.

In addition, the Board members reviewed preparations for the 24th Alzheimer Europe Conference, which will take place in October 2014 in Glasgow. The conference will be preceded by an Annual General Meeting that will include elections for a new Board.

The next AE Board meeting will take place in July 2014 in Luxembourg.

18 February: AE holds a lunch debate on IMI - the Innovative Medicines Initiative

Michel Goldman, Executive Director of IMI, was the featured speaker at Alzheimer Europe’s lunch debate on 18 February in the European Parliament. Hosted by French MEP Françoise Grossetête, the debate focused on the current and future activities of IMI - the Innovative Medicines Initiative. Ms Grossetête, who is also the Chair of the European Alzheimer’s Alliance (EAA), welcomed the 60 participants and presented a short outline of IMI.

The IMI public-private initiative began in 2008 as a five year partnership between the EU and EFPIA, the European
research projects that aim to: leading to faster progress for all disease areas. To date, during the IMI years. He predicted that this will continue, that the level of collaboration increased remarkably productivity of all researchers. Mr Goldman explained that no single company, institution or government will be able to develop effective treatments, particularly for neurodegenerative diseases.

However, a collective approach can improve the productivity of all researchers. Mr Goldman explained that the level of collaboration increased remarkably during the IMI years. He predicted that this will continue, leading to faster progress for all disease areas. To date, IMI has invested EUR 167 million in four neurodegenerative research projects that aim to:

- Develop models to predict the efficacy of drug candidates in patients.
- Connect data on 40 million individuals to decipher links between genetic background, biological abnormalities and other factors.
- Identify subgroups of the disease, allowing tailored therapies according to the different variables involved.
- Implement innovative trial designs.

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

18 February: AE holds corporate meeting in Brussels

On 18 February, Alzheimer Europe (AE) also held a corporate sponsorship meeting that was attended by numerous delegates from the pharmaceutical industry and AE member associations.

AE Executive Director Jean Georges opened the meeting with a presentation on this year’s activities and opportunities for corporate collaboration with Alzheimer Europe. In particular, Mr Georges highlighted the following priorities for action in 2014:

- The 2014 Dementia in Europe Yearbook will feature a comparison of care pathways for people with dementia in 35 European countries.
- The Dementia Ethics Network will continue its work and deal with day-today ethical dilemmas faced by informal carers of people with dementia.
- The European Working Group of People with Dementia (EWGPWD) will continue to advise AE on dementia-friendly activities.
- AE will increase its participation in IMI and Horizon 2020 research projects.
- AE will continue to develop the European Dementia Observatory and will establish a Scientific Advisory Board.

Annette Dumas, Public Affairs Advisor for AE, followed Mr Georges with further details on AE’s European activities. These will focus on the elections and AE has already launched the “European Dementia Pledge” - a campaign to make MEP candidates aware of the challenges of dementia. Following the election, AE will re-launch the European Alzheimer’s Alliance (EAA) and will continue its campaign to make dementia a priority in the new Parliament. For instance, AE plans to present a call for the development of a European dementia strategy during a lunch debate with the new Members of the European Parliament in December 2014.

AE is also developing databases on clinical trials and national clinical guidelines. These projects will be carried out by Ana Diaz, Project Officer for AE. Ms Diaz explained that the clinical trial database will be dementia-friendly, i.e. specifically designed for clarity and ease of use. AE’s ultimate objective is to provide information about clinical trials directly to people with dementia and their carers. This will allow them to make more informed choices and thereby increase the effectiveness of future clinical trials.

The clinical guideline database will compile information on the diagnosis, treatment and management of dementia in Europe. The database will only contain guidelines that are supported by scientific evidence. This may include health care professionals as well as patient organisations and members of the public. The database will also include recommendations intended to optimise the care of people with dementia.

Mr Georges then led a lively discussion period and finally expressed his appreciation for the delegates’ active participation. He pointed out that Alzheimer Europe’s projects are founded on the principle of collaboration with its member associations and partners; their success may often be measured by the high degree of cooperation during such meetings.

www.alzheimer-europe.org/Donation

19 February: Alzheimer Europe holds public affairs meeting in Brussels

On 19 February, Alzheimer Europe (AE) held a public affairs meeting in Brussels. The meeting was attended by AE board members and staff members, 17 delegates from 16 member associations and two representatives of the ALCOVE Joint Action.

To kick off the meeting, AE staff members made presentations about communications (AE newsletter and Dementia in Europe magazine) and projects in 2014 (Continence care and Ethical dilemmas).
Annette Dumas, AE EU Public Affairs Advisor then spoke about the European Alzheimer’s Alliance (EAA) and the Dementia Pledge. This was followed by a lively discussion concerning the importance of promoting the EAA and the Dementia Pledge during the run up to the upcoming EU Elections. Jean Georges encouraged members to use Twitter to promote the pledge and the EAA and also to keep themselves and Alzheimer Europe informed of any developments, in particular regarding new Dementia Pledgees.

Jean Georges also presented new staff members and AE’s new offices in Luxembourg.

Presentations and open discussion sessions about various aspects of care pathways then began, facilitated by Ana Diaz, AE Project Officer, covering:

- Alzheimer Europe’s work on comparing national care pathways for people with dementia and background information about the national care pathways for people with dementia (Ana Diaz).
- Mapping care pathways in Denmark (Anne Arndal).
- Transitions in the care pathway in Sweden (Krister and Kristina Westerlund).
- Navigating the pathway: information and structures available to people with dementia and their carers in Portugal (Maria do Rosário Zincke dos Reis).

Some of the questions raised were:

- Whether care pathways are specifically addressed in national plans.
- Whether, if a national guideline exists, it is followed and whether it would be possible or desirable to implement legislation to make the guidelines compulsory.
- How members would prefer to approach giving information on their country’s pathways and national guidelines for the 2014 AE yearbook.
- Whether members could focus on the reality of the care pathway in their country when replying to the questions, and not just the theory or the ideal.

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

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe closed the meeting, thanking all for their attendance and stressing the importance of these meetings for better communication among members.

The next AE Public Affairs meeting will take place in July 2014 in Luxembourg.

28 February: Alzheimer Europe opens call for 2014 Conference abstracts

Alzheimer Europe and Alzheimer Scotland are pleased to announce that the call for abstracts for the 24th Alzheimer Europe Conference in Glasgow is now open. Abstracts for oral and poster presentations are welcome in the following categories:

- Care: Home care, Hospital care, Palliative care, Residential care.
- People: Dementia-friendly communities, Involving people with dementia, Peer support groups, Perceptions and image of dementia.
- Policy: Dementia strategies, Post-diagnostic support, Prevention, Socio-economic cost of dementia and financing of care.
- Rights: Consent and advance directives, Ethics, Proxy decision-making, Rights and responsibilities of people with dementia.

The call for abstracts will close on 30 April 2014. Additional information is available on the AE website.

www.alzheimer-europe.org/Conferences/2014-Glasgow/Call-for-abstracts

Impressions from the lunch debate

L-R: Françoise Grossetête, MEP (France) and host of the lunch debate with Annette Dumas (AE)  
Michel Goldman, Executive Director of IMI, presents the activities of the Innovative Medicines Initiative
Marina Yannakoudakis, MEP (UK) and Alison Cook (UK)
Impressions from the company round table

Lee Dunster (Roche) and Anne Rita Øksengård (Norway)
Krister and Kristina Westerlund (Sweden)
Štefanija Lukšič Zlobec (Slovenia), Helga Rohra (EWGPWD) and Sabine Henry (Belgium)

Impressions from the public affairs meeting

Ninoslav Mimica (Croatia) and Maria do Rosário Zincke dos Reis (Portugal) giving their presentations
Dianne Gove (AE), Veselka Yotkova (Bulgaria), Eila Oikonen (Finland) and Ana Diaz (AE) enjoying the discussions
Armelle Leperra-Desplanques and Pierre Krolak Salmon (ACCOWE) with Tina Leonard (Ireland)

AE Projects

1 February: DECIDE project inspires Horizon 2020 coordinators

The aim was to introduce the programme to local companies and thereby encourage their participation.

The event included “Success Stories” from Luxembourg-based organisations that had participated in FP7 projects - including Alzheimer Europe and its involvement in the DECIDE project.

DECIDE, or “Diagnostic Enhancement of Confidence by an International Distributed Environment”, brought together

LuxInnovation, Luxembourg’s national agency for innovation and research recently organised a launch event for Horizon 2020, the new EU research funding programme that replaces the Seventh Framework Programme (FP7).
13 partners from five European countries to develop and launch an e-service that allows the early diagnosis of Alzheimer’s and other neurodegenerative diseases. According to Dr Fulvio Galeazzi, Project Coordinator, DECIDE enables a physician at any remote hospital to analyse an MRI or a Positron Emission Tomography (PET) scan in a few minutes, whereas the same task on a single computer might take weeks or months.

Alzheimer Europe’s main role was to represent its member associations and to communicate the project outcomes back to its members and, through them, to people with dementia and their families all over Europe. The Alzheimer Europe/DECIDE Success Story is available on Luxembourg’s Horizon 2020 website.

www.horizon2020.lu/success-stories
www.eu-decide.eu

4 February: Ana Diaz attends meeting on improving assessment in early AD

On 4-5 February, Ana Diaz, Project Officer for Alzheimer Europe, attended the “Consensus panel: Improving assessment in early Alzheimer’s disease” in London. The meeting was co-chaired by the University of Stirling and QCTR, an independent clinical research company specialising in neurology and psychiatry.

The expert panel comprised clinicians; rating scale, regulatory and statistical experts; patient advocacy groups (Alzheimer Europe) and family carers. Expert consensus methodology was used to identify the most relevant domains that an outcome measure for early Alzheimer’s disease should assess.

The outcome measure is intended for use in clinical trials and should be of clinical relevance, measurable in mild AD but also meaningful to people with Alzheimer’s disease and their families. Results of the consensus meeting will be published in a peer reviewed scientific journal.

6 February: AETIONOMY officially announces project kick-off

On 6 February the AETIONOMY consortium formally announced its new project, which kicked off in January. It aims to take a new approach to disease classification, with a focus on neurodegenerative conditions, particularly Alzheimer’s and Parkinson’s diseases.

The new classification will be generated using data derived from a wide range of new biological approaches and will be based on the underlying causes of the diseases. Currently, Alzheimer’s and Parkinson’s diseases are classified by their symptoms and severity but the project leaders say it is clear that this “does not represent the many different causes of these diseases. It has been widely recognised that within these broad disease groups there are sub-groups where the different causes result in the symptoms of memory loss or movement disorder.”

The project will involve the collection of clinical data, imaging and genetic data and will create a new way to combine all of these together to look for patterns which could identify sub-groups of patients with similar causes of their disease.

The project is the result of Innovative Medicines Initiative (IMI)’s 8th Call for proposals and will run for the next five years.

www.aetionomy.eu/index.php?id=5306

19 February: Annette Dumas attends a European Parliament event

On 19 February 2014, Annette attended an event co-hosted by MEPs Marian Harkin and Linda McAvan in the European Parliament when The Economist Intelligence Unit presented “Out of office! – An overview of workplace absenteeism in Europe”. The event was organised in cooperation with the European Federation of Neurological Associations, Pain Alliance Europe and GAMIAN Europe.

20 February: Annette Dumas attends EP debate

On 20 February 2014 (Brussels), Annette attended a breakfast debate organised by MEP Angelika Werthmann in Brussels when Charles River Associates report “Access to medicines for multiple sclerosis: Challenges and opportunities” was presented. The report highlighted the inequalities in access to multiple sclerosis treatment in Europe, their policy implications and considered policy options to address them.

24-25 February: Dianne Gove attends PACE project meeting

Dianne Gove recently attended the kick-off meeting of the PACE project in Brussels. The aims of this project are to describe and compare the effectiveness of healthcare systems in six European countries with (BE, UK and NL) and without (PL, IT and FIN) formal palliative care structures for long-term care facilities in terms of patient and family outcomes, quality of palliative care and cost-effectiveness, and in terms of staff knowledge, practices and attitudes.

27 February: Dianne Gove attends ethics workshop

On 27 February, Dianne took part in the workshop organised by the Hannover Medical School/Centre for Ethics and Law in Life Sciences on “Whether and how to integrate ethical issues in clinical practice guidelines”. Serge Gauthier, Frank Jessen and Julian Hughes explained how their national guidelines on dementia in Canada, Germany and the UK had addressed ethical issues and Katherine Wright explained how the Nuffield Council of Bioethics had dealt with ethical issues in the development of the report “Dementia: ethical issues”. Marcel Mertz and Daniel Strech presented a six step approach for the systematic and transparent inclusion of ethical issues in clinical guidelines. The discussion focussed on identifying an appropriate methodology to ensure that ethical issues are addressed in such guidelines and on the role of ethicists, patient groups and patients in clinical guideline development.
Alzheimer Europe Networking 2014

On 29-30 January (Barcelona, Spain), Heike was a speaker at the “Impact of Aging on Mental Health and Well-being” conference.

On 4.5 February (London, UK), Ana attended the “Consensus panel: Improving assessment in early Alzheimer’s disease”.

On 4.5 February (Luxembourg, Luxembourg), Jean attended a meeting of government experts organised by the European Commission dedicated to an analysis of ongoing initiatives in the field of dementia.

On 11 February (Luxembourg, Luxembourg), Jean met with Charlotte Norvildt from Sandoz for an exchange of views.

On 17-18 February, AE Staff and the Board attended the Board meeting and AE lunch debate at the European Parliament on Innovative medicines initiative and Company round table meeting (Brussels, Belgium).

On 19 February (Brussels, Belgium), Annette attended an EPNA EP lunch debate featuring the Economist Intelligence Unit presentation “Out of office” - an overview of workplace absenteeism in Europe.

On 20 February (Brussels, Belgium), Annette attended the EP breakfast meeting “Paving the way to equitable access to treatment in Europe”.

On 24 and 25 February 2014 (Brussels, Belgium), Dianne took part in the kick-off meeting of the PACE project.

On 26 and 27 February (London, UK), Jean attended a meeting of the Patients’ and Consumers’ Working Party at the European Medicines Agency.

On 25 February (Hannover, Germany), Dianne took part in the workshop organised by the Hannover Medical School/Center for Ethics and Law in Life Sciences on "Whether and how to integrate ethical issues in clinical practice guidelines".

On 11 February (Luxembourg, Luxembourg), Jean met with Charlotte Norvildt from Sandoz for an exchange of views.

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 72, representing 23 Member States of the European Union and all seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their continued support of the European Alzheimer’s Alliance:

**Austria:** Becker K. Heinz (EPP), Werthmann Angelika (NI), Belgium: Demesmaeker Mark (Greens/EFA), Ries Frédérique (ALDE), Staes Bart (Greens/EFA), Tarabell Marc (S&D). Bulgaria: Parvanova Antonia (ALDE). Cyprus: Triantaphyllides Kyriacos (GUE/NGL). Czech Republic: Cabroch Milan (ECR), Kohlicek Jaromir (GUE/NGL), Roithova Zuzana (EPP). Denmark: Christensen Ole (S&D), Roade Jens (ALDE), Schaldemose Christel (S&D).

Finland: Saakonsaari Liisa (S&D), Jäätteenmäki Anneli (ALDE), Pietikäinen Sirpa (EPP), France: Audy Jean Pierre (EPP), De Veyrac Christine (EPP), Griesbeck Nathalie (ALDE), Grossetête Françoise (EPP), Juisin Philippe (EPP), Morin-Charister Elisabeth (EPP), Pargneaux Gilles (S&D).

Germany: Niebler Angelika (EPP), Roth-Behernt Dagmar (S&D), Ulmer Thomas (EPP), Greece: Chounits Nikolaos (GUE/NGL), Koppa Maria Elena (S&D), Kratsa-Tsagaropoulou Rodi (EPP). Ireland: Aylward Liam (ALDE), Childers Nessa (non-attached), Crowley Brian (ALDE), Higgins Jim (EPP), McGuinness Mairead (EPP), Mitchell Gay (EPP). Italy: De Martini Susy (ECR), Panzeri Pier Antonio (S&D), Patriciello Aldo (EPP), Tosa Patrizia (S&D).


Slovakia: Mikolask Mikolas (EPP), Zaborska Anna (EPP). Slovenia: Kleva Kekus Mojca (S&D), Preterle Alzog (EPP). Spain: Badia i Cutchet Maria (S&D), Estaraza Ferragut Rosa (EPP). United Kingdom: Anderson Martina (GUE-NGL), Ashworth Richard (ECR), Hall Fiona (ALDE), McAvan Linda (S&D), McCarthy Arlene (S&D), Moraes Claude (S&D), Simpson Brian (S&D), Taylor Keith (Greens/EFA), Vaughan Derek (S&D), Watson Graham (ALDE), Willmott Glenis (S&D), Yannakoudakis Marina (ECR).

Therefore, the EU should lead the improvements that are still to be made so as to fight inequalities in health sector - particularly when it comes to vulnerable population sectors - and to harness the full potential and possibilities offered by ICTs to enhance health and assistance systems and services.

Heinz K. Becker (Austria): As co-chair of the European Parliament’s “Interest Group on Carers”, I am focusing on the issue of dementia in order to strongly raise awareness, to strengthen all levels of prevention such as lifetime active ageing and to find new innovative solutions for keeping the elderly independent for as long as possible. Let me also refer to the “Ambient Assisted Living Joint Programme (AAL JP)”, which will be continued within the new framework of Horizon 2020, as one of the European co-financed transnational programmes.

Among other aspects it offers new devices and strategies to help people with Alzheimer’s disease to manage their daily life better and at the same time supports relatives or informal carers in their caring function.
Maria da Graça Carvalho (Portugal): As rapporteur for the Specific Programme implementing Horizon 2020, I defended an adequate budget for Research and Innovation in Europe. One of my priorities was the Health and Wellbeing sector, which has a dedicated budget of EUR 7.5 bn, the highest budget among the 7 Societal Challenges addressed in Horizon 2020.

I consider that the structure of this programme, targeting specific diseases such as Alzheimer’s disease, and the new features of the framework programme, covering the whole innovation cycle, will make a difference in the near future in the acceleration of research results in Europe. I hope that in the future the European Parliament continues supporting science and innovation in this field as well as other aspects related with this illness.

24 February: 13 European Parliamentary candidates have signed the European Dementia Pledge

The latest signatory of the European Dementia Pledge, on 24 February was Linda McAvan, MEP (UK). Ms McAvan’s participation brings the total number of signatories to 13:

- Heinz K. Becker, MEP (Austria)
- Angelika Werthmann, MEP (Austria)
- Ádám Kósa, MEP (Hungary)
- Marian Harkin, MEP (Ireland)
- Jim Higgins, MEP (Ireland)
- Roberta Metsola, MEP (Malta)
- Mojka Kleva Kekuš, MEP (Slovenia)
- Ivo Vajgl, MEP (Slovenia)
- Pablo Zalba Bidegain, MEP (Spain)
- Jayne Bryant (UK)
- Linda McAvan, MEP (UK)
- Claude Moraes, MEP (UK)
- Glenis Willmott, MEP (UK)

The European Dementia Pledge is a simple commitment by MEP candidates to support the campaign to make dementia a priority in the new European Parliament.

Alzheimer Europe wishes to thank all the signatories and invites all other candidates for the 2014 European Parliament elections to sign the European Dementia Pledge, to show their commitment to people with dementia and their carers.

12 February: MEPs launch a new Written Declaration on the rights of people with disabilities

On 12 February, ten MEPs launched a Written Declaration (WD 0008/2014) on the rights of persons with disabilities. The declaration calls on the European Commission to promote independent living for people who are discriminated against due to functional diversity (PDFD). It includes standards of personal care and protection of social rights based on their needs, abilities and aspirations as EU citizens.

The original sponsors of Written Declaration WD 0008/2014 are shown below; they invite their fellow MEPs to show their support by 16 April 2014:

- François Alfonsi, MEP (France)
- Martina Anderson, MEP (UK) and member of the European Alzheimer’s Alliance (EAA)
- Itzkun Bilbao Barandica, MEP (Spain)
- Nikos Chrysogelos, MEP (Greece)
- Mark Demesmaeker, MEP (Belgium) and member of the EAA
- Jill Evans, MEP (UK)
- Ifaki Irazarbelaita Fernández, MEP (Spain)
- Marisa Matias, MEP (Portugal) and member of the EAA
- Antolín Sánchez Presedo, MEP (Spain)
- Marie-Thérèse Sanchez-Schmid, MEP (France).

26 February: European Parliament approves 3rd EU Health Plan

On 26 February, the European Parliament overwhelmingly approved the text of the 3rd EU Health Plan, following a compromise reached with the Council the previous day.
MEP Françoise Grossetête (France) led the discussions in her role of rapporteur. She said that the programme would focus on four key areas:

1. Disease prevention, especially of those diseases caused by lifestyle factors like tobacco or alcohol use, unhealthy foods, or a sedentary lifestyle.
2. Better preparation for health emergencies, especially across borders.
3. Promoting innovation in the health sector.
4. Improving access to quality health services.

Ms Grossetête pointed out that considerable attention will be given to conditions associated with aging, with a special focus on dementia. Mr Tonio Borg, Commissioner for Health and Consumer Policy, said that the four principal objectives of the plan are as follows:

1. Reduce health inequality across regions and Member States.
2. Increase the sustainability of national healthcare systems.
3. Encourage innovation in the healthcare sector.
4. Reduce cross-border health risks.

Mr Borg explained that, for the first time, the plan would undergo a midterm review and would place more emphasis on communicating the outcomes of the projects. He also reminded his colleagues that "a financial crisis should not become a health crisis" and that Commission measures - including this programme - are meant to ensure the sustainability of European healthcare systems.


27 February: European Innovation Partnership on Active and Healthy Ageing (EIP AHA) releases report

The European Innovation Partnership on Active and Healthy Ageing released a report on "European Innovation Partnerships [EIPs] as a Tool for Systemic Change" on 27 February.

The report, carried out by an independent expert group under the chairmanship of former Finnish Prime Minister, Esko Aho provides recommendations on improvements in the current EIPs and conditions for future EIPs.


28 February: IMI releases video seminars for 11th call for funding

IMI - the Innovative Medicines Initiative - has released a series of video seminars that provide guidance on submitting proposals for IMI’s 11th call for funding.

These webinars introduce IMI’s rules and procedures, as well as its intellectual property policy. Viewers also learn about the role of the project coordinators and discover tips on the preparation of an Expression of Interest (EoI) for an IMI project. The webinars are available on IMI’s website.

www.imi.europa.eu/events/2013/12/03/imi-11th-call-webinars

Members’ News

31 January: Norway’s Health Association holds a dementia seminar in the Parliament

On 31 January, the Norwegian Health Association - in cooperation with the Christian Democratic Party - held a seminar on dementia in Norway’s Parliament in Oslo.

The seminar attracted representatives from almost all the political parties in the Parliament, who heard an update from medical professionals and discussed the various challenges and possibilities in dementia care. However, the most captivating presentation of the day was made by Ms Toril Marie Nystad Krøvel, who is living with dementia.

Ms Krøvel had a great impact on her listeners as she described her daily challenges and listed the types of support and help she needs in her everyday life. With both her eyesight and memory failing, she needs help with things like finding suitable clothes, but also to establish good routines and procedures to get her through the day: “I need an assistant who can be my eyes”.

She was followed by Ms Kristine Schille, a representative from a care association, who spoke about the pressing need for support and relief for caregivers. Ms Schille cited many of her own experiences, as her father developed dementia at an early age.

Both speakers were very pleased at the opportunity to have a frank discussion with the Members of Parliament and were glad that their audience was so attentive and receptive to their words.

The seminar concluded with a panel discussion led by Ms Lisbet Rugtvedt, General Secretary of the Norwegian Health Association. She said that the government must guarantee the right to day care services for every person with dementia in Norway. While the Parliament has already allocated large sums over several years for this purpose, few municipalities have made effective use of the funds. All the politicians present agreed that the current system must be improved. Ms Rugtvedt specifically pointed out that the state should finance the whole system, including the staff members – just as it finances the education of all Norwegian children.

Norwegian MP Olaug Bollestad (centre) hugs Ms Krøvel during a dementia seminar in the Parliament as Mr Krøvel looks on.
1 February: Alzheimer Nederland welcomes new Chair of the Supervisory Board

On 1 February, Ms Liesbeth Spies became the new Chairperson of the Supervisory Board of Alzheimer Nederland. Ms Spies is a former Minister of Home Affairs.

Alzheimer Nederland wishes to thank Ms Van der Hoeve, who was also a career politician. Alzheimer Nederland is pleased to report that 137 research proposals were submitted for the first call of the Dutch "Delta Plan Dementia".

These proposals are being reviewed by a team of researchers and caregivers of people with dementia that will determine the 53 most promising projects. The managers of the shortlisted projects will then be invited to submit a full proposal.

In this final round, patients and caregivers play an important role. Firstly, they have to be involved in the preparation and implementation of a research project. Secondly, the relevance of the submitted research projects will be assessed by patients and carers in focus groups organized by Alzheimer Nederland. The scientific quality of the research proposals is assessed by researchers.

The winning projects, which will receive total funding of EUR 16 million, will be announced on 1 July 2014.

3 February: Alzheimer Portugal opens fourth dementia care centre

Alzheimer Portugal recently opened a new day care centre in the city of Pombal. This is the association’s fourth specialised facility for people with dementia and is named after the Marquis of Pombal, a prominent 18th century nobleman. The "Day Care Centre of the Marquis" was specifically designed to accommodate the needs of people with dementia, similar to the other successful centres in Lisbon, Estoril and Matosinhos.

Alzheimer Portugal’s facilities all aim to be models of good practices in caring for people with dementia. Care is based on a person-centered approach that takes every person’s life history, emotions and desires into account. The centres seek to improve residents’ quality of life by promoting autonomy and social involvement, in accordance with their fundamental rights to freedom and self-determination.

The Day Care Centre of the Marquis offers a wide range of relaxation, leisure and cognitive stimulation activities. These are offered in both individual and group sessions and have been specifically developed for people with Alzheimer’s disease or another form of dementia.

Activities include dance, plastic expression, culinary workshops, gardening, agriculture, reading and writing.

The new centre was built on land donated by the Municipality of Pombal, while the construction of the building was entirely funded by the Marquês of Pombal Lions Club. Alzheimer Portugal is very grateful to all the beneficiaries who are helping to improve the life of people with dementia and their families.

6 February: German society releases 3 publications as e-books

On 6 February, the German Alzheimer Society (Deutsche Alzheimer Gesellschaft) released three of its publications as e-books. These can be purchased and downloaded for use on all e-readers via popular platforms on the internet as well as via their own website www.deutsche-alzheimer.de.

The compact guidebook “Das Wichtigste über die Alzheimer Krankheit und andere Demenzformen” (“The most important things about Alzheimer’s disease and other forms of dementia”) contains basic information on various medical, legal and social aspects of dementia.

The brochure “Miteinander aktiv. Alltagsgestaltung und Beschäftigungen für Menschen mit Demenz” (“Active together. Shaping daily life and activities for people with dementia”) contains ideas about how everyday life for people with dementia can be enhanced through sociability, movement, art and music.

The society’s 15th edition of its “Leitfaden zur Pflegeversicherung” (Guide to care insurance) explains which services people with dementia are entitled to and gives information on the application process, among other things.

The society has said that they see one of their main tasks as providing practical, clear information. Their hope is that these new e-books will benefit both older people and young people who are concerned about their parents or grandparents, according to Chairperson, Heike von Lützau Hohlbein.


19 February: Alzheimer’s Society “Dementia Friends” launch in Wales

On 19 February, the Alzheimer’s Society launched a year-long pilot of its Dementia Friends programme in Wales, with funding from the Welsh government. Free volunteer-led information sessions will initially be rolled out across South Wales.

The sessions aim to improve public knowledge of dementia, by helping people to understand what living with the condition might be like, and giving them tips on little things that they can do to make a difference to people living with dementia in their local area. Volunteers can become Dementia Friends by attending such information sessions, or can register online to become Dementia Friends Champions.
20 February: The Scottish Dementia Working Group gets connected

The Scottish Dementia Working Group committee held a meeting on 20 February that included an historical event. It was the first time the group used technology to communicate with group member Nancy McAdam, who could not attend the meeting held in the city of Dundee.

Nancy lives on the Black Isle in the Scottish Highlands but was able to participate in the meeting by using the Facetime app on an Ipad. She travelled to the Alzheimer Scotland Resource Centre in Inverness and was assisted in joining the meeting by Dementia Advisor Geraldine Ditta using the Resource Centre’s Ipad.

Both Geraldine and Nancy were able to speak about the issues on the agenda and were able to see the committee members as the Ipad was passed around the table to whoever was speaking.

SDWG Chairman Henry Rankin was amazed at how easy it was to link up with Nancy and described the experience as “fantastic”. Nancy was moved to tears as the meeting closed, describing her experience of Facetime as “just wonderful”.

The Scottish Dementia Working Group intends to roll out this type of technology in the near future - using Ipads to strengthen communication between group members and also between local groups in Scotland and possibly further afield.

Nancy is very much looking forward to getting her own Ipad and participating in future meetings from her home in the Black Isle, leaving her long bus journey to attend meetings well behind her.

20 February: Danish Alzheimer Association launches carer campaign

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

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

This campaign was made in cooperation between the Danish Alzheimer Association, students at Denmark’s School for Visual Communication and various advertising agencies.

25 February: France Alzheimer launches online campaign to reform loss of autonomy legislation

France Alzheimer has launched a campaign to support a proposed law that will improve the conditions of people who have lost autonomy. The campaign is based on the following key issues:

- Diminishing the cost of the disease
- Reducing the burden of loss of autonomy for families
- Supporting caregivers who are too often exhausted
- Lowering families’ investment
- Ending the unequal distribution of public benefits

The association has created a website to gather signatures from all those who support these measures and the site has already collected more than 18,500 signatures.

Marie-Odile Desana, President of France Alzheimer, invites all those who support better conditions for people with dementia and their caregivers to sign the campaign manifesto. This can be found on the website shown below. While the campaign is open worldwide, people who are not residents of France should not fill in the “Code postal” field.

http://lemansliste.francealzheimer.org/

26 February: Romania holds 4th Annual Alzheimer Conference

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

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

The conference also covered EU policies in dementia, including a presentation by Annette Dumas, Public Affairs Advisor for Alzheimer Europe. Ms Dumas outlined the existing European tools that can help countries prepare and implement a national dementia strategy, as well as EU opportunities in the area of sharing best practices and joining forces, especially in the field of research.
The Romanian Alzheimer Society wishes to thank all the speakers and delegates - including people with dementia - who attended the conference, as their involvement made the conference a success.

26 February: Launch of Dementia Friendly Communities in Northern Ireland

The Alzheimer’s Society Dementia Friendly Communities project was launched for Northern Ireland at Parliament buildings in Stormont on 26 February.

Heather Lundy, Dementia Friendly Communities Manager said: “Alzheimer’s Society is working towards creating dementia-friendly communities in villages, towns and cities across Northern Ireland in a bid to challenge stigma surrounding dementia and increase awareness of how best to communicate, relate and support people with dementia.”

Celebrity Chef Paul Rankin joined over 30 Members of the Legislative Assembly (MLAs) at the launch. Mr Rankin, who has been personally affected by dementia (his grandfather had dementia and his father was diagnosed with Alzheimer’s disease 14 years ago, at the age of 70) has pledged his support for Dementia Friendly Communities.


Policy Watch

1 February: Australian petition to make dementia a G20 priority

In advance of the next G20 summit in Australia in November 2014, scientists and advocates Professor Perminder Sachdev and Professor Henry Brodaty have started a campaign to place dementia prominently on the agenda. The co-directors of the Centre for Healthy Brain Ageing at the University of New South Wales have launched a campaign urging Prime Minister Tony Abbott to follow the lead of British Prime Minister David Cameron who hosted the G8 Dementia Summit in London in December 2013, during which the G8 countries made a firm commitment to developing a cure for dementia by 2025.

The petition, supported by Alzheimer’s Australia, reads: “In many parts of the world, research into dementia is non-existent. This, combined with the relative neglect of dementia research in rich countries, has created a major gap between the disability and suffering attributable to dementia and the research investment into its diagnosis, treatment and appropriate care.

“Greater research funding will help develop new treatments, but more importantly, exploit the current knowledge to develop strategies to prevent dementia or delay its onset. The G8 has set ambitious targets. We ask Mr Abbott to take the lead and make it a truly global fight against the dementia time bomb.”

Glenn Rees, the CEO of Alzheimer’s Australia, said “Member countries of the G20 will have 71 per cent of the total world population of people with dementia by 2050. As chair of the meeting of the G20 in November, the Prime Minister should continue Australia’s successes in bringing dementia to the forefront by galvanising the global support and recognition that dementia demands at the G20 summit”.

The petition is aiming for 20,000 signatures. At the time of writing it had achieved more than 8,900 signatures.

https://secure.avaaz.org/en/petition/Australian_PM_Tony_Abbott_Make_dementia_research_and_prevention_a.Priority_agenda_ITEM_at_the_G20/

19 February: Council of Europe upholds the rights and freedoms of older persons

On 19 February, the Committee of Ministers of the Council of Europe adopted a recommendation to governments aiming at ensuring that older persons fully enjoy all human rights and fundamental freedoms guaranteed in the European Convention on Human Rights.

The recommendation sets out a number of principles to be followed and gives examples of good practices that can help governments adopt appropriate measures. The text adopted underlines the importance of ensuring that older people enjoy their rights and freedoms without discrimination on any grounds, including age.

Mr Thorbjørn Jagland, Secretary General of the Council of Europe, said: “I welcome the adoption of this recommendation which applies for the first time a human rights-based approach to the situation of all older persons, with a view to ensure that they enjoy their fundamental rights and freedoms on an equal basis with other people.”

https://wcd.coe.int/ViewDoc.jsp?id=2162283&Site=COE&BackColorInternet=CF1E26&BackColorIntranet=EDB021&BackColorLogged=F5D383

www.alzheimer-europe.org/Donation

20 February: Malta releases consultation paper for dementia strategy

On 20 February, a consultation document for Malta’s national dementia strategy was released for comments. The consultation process is open until the end of May 2014 and aims to elicit feedback, comments and opinions. These will be collated, analysed and added to the final strategy document that will be published in October 2014.

Feedback can be sent by email to dementia.mfss@gov.mt and the full text of the document can be seen on the government website below.

www.activeageing.gov.mt
28 February: French visit helps prompt UK dementia investment

On 28 February UK Health Secretary Jeremy Hunt announced that NHS England will invest GBP 90 million (EUR 108.5 million) in a bid to diagnose two-thirds of people with dementia in the UK by March 2015 and to increase funding for research and care provision.

Following on from December’s G8 Dementia Summit, Mr. Hunt had been in France the previous day, to exchange information and views with French dementia experts and with French Minister for Social Affairs and Health, Marisol Touraine. Mr. Hunt and Mrs. Touraine visited two of France’s centres of excellence together, the Institute for the Brain and Spinal Cord (ICM) and the Institute for Memory and Alzheimer’s Disease (IM2A).

Evidence shows that in France, more GPs spot the early signs of Alzheimer’s disease than friends and family – in stark contrast to the UK. Upon his return to London, Mr. Hunt stated that he was shocked at how far the UK lags behind in dealing with dementia and in particular where earlier diagnosis is concerned. His fact-finding mission to France, to learn how this has been achieved and to learn about France’s plans for even faster diagnosis helped pre-empted Mr. Hunt’s investment announcement.

Jeremy Hughes, Chief Executive of Alzheimer’s Society, said: “It is unacceptable that some people with dementia have to wait months to get a diagnosis. Today’s announcement is a positive step forward to increasing diagnosis rates and ensuring that no matter where you live you will receive a timely assessment.”

28 February: UK appoints World Dementia Envoy

On 28 February the UK government announced the appointment of Dr Dennis Gillings as World Dementia Envoy. He plans to create a World Dementia Council to raise funds for Alzheimer’s disease research. The announcement was made as part of a new dementia package which aims to speed up diagnosis, fund research and encourage businesses and services in the country to become dementia-friendly.

Dr Gillings is the founder of Quintiles, a provider of biopharmaceutical development services, and has provided consultancy to numerous companies and health organisations.

Science Watch

22 January: Electroacupuncture may help relieve cognitive impairment

Researchers from the departments of Anaesthesiology at The Fourth Military Medical University, Xi’an, China and Stony Brook University School of Medicine, New York, USA have completed a study into the effects of electroacupuncture on cognitive impairment and neurogenesis.

Using double transgenic mice, the study investigated whether repeated electroacupuncture (EA) stimulation applied for 30 minutes per day, five days per week for four weeks, would improve cognitive function and the pathological features of Alzheimer’s disease in amyloid precursor protein (APP)/presenilin 1 (PS1).

Cognitive function was assessed using the Morris water maze test before and after treatment. Levels of amyloid β-peptide (Aβ) deposits in the hippocampus and cortex were evaluated by immunofluorescence, western blot and enzyme-linked immunosorbent assay. Expression of brain-derived neurotrophic factor (BDNF) was also examined by immunofluorescence and western blot. The neurogenesis was labelled by the DNA marker bromodeoxyuridine.

According to the research team the results showed that EA stimulation significantly improved the learning and memory deficits of AD mice by shortening escape latency and increasing the time spent in the target zone during the probe test. They also found that it decreased Aβ deposits and increased BDNF expression and neurogenesis in the hippocampus and cortex of EA-treated AD mice. This change was also detected in wild-type mice after EA treatment, as compared with wild-type mice without.

The team concluded that “repeated EA stimulation may improve cognitive function, attenuate Aβ deposits, up-regulate the expression of BDNF and promote neurogenesis in the APP/PS1 double transgenic mice. This suggests that EA may be a promising treatment for AD.”

www.biomedcentral.com/1472-6882/14/37

24 January: AGES in some cooked foods could be linked to Alzheimer’s

According to a study published on 24 January in the journal of Proceedings of the National Academy of Sciences of the United States of America (PNAS), advanced glycation endproducts (AGES), found in cooked food, particularly high fat proteins such as animal meat, might contribute to Alzheimer’s disease.

According to the study’s authors, AGES suppress SIRT1, a protein in the body thought to protect against neurodegeneration. Foods high in AGES could contribute to the buildup of beta-amyloid, a hallmark of Alzheimer’s disease.

The researchers found that a diet low in AGES boosted levels of SIRT-1 protein and prevented the accumulation of beta-amyloid in the brains of mouse models. In contrast, a diet high in AGES meant that the mouse models developed beta-amyloid deposits and showed poor performance in both cognitive and motor tests. In addition, a small clinical study of healthy humans over the age of 60, found that people who had high AGES in their blood also had low SIRT1 levels and developed cognitive decline over a nine month period.

“Diets with low levels of the compounds show promising effects in mice and should be further explored as a way to prevent dementia through changes in diet. Of course, we must not forget that the majority of research was conducted in mice and the human element of this study is too small to draw any conclusions” commented Dr Doug Brown, Director of Research and Development, Alzheimer’s Society.

www.pnas.org/content/early/2014/02/19/1316013111.abstract
24 January: Amoebas used in Alzheimer’s disease research

Researchers at Royal Holloway, University of London and the Institute of Psychiatry, King’s College London have released a new study identifying the social amoeba, Dictyostelium as an important aid in understanding the role of presenilin proteins in Alzheimer’s disease. The study was published in the Journal of Cell Science on 24 January.

Mutations in presenilin proteins cause inherited forms of Alzheimer’s disease, and these proteins also play a major role in the age-related onset of the condition. Historically, animals have been used in this research area, but these experiments have been problematic, due to deletions of the proteins in animal cells causing a loss of viability.

“This discovery allows us to examine the role for the human presenilin 1 protein, without the use of animal testing. It is amazing that so simple an organism lends itself to the study of such a complex disease,” said Professor Robin Williams from the School of Biological Sciences at Royal Holloway.

http://jcs.biologists.org/content/early/2014/01/23/jcs.140939.abstract?sid=348312a-5dbb-47f6-9f8b-9cb728044401

24 January: ALCOVE findings on timely diagnosis of dementia published

An article on recommendations about timely diagnosis emerging from the Alzheimer’s COoperative Valuation in Europe (ALCOVE) project was published in the online Journal of Geriatric Psychiatry on 24 January.

The article, “Public health guidance to facilitate timely diagnosis of dementia”, by Dawn Brooker et al. provides detailed recommendations for timely detection of dementia, the diagnostic process, complex diagnoses and response to early cognitive changes.

Concerning diagnosis in the earliest stages of dementia, the authors reflect that it is not recommended as regular practice, but rather that “On balance, it is suggested that citizens should have access to accurate diagnosis at a time in the disease process when it can be of most benefit to them. The term timely diagnosis is used to reflect this.”

They conclude that the ALCOVE recommendations can be used at a local, national and European level to benchmark progress.


28 January: New study suggests link between AD and exposure to DDT

A new study suggests that people who were exposed to DDT and carry the APOE-4 gene are more likely to develop dementia. DDT was a widely used pesticide in the 1970s and 1980s, but was banned in many countries - including the US and the UK - after proving harmful to wildlife and the environment.

Previously, the authors of the study had found raised levels of a chemical called dichlorodiphenyldichloroethylene (DDE), a byproduct of DDT, in a small but significant number of late-onset Alzheimer’s patients. In the new study, the researchers wanted to further explore the link between DDT and Alzheimer’s disease.

To do this, they studied existing blood samples from 86 patients with Alzheimer’s disease and 79 healthy controls and measured the levels of DDE in the blood. The researchers detected DDE in the blood of 70% of the control group and in 80% of the Alzheimer’s patients. In the people with Alzheimer’s disease, levels of DDE were 3.8 times higher than in the members of the control group. Testing the cognitive function of the Alzheimer’s patients, the researchers also found that the disease was more advanced in the people who had the highest levels of DDE and who also carried the APOE-4 gene that is linked to a higher incidence of Alzheimer’s disease.

The study was a cooperative effort led by Dr Jason R. Richardson, Assistant Professor of Environmental and Occupational Medicine at Rutgers University and colleagues from the Emory University School of Medicine and the University of Texas Southwestern Medical Center.

Dr Doug Brown, Director of Research and Development at the UK Alzheimer’s Society, suggested that these results be taken with caution: “This small study suggests that increased levels of DDT in the blood might be linked to an increased risk of Alzheimer’s disease. Whilst this isn’t the first time DDT has been linked to health problems, it is hard to draw any firm conclusions from this small sample of people from the United States.

“Alzheimer’s disease is a complex condition and we know that genetics, the environment and lifestyle factors can all contribute to its development. More research is needed to unravel its causes and determine whether testing for pesticides in the blood could be useful to predict who is at greater risk of developing Alzheimer’s.”


31 January: Top Portuguese and Finnish scientists to lead IMI Scientific Committee

On 31 January, IMI - the Innovative Medicines Initiative - announced that Professor Maria Beatriz da Silva Lima of the University of Lisbon in Portugal will be the new Chair of the IMI Scientific Committee. The Vice Chair will be Professor Markus Perola of Finland’s National Institute for Health and Welfare.

The pair was elected by the rest of the 12-strong committee. “The IMI Scientific Committee consists of some of the most skilled scientists in Europe, and being part of it is one of the highlights of my scientific career. To be appointed Chair is a great honour,” said Professor da Silva Lima. Professor Perola added: “I am very excited about working for IMI. Public-private partnership is an underused tool in Europe, and I see a lot of potential in it to advance the health and welfare of all people.”

The Scientific Committee provides the IMI Governing Board and Executive Office with strategic, scientific advice, for example on the IMI research agenda and the annual scientific priorities (which form the basis of the Call topics). In addition, the Scientific Committee participates in the consultations on new topics for Calls for proposals, and plays an active role in reviews of ongoing IMI projects. Members are nominated by IMI’s
5 February: Study into age-related decline in motor function published

Researchers at the School of Medicine of the University of Texas Health Science Center, USA, have completed a study, recording changes in the neuromuscular junction synapses of fruit flies. The team, led by Dr. Benjamin A. Eaton, Assistant Professor of Physiology, published their study in The Journal of Neuroscience on 5 February.

“The body has a set point for temperature (98.6 degrees), a set point for salt level in the blood, and other homeostatic (steady-state) set points that are important for maintaining stable functions throughout life,” said Dr. Eaton. The researchers observed a change in set points that resulted in significantly diminished motor function in ageing fruit flies. Their findings seem to show that set points in the nervous system are not indelibly determined during development but instead may be reset with age.

Aside from motor function decline during the ageing process in animals, study co-author, Rebekah E. Mahoney said that “a new functional set point in neuromuscular junctions could put the synapse at risk for developing neurodegeneration — the hallmark of disorders such as Alzheimer’s and Parkinson’s diseases.”

5 February: Accelerating Medicines Partnership formed

The US National Institutes of Health (NIH) has brought together ten of the world’s largest pharmaceutical companies and several disease-specific non-profit organisations to form a five-year collaboration called the Accelerating Medicines Partnership (AMP). The partnership has been referred to by NIH Director, Dr. Francis Collins as a research “dream team”.

It includes the likes of GlaxoSmithKline, Merck and Pfizer, who have agreed to invest USD 230 million (EUR 146 million) during the collaboration period to try to identify biological targets of disease most likely to respond to new therapies. This investment of time and money is hoped to accelerate the discovery of new medicines to treat Alzheimer’s disease as well as type-2 diabetes, rheumatoid arthritis and lupus. The NIH said it had chosen biological targets of disease most likely to respond to new therapies.

Dr. Collins said that the challenge faced in trying to treat these diseases is calls for companies and organisations “to work together in new ways, to increase our collective odds of success.”

The data and analyses generated from the joint work of the new AMP will be made available to the broader biomedical community.

6 February: AstraZeneca and Merck announce BACE inhibitor trials

During the announcement of its full-year results on 6 February, British pharmaceutical company AstraZeneca (AZN) revealed plans to move its BACE inhibitor, AZD3293 into phase three, the final phase of testing.

Only weeks earlier on 10 December 2013, US pharmaceutical company Merck had announced plans to start similar final-stage research on its own BACE inhibitor, MK-8931.

13 February: Common infections may increase risk for memory decline

According to research presented on 13 February at the American Stroke Association’s International Stroke Conference in San Diego, USA, exposure to common infections may be linked to decline in memory and brain function.

In a collaborative study by researchers at the Evelyn F. McKnight Brain Institute at the University of Miami, USA and at Columbia University, an index of antibody levels caused by exposure to Chlamydia pneumoniae, Helicobacter pylori, cytomegalovirus, and herpes simplex viruses 1 and 2 was found to be associated with worse cognitive performance. This included memory, speed of mental processing, abstract thinking, planning and reasoning ability.

The study conducted brain function tests and took blood samples from 588 participants in the Northern Manhattan Study. Half of the participants then took cognitive tests again five years later.

The study’s lead researcher Dr. Clinton Wright, Scientific Director of the Evelyn F. McKnight Brain Institute stressed that “There is no evidence yet that treating these infections is beneficial,” because the initial exposure to the viruses may have happened decades earlier and the damage may be the result of a gradual process. “It would be great if treatment prevented these bad outcomes, but we’re very far away from having that type of evidence.” Further studies will need to be conducted, he said.

20 February: Commission approves Piramal’s florbetaben (18F)

On 20 February, the European Commission granted marketing authorisation to Piramal Imaging GmbH for florbetaben (18F), a medicinal product for human use. This decision follows the positive opinion issued by the EMA’s Committee for Medicinal Products for Human Use (CHMP) on 19 December 2013.

Florbetaben is a radiopharmaceutical indicated for Positron Emission Tomography (PET) imaging of β-amyloid neuritic plaque density in the brains of adult patients with cognitive impairment who are being evaluated for Alzheimer’s disease and other causes of cognitive impairment. The active substance is florbetaben (18F), a radiopharmaceutical indicated for PET imaging of β-amyloid neuritic plaque density.
The benefit of florbetaben is its ability to estimate beta-amyloid deposition, thereby contributing additional information to the clinical diagnostic process in Alzheimer’s disease.

Dementia in Society

3 February: Bobby Vee makes album 3 years after Alzheimer’s disease diagnosis

On 3 February rock ’n’ roll singer Bobby Vee, who was diagnosed with Alzheimer's disease in 2011, released a new album called “The Adobe Sessions”. It is an 18-song collection, recorded in a jam session format with his family, featuring some original material along with some covers of artists who have influenced him over the years. The album’s release date was timed to coincide with the 55th anniversary of the plane crash that killed rock ‘n’ roll pioneers Buddy Holly, Ritchie Valens and J.P. “The Big Bopper” Richardson, and was dubbed “the day the music died”.

After his 2011 diagnosis, Vee had taken the decision to officially retire from music, but he recently got back into playing music again and says that making the album with his family by his side “was really like therapy for all of us”. His memory has not really been affected, but rather his speech. The singer does daily exercises and speech therapy and has renewed his passion for painting and of course, there is music. He is still a skilled rhythm guitarist.

“It’s not getting any better, I can tell you that,” Vee said. “But I’m doing the best I can.”

12 February: “The Call” film released to help raise funds and awareness

Released via You Tube on 12 February to much critical acclaim, “The Call” is a short film by young British director, writer and filmmaker David Cooper. The film was made in conjunction with Alzheimer’s Disease International (ADI) to spearhead a global campaign for charities that are researching, supporting and caring for people affected by dementia.

Written using the actual words and experiences of just a few of those living with dementia and their families and carers, “The Call” aims to raise awareness of dementia as well as helping to fundraise.

It features an appeal by actor Sir Patrick Stewart of Star Trek and X-Men fame and has also received celebrity Twitter endorsement from Stephen Fry and Britt Ekland, among others.

The film’s website homepage has donation links to its charity partners: the national Alzheimer’s disease societies for Ireland, Australia, USA, New Zealand, Canada, South Africa and the UK, as well as ADI who promises to ensure donations go where they are most needed.

www.thecallshortfilm.com

26 February: Seth Rogen testifies to US Senate on Alzheimer’s disease

Canadian comic actor, writer and director, Seth Rogen gave testimony at a US Senate hearing about the state of Alzheimer’s disease research, on Capitol Hill on 26 February. Rogen delivered a speech detailing his mother-in-law’s struggles with the disease and strongly criticised the state of research as well as the public perception of people living with the disease. He called on the committee and the government to take more steps in the fight against Alzheimer’s disease.

Prior to his testimony, Rogen had already been involved in Alzheimer’s disease advocacy for several years, acting as a celebrity spokesman and fundraiser for the National Alzheimer’s Association. He and his wife also started the non-profit organisation “Hilarity For Charity” to help raise funding for Alzheimer’s disease care, support and research as well as awareness of the disease, particularly among younger people.

New Publications & Resources


It tells the story of a young boy, Léo and his grandfather, Céléstin, who is losing some of his memories, which he stores in a large book. The pair begin an investigation to find the missing memories and along the way they meet Mr Zheimer, who is found to be “archiving” the memories.

www.lescramoteur.com/#!leo-et-clestin/cuj4

31 January: New online tool to help nurses support carers

A new online tool was launched on 31 January to help community nurses to support carers more fully. The resource, developed throughout 2013 with funding from the Department of Health, is hosted on the Queen’s Nursing Institute (QNI) website and is completely free to access.

The resource is divided into seven chapters: Supporting Carers; Assessment of Carers; Signposting Carers; Mental Health, Learning Disability and Dementia; End of Life Care, Professional Roles; and Personal and Professional Development. Each module contains a quiz and a self-assessment exercise to consolidate learning. There are also nine short films, which recount some real-life stories and challenges faced by carers.

www.qni.org.uk/for_nurses/supporting_carers

7 February: UK Alzheimer’s Society publishes guide for customer-facing staff

The Alzheimer’s Society has published a new booklet called “How to help people with dementia: A guide for customer-facing staff”.

The booklet gives an introduction to dementia and how it can affect people, tips outlining the important elements
of communication and it also explains how other physical, environmental and sensory factors can cause difficulties for customers with dementia, while suggesting ways in which staff can help to reduce their impact.

It is available to download for free or to order printed copies:


10 February: Alzheimer Society releases audio factsheets

The UK Alzheimer’s Society has released all of its factsheets in audio format, including its most popular factsheets “What is dementia?” and “Diagnosis and assessment”. The audio factsheets are freely available on the Society’s website.

11 February: ADI releases report on nutrition and dementia

A new ADI report highlights that under-nutrition is a major problem among people with dementia and stresses the importance of recognising nutrition as a potential key factor in the wellbeing of people with dementia.

Alzheimer’s Disease International (ADI) and Compass Group commissioned a team of researchers, led by Professor Martin Prince from the King’s College London Global Observatory for Ageing and Dementia Care, to produce "Nutrition and dementia: a review of available research".

Research reviewed in the report finds that 20-45% of those with dementia in the community experience clinically significant weight loss over one year. The report reviews existing research on dietary factors across the life course that might increase or decrease the risk of developing dementia in later life. While obesity in mid-life may be a risk factor for developing dementia in late life, weight loss tends to become a more significant issue in the decade leading up to the clinical onset of the disease and accelerates thereafter.

The report also details actions that could improve the nutrition of people with dementia through diet and external factors such as modifying the mealtime environment, and supporting and training carers. Given the evidence for effective interventions, there is much untapped potential to improve the food intake and nutritional status of people with dementia.

The new report is available for download on ADI’s website.

14 February: AE releases new issue of Dementia in Europe magazine

Alzheimer Europe has circulated issue 16 of the Dementia in Europe magazine. The new issue features an interview with José Manuel Barroso, President of the European Commission, a report from the G8 Dementia Summit in London and an article about the lunch debate hosted by Maltese MEP Joseph Cuschieri.

In addition, 31 MEPs speak out on dementia and AGE Platform Europe presents its dementia-friendly community project. There is also a presentation of Alzheimer Europe’s 2013 Dementia in Europe Yearbook and an update on “Perceptions and portrayal of dementia”, a report produced by the European Dementia Ethics Network.

Finally, a special "spotlight" section of the magazine is dedicated to Alzheimer Europe’s 23rd conference in Malta in October 2013.

“Dementia in Europe” magazine appears three times per year and reaches more than 3,000 readers. Issue 17 will appear in June and issue 18 in December 2014. The magazine is available for purchase on the Alzheimer Europe website.

20 February: “BrainyApp” released in Spanish

On 20 February “BrainyApp” was released in a new Spanish version, “BrainyApp español”, which is the first non-English version of the app.

Originally developed in Australia in late 2011 by Alzheimer’s Australia and the Bupa Health Foundation, “BrainyApp” aims to help users to monitor and improve their physical, mental, dietary and social lifestyles in order to help prevent brain and heart disease.

“BrainyApp español” is available as a free download from various smart phone app stores.

19 February: Bradford Dementia Group seeks a Senior Lecturer

The Bradford Dementia Group, part of the University of Bradford, has announced a vacancy for a “Senior Lecturer in Quality Improvement in Dementia Care”.

The ideal candidate will be a dynamic and committed individual who has proven capability of conducting research and development projects in real world settings which seek to have a direct impact on care practice and quality of life.

Established over 20 years ago, the aim of Bradford Dementia Group is to ensure quality of life and quality of care for people affected by dementia through excellence in research, training, education and consultancy.

The closing date for applications is 20 March and interviews will be held on 2 April 2014. Prior to application, informal enquiries may be made to Professor Murna Downs, Head of Bradford Dementia Group, by telephone (01274 233996/1) or e-mail to m.downs@bradford.ac.uk
## AE Calendar 2014

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-4 March</td>
<td>Meeting of the EWGIPWD Executive (Luxembourg, Luxembourg)</td>
<td>Dianne, Jean, Ana, Kate</td>
</tr>
<tr>
<td>10 March</td>
<td>EFPIA Think Tank meeting (Brussels, Belgium)</td>
<td>Annette</td>
</tr>
<tr>
<td>13 March</td>
<td>Hearing at the Council of Europe (Paris, France)</td>
<td>Dianne</td>
</tr>
<tr>
<td>13-14 March</td>
<td>PredictND launch meeting (Espoo, Finland)</td>
<td>Dianne &amp; Jean</td>
</tr>
<tr>
<td>18 March</td>
<td>European Commission conference “Health in Europe: making it fairer” (Brussels, Belgium)</td>
<td>Annette</td>
</tr>
<tr>
<td>18-19 March</td>
<td>EMIF work package 16 meeting (Brussels, Belgium)</td>
<td>Alex</td>
</tr>
</tbody>
</table>

## Future Conferences

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-22 March 2014</td>
<td>58th Annual meeting of the German society for clinical neurophysiology and functional imaging (DGKN), <a href="http://www.dgkn-kongress.de">www.dgkn-kongress.de</a></td>
<td>Berlin, Germany</td>
</tr>
<tr>
<td>1-4 May 2014</td>
<td>29th ADI Conference, <a href="http://www.adi2014.org">www.adi2014.org</a></td>
<td>San Juan, Puerto Rico</td>
</tr>
<tr>
<td>16-17 May 2014</td>
<td>The Alzheimer’s Show, <a href="http://alzheimershow.co.uk/">http://alzheimershow.co.uk/</a></td>
<td>London, UK</td>
</tr>
<tr>
<td>31 May-9 June 2014</td>
<td>EFNS-ENS Joint Congress of European Neurology 2014, <a href="http://www.jointcongressofeuropeanneurology.org">www.jointcongressofeuropeanneurology.org</a></td>
<td>Istanbul, Turkey</td>
</tr>
<tr>
<td>12-14 June 2014</td>
<td>12ème Réunion francophone sur la maladie d’Alzheimer et les syndromes apparentés</td>
<td>Montpellier, France</td>
</tr>
<tr>
<td>26-27 June 2014</td>
<td>International Dementia Conference, &quot;Risky Business 2 - this time it’s personal!&quot;, <a href="http://www.dementiaweek.com/call-for-papers">www.dementiaweek.com/call-for-papers</a></td>
<td>Sydney, Australia</td>
</tr>
<tr>
<td>12-17 July 2014</td>
<td>AAN Conference 2014, <a href="http://www.atiz.org/aac">www.atiz.org/aac</a></td>
<td>Copenhagen, Denmark</td>
</tr>
<tr>
<td>23-25 October 2014</td>
<td>9th International Conference on Frontotemporal Dementias, <a href="http://www.ucbcpd.ca">www.ucbcpd.ca</a></td>
<td>Vancouver, Canada</td>
</tr>
<tr>
<td>20-23 June 2015</td>
<td>1st Congress of the European Academy of Neurology (EAN), <a href="http://www.eaneurology.org/berlin2015">www.eaneurology.org/berlin2015</a></td>
<td>Berlin, Germany</td>
</tr>
</tbody>
</table>

Contact Alzheimer Europe:
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Alzheimer Europe Board
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24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014
Mark the dates!

www.alzheimer-europe.org/conferences

The Alzheimer Europe newsletter arises from the 2014 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.