Editorial

Welcome!

May has been another busy month, not just for us but for all of our member organisations, with a lot of tireless campaigning going on in the run-up to the European elections. We would like to say a special thanks to everyone who worked so hard to get EP candidates signed up to our EU Dementia Pledge. The efforts have paid off: We surpassed our target of 200, ending up with 219 pledgees; 89 of these in May alone! The ballot-counting over, it looks like we will start the new parliamentary term with 83 EAA members; an increase of 11 compared with the end of the last term. We are looking forward to working with existing and new members from all political parties. Thank you to the existing members of the EAA who either did not stand or were not successful in the elections, for all of their hard work and thank you also to the new pledgees who were not elected and will therefore not be joining the EAA at this time.

Activities surrounding the elections have taken up a lot of our time this month, but there has been plenty else happening too:

The UK Department of Health and ADI convened a side event dedicated to dementia at this year’s World Health Assembly in Geneva on 19 May, at which I represented AE. It was fantastic to have Ministers of Health from the UK, Mauritius and Canada as well as the WHO Director General attending and showing their commitment to dementia.

Our chairperson, Heike travelled to the 29th annual ADI conference in Puerto Rico from 4 to 6 May. Helga, chairperson of our EWGPWD was on the Health and Innovation panel at the annual OECD forum in Paris on 5 May. On 22 and 23 May, she also travelled to Luxembourg where we welcomed her and her fellow EWGPWD members for their first full meeting of 2014. On 12 and 13 May, Annette and I attended the EPF AGM in Brussels and Alex attended the NILVAD project’s 3rd General Assembly in Lille. Also on the project front, EMIF released its first external newsletter.

There has been a wealth of EU and global policy news this month as well, with the European Council adopting the IMI 2 regulation, the Commission rejecting the “One of Us” initiative to put a halt to stem cell research funding in the EU, the new World Dementia Council releasing its statement of purpose and the UN appointing a new expert to focus on the human rights of older persons.

Work also continues for the AE conference in Glasgow and the Programme Committee has reviewed all submitted abstracts this month. We are currently informing all authors of the decisions made and would like to remind accepted presenters that they must register for the conference by 30 June, via our website.

Finally, our friends at Bournemouth University in the UK are looking for a Post-Doctoral Research Fellow at their Dementia Institute (BUDI). The closing date for applications is 19 June.

With summer fast-approaching, we wish you a warm and successful June!

Jean Georges
Executive Director
Alzheimer Europe

8 April: Nina Baláčková from EWGPWD appears in US Against Alzheimer’s video

On 8 April, US Against Alzheimer’s released a video online, featuring people with early onset Alzheimer’s disease from around the world, the aim being to promote awareness of young onset dementia and of the need for investment in research.

Each person with dementia in the video selected a photograph of themselves and submitted a quote to go with it. These were put in a virtual “book” which is shown, page by page, in the video.

Nina Baláčková, Vice Chairperson of the European Working Group of People with Dementia (EWGPWD), appears in the video alongside her husband and says “I am training my brain, exercising, walking, sharing my opinion about life with dementia with others. My hobbies are travelling, music and our grandchildren”. Nina is 55 years old and has been living with dementia for the past 6 years.

Dr. Rudolph Tanzi, chairperson of the Cure Alzheimer’s Fund Research Consortium is also quoted in the video, saying “Alzheimer’s is the ultimate budget-constrained, not knowledge-constrained, field... We have tons of stuff we need to do, and it sits on the shelf because we are constrained by budget”.

The video can be found here: www.youtube.com/watch?v=Brqi45pado&feature=youtu.be

More information about US Against Alzheimer’s can be found here: www.usagainstalzheimers.org/

4-6 May: AE’s chairperson Heike von Lützau-Hohlbein reports on ADI’s 29th annual conference

Palm trees, blue Carribean water and Alzheimer’s: How does that all fit together? This 29th ADI-conference made it quite clear again, how dementia is a worldwide issue. Nearly 600 participants from all over the world came together to listen, discuss and work on the network.

The programme, under the motto “Dementia: Working together for a global solution” showed the variety of subjects from newest results in research, presented by Serge Gauthier, the chairman of ADI’s medical and scientific panel, up to the involvement of people with dementia as presented by Kate Swaffer from Australia among others. Key note speakers came from around the world, including Colin Masters from Australia, Laura Fratigioni from Sweden and Steve DeKosky from the USA.

A particular highlight was a panel discussion which debated whether or not people should be informed of their risk of developing dementia.

The most important topics from my point of view were the sessions about prevention and risk factors, where health ministers can see the benefit for the future. As always, however, the newest information about non-pharmaceutical interventions and quality of life are of equal importance.

One main issue was the presentation and discussion about public policies and the power of advocacy and Alzheimer plans. In these policies, the role of people with dementia should not be underestimated. The G8 (now G7) legacy meetings and plans, as follow-up from the G8 Dementia Summit of December 2013 in London, were presented by the UK government representative Gill Ayling, who stressed the importance of the UK Prime Minister’s Dementia Challenge, which aims to have a cure for Alzheimer’s disease by 2025. For me, as Alzheimer Europe Chairperson, it was essential to bring the voice of Europe to the discussions.

During nearly all of the sessions it was emphasised that only with the engagement of the Alzheimer associations around the world can the aims of working together for a global solution be achieved.

During the ADI award ceremony included in the conference programme, Prof. Martin Prince was announced as winner of the 2014 ADI award for “his extraordinary contribution towards increasing awareness of dementia and encouraging policy initiatives and improvements in the quality of life of people with dementia and their carers”.

During the Annual Meeting held before the conference Glenn Rees from Australia was elected as the next chairman of ADI, starting his term in 2015. From the social point of view the conference dinner held in the conference venue brought the joie de vivre of our Puerto Rican hosts to all of us.

5 May: EWGPWD chair, Helga Rohra speaks at OECD forum in Paris

The Organisation for Economic Co-operation and Development (OECD) held its annual forum in Paris on 5 and 6 May. The afternoon session on 5 May, titled “Health and Innovation” was moderated by Kenneth Cuki, Data editor for The Economist. The keynote speaker was Professor Shinya Yamanaka, Nobel Laureate in Physiology, Center for IPS Cell Research and Application, Kyoto University, Japan and other panellists included the chairperson of the European Working group of people with dementia (EWGPWD), Helga Rohra.

The keynote speech centred on finding new treatments, in particular for dementia, through the use of iPS cells (induced pluripotent stem cells). Prof. Yamanaka told the audience that “vision and hard work” as well as an international collaborative effort involving not only scientists, but also ethical experts, patents, regulation, public relations, pre-clinical trials and more, would be needed to “find our cells’ true potential”.
Helga Rohra reminded the other panellists as well as forum participants and webcast viewers that while innovation in terms of research into treatments and a possible cure for dementia is important, these are not the only important things. "Dementia is like a sponge, it takes out everything you learnt but please focus on what’s left”, said Ms Rohra. She implored scientists and medical professionals to “include the experts...and the experts are people who live daily (with dementia)” in the process of finding innovative therapies and possible cures.

Ms Rohra spoke of another kind of innovation, citing Alzheimer Europe’s creation of the EWGPWD two years ago. She said “this is also innovation, to include people, to listen to them”.

19 May 2014: Dementia featured as priority at World Health Assembly

The UK Department of Health and Alzheimer’s Disease International (ADI) convened a side event dedicated to dementia at this year’s World Health Assembly in Geneva. 

Chaired by Jeremy Hughes of the Alzheimer’s Society, the well-attended event brought together ministers of health and representatives of the wider dementia and public health community.

In his introductory comments, Jeremy Hunt, the UK Secretary of Health reminded the audience of the importance of taking action on dementia because of the significant impact of the disease on individual patients and caregivers but also its societal impact due to the costly nature of the disease which could potentially bankrupt healthcare systems unless preventative measures or a cure for the disease were developed. He presented the UK’s commitment to dementia exemplified by the Prime Minister’s Dementia Challenge which aimed at improving diagnosis rates, dedicate additional funds for research into new treatments and the roll out of an exemplary campaign of recruiting dementia friends. Since the G8 Summit in London in December, Jeremy Hunt praised the appointment of a World Dementia Envoy and of a World Dementia Council as concrete actions.

Margaret Chan, the Director General of the World Health Organisation showed her commitment to dementia as a “neglected disease” by attending the initial part of the meeting and reiterating her own support to the conclusions of the G8 Dementia Summit.

Health Ministers Lormus Bundhoo from Mauritius and Rona Ambrose from Canada also identified dementia as a public health and social care priority, presented some of the actions which had been taken on a national level to improve research and the support of people with dementia and promised delegates that they would bring the subject to the attention of the World Health Assembly in 2016 at the latest.

Claude Bilat, a Swiss person with dementia took part in the side event to talk about his personal experience of being diagnosed and living with Alzheimer’s disease and reminded the audience that simple things like being patient or smiling can make a real difference for people with dementia. He welcomed the growing attention that policy makers gave to dementia. Cary Adams, the chair of the Non-communicable diseases Alliance and Stefan Seebacher from the International Federation of Red Cross & Red Crescent Societies shared their willingness of collaborating with the dementia movement.

In the ensuing discussion, Jean Georges, the Executive Director of Alzheimer Europe highlighted the importance of providing hope by investing into research for a future cure or prevention of Alzheimer’s disease whilst making sure not to forget to find practical answers for the issues faced by people living with dementia today. This thought was echoed by Jeremy Hughes who shared the important motto of the Alzheimer’s Society of “Care today, cure tomorrow”.

Jacob Roy Kurjakose, the ADI Chair concluded the event by officially launching the Global Alzheimer’s and Dementia Action Alliance (GADAA) which will bring together NGOs, professional associations, governments and other members of the wider civil society to raise awareness and tackle dementia internationally.

20-21 May: AFE-Innovnet project kicks off

Dianne Gove took part in the kick-off meeting of the AFE-Innovnet project on 20 and 21 May. Participants systematically went through the various work packages, clarified the roles of each participating organisation and discussed the taxonomy for good practices within the context of age friendly environments which had already been developed. The next meeting is planned for 1-2 October 2014.

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22-23 May: AE organises first full EWGPWD meeting of 2014 in Luxembourg

On 22-23 May, Dianne, Kate Ellis and Jean took part in the meeting of the European Working Group of People with Dementia (EWGPWD) which was held in Luxembourg. The working group discussed and agreed on their participation in the annual Alzheimer Europe meeting in Glasgow. They also discussed the coverage by the national Alzheimer associations in their countries of their contribution to the last annual conference in Malta, and how this could perhaps be improved. Kate provided a short overview of the guide she had prepared on how to use Facebook. It is hoped that this will be helpful in promoting communication within the group.

Dianne Gove provided an overview of her projects on improving continence care and on the ethical dilemmas faced by people with dementia and their carers, as well as of the project being carried out by Ana Diaz to develop a database of clinical trials for dementia in Europe. Members of the EWGPWD expressed their interest in continuing to contribute towards these on-going projects and which members would be most actively involved. Finally, Jean Georges described the procedure for the nomination of future members of the EWGPWD as the first term of office is due to end in October. The group was very enthusiastic about continuing its work and in welcoming some new members to the group.

23 May: Ana Diaz attends symposium on dementia and caregiving

Ana Diaz attended the Symposium on Dementia and Caregiving organized by the Dementia Services Information and Development Centre in partnership with Trinity College Dublin and the Irish Centre for Social Gerontology (NUI Galway), in Dublin, Ireland. In the opening speech, Professor Steven Zarit, presented some examples of empirically validated interventions in the United States that can help family caregivers cope with the stress of providing care to a relative with dementia. Effective interventions for caregivers share four overlapping characteristics: a psychological rather than a purely educational approach, multidimensionality, flexibility and sufficiency in the amount or dosage of treatment. Other topics addressed in the Symposium were the cost of the care and provision of dementia care in residential settings in Ireland. During the symposium Ana presented some of the findings of her doctoral thesis on quality of life of people living with dementia.

31 May: Alzheimer Europe finalises abstract selection for 24th annual conference

Alzheimer Europe would like to thank all the people who submitted abstracts for its 24th annual conference in Glasgow in October. The Scientific Committee has reviewed all 331 submitted abstracts and has approved 140 oral presentations and more than 100 poster presentations.

Notifications will be sent out to all applicants in the early part of June. All selected presenters for poster and oral presentations must register by 30 June, when Early Bird registration closes.

AE Projects

12 May: NILVAD hosts 3rd General Assembly

The NILVAD project partners held their 3rd General Assembly on 12-13 May in Lille, France. The meeting began with a general project update and individual reports from the nine countries where the Nilvadipine clinical trial is taking place. The country monitors also held a workshop to discuss specific aspects of the trial, which has already recruited more than 220 people with mild to moderate Alzheimer’s disease. In addition, participants heard about the progress of the three substudies and discussed upcoming communication activities - including a dedicated newsletter for the trial participants and their caregivers. In general, the NILVAD work streams are progressing very well and the partners look forward to achieving their goal of 500 trial participants by the end of the year.

14 May: EMIF bolsters its external communication activities

The EMIF communications team is pleased to announce that the first external EMIF newsletter appeared on 14 May, as an e-mail delivered to all the project partners. This first edition provides a short introduction to the project and focuses on the achievements of the first year of the European Medical Information Framework project. The external newsletter is one of several dissemination channels that are in development - all of which can be followed via the project website www.emif.eu

The website, which recently acquired a new look, also contains a series of video clips that explain the background and aims of the EMIF project. These clips have already proven to be quite popular internally and the communications team is already planning a dedicated EMIF YouTube channel. The website also holds a corporate presentation and a one-page factsheet that quickly summarises the main aspects of the project.

The sign-up area for the EMIF newsletter is available at www.emif.eu/emif/newsletter-signup and the videos can be seen at www.emif.eu/emif/about-emif/emif-video
On 9 May [Brussels, Belgium] Jean had a meeting with Lilly.

On 12-13 May [Ulik, France] Alex attended the 3rd NIVAD General Assembly.

On 12-13 May [Brussels, Belgium] Annette and Jean attended EPI AGM and related working sessions in Brussels.

On 12-14 May [Athens, Greece], Dianne took part in the EIP AHA symposium meeting in the sub-group "patient empowerment" and then attended the sessions of the EIP AHA organised in the context of the eHealth Forum 2014.

On 19 May [Geneva, Switzerland], Jean attended a dementia briefing during the World Health Assembly of the World Health Organisation.

On 20-21 May [Brussels, Belgium], Dianne took part in the kick-off meeting of the AFE-Innoven project.

On 22 – 23 May [Luxembourg, Luxembourg], AE’s European Working Group of People with Dementia met.

On 23 May [Dublin, Ireland] Ana attended the Symposium on Dementia and Caregiving organized by the Dementia Services Information and Development Centre in partnership with Trinity College Dublin and the Irish Centre for Social Gerontology (NUI Galway).

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**European Parliament Election Update**

The final list of 219 EP candidates supporting greater EU collaboration on dementia is hereunder. Candidates whose names are highlighted in green have been elected for the new parliamentary term.

**Austria:** Heinz K. Becker, MEP; Angelika Werthmann, MEP. **Belgium:** Mark Demesmaeker, MEP; Frédérique Ries, MEP; Bart Staes, MEP; Marc Tarabella, MEP; Kathleen van Brempt, MEP. **Bulgaria:** Daniela Bozhinova, MEP; Hristo Bozov; Andrey Kovatchev, MEP; Antoniya Parvanova, MEP; Stefan Shilev. **Croatia:** Biljana Borzan; Vlaha Fortuna; Damir Hršak; Neven Mimica; Tonino Picula, MEP; Milorad Pupovac; Ruža Tomašić. **Cyprus:** Simos Angelides; Eleni Chrysohotomou; Androulla Eleftheriou; Yiorgos Lillikas; Alexandros Michaelides; Yiannis Panayiotou; Antigoni Papadopoulou, MEP; George Perdikis; Charis Polycarpou; Vera Polycarpou; Christos Stylianides; Elef Theoccharous, MEP; Kyriacos Triantaphylides, MEP. **Czech Republic:** Zuzana Brzobohatá; Jaromír Kohlček, MEP; Zuzana Roithová, MEP; Libor Rouček, MEP; Zdeněk Šišek; Olga Sehnalová, MEP; Pavel Svoboda; Oldřich Vlasák; Tomáš Zdechovsky. **Denmark:** Lave K. Broch; Ole Christensen, MEP; Jens Rohde, MEP; Christer Schaldemose, MEP; Britta Thomsen, MEP. **Finland:** Pirkka Aalto; Eila Aarnos; Jari Andersson; Anne Bland; Rita Dahl; Jörn Donner; Sari Essayah; Kyyu Eturautti; Sviatlana Kuchkina; Liis Elokyniemi; Itro Saarinen; Annika Tynkkynen; Veera Tiainen; Mari Vartiainen; Maria Yannakoudakis, MEP. **France:** Jean-Pierre Audy, MEP; Christine de Veyrac, MEP; Nathalie Griesbeck, MEP; François Grossetête, MEP; Philippe Juvin, MEP; Elisabeth Morin; Christel Schaldemose, MEP; Pavel Svoboda; Oldřich Vlasák; Tomáš Zdechovsky. **Germany:** Angelika Nieder, MEP; Thomas Ulmer, MEP. **Greece:** Nikolaos Chountis, MEP; Nikos Davvetas; Konstantinos Holevas; Panagiotis Ioakeimidis; Giorgos Iwannidis; Dimitris Kontopidis; Maria Eleni Koppa, MEP; Rodi Kratsa; Neven Mimica; Hristo Bozov; Milorad Pupovac; Ruža Tomašić. **Ireland:** Thomas Byrne, MEP. **Italy:** Suzy de Martini, MEP; Pier Antonio Panzeri, MEP; Roberta Metsola, MEP; Gianluca Buonanno; Roberto Mota, MEP; Suzy De Martini, MEP; Pier Antonio Panzeri, MEP; Roberta Metsola, MEP. **Lithuania:** Vilija Biskevičiute, MEP. **Luxembourg:** Marc Angel; Georges Bach, MEP; Jean Colombera; Frank Engel, MEP; Charles Goerens, MEP; Christophe Hansen; Tom Junge; Marianne Pesch-Dondelinger; Marie-Paule Prot-Henisch; Viviane Reding; Isabel Wiseler; Sasja Baijer; Peter Spuhler. **Malta:** Joseph Cuschieri, MEP; Roberta Metsola, MEP. **Netherlands:** Esther de Lange, MEP; Lambert van Nistelrooij, MEP. **Poland:** Marek Balicki; Julia Holak; Urszula Iwicka; Beata Kij; Elżbieta Lukaniewska, MEP. **Portugal:** Carlos Coelho, MEP; Marisa Matias, MEP; Portugal: Carlos Coelho, MEP; Marisa Matias, MEP. **Romania:** Silviu Dumitrut; Daciana Octavia Sârbu, MEP; Claudiu Ciprian Tanasescu, MEP; Renate Weber, MEP. **Slovakia:** Miroslav Mikoláš, MEP; Anna Zázvorská, MEP. **Spain:** Britta Bialczak, MEP; Francisco Gómez; Ángel Cáceres; María del Carmen Martínez; Carmen Solé; José Antonio Gómez; Carmen Bescansa; Juan Luis Martín. **Sweden:** Cecilia Wikström, MEP. **United Kingdom:** Martina Anderson, MEP; Richard Ashworth, MEP; Katharina Böttger; Jayne Bryant; Maggie Chapman; Peter Cranie; Euan Davidson; Stephen Gethins; Tony Giugliano; Ian Hudghton, MEP; Christine Jardine; Jean Lambert, MEP; Anna Lo; George Lyon, MEP; Linda McAvan, MEP; Iain McGill; Claude Moraes, MEP; Jean Lambert, MEP; Anna Lo; George Lyon, MEP; Linda McAvan, MEP; Iain McGill; Claude Moraes, MEP; Ivo Vajgl, MEP; Milan Zver, MEP. **Switzerland:** Anne Thomas; Derek Vaughan, MEP; Graham Watson, MEP; Alastair Whitelaw; Glenis Willmott, MEP; Marina Yannakoudakis, MEP.
European Alzheimer’s Alliance

15 May: MEP Marisa Matias makes national dementia plan appeal

On 15 May, MEP Marisa Matias was interviewed by representatives of Portugal’s media at the Lisbon offices of Alzheimer Portugal (APFADA). She spoke of the urgency she feels ought to be accorded to implementing a National Alzheimer’s Plan in Portugal. Ms Matias lamented the fact that Portugal is among the few countries in the European Union without a national plan.

Ms Matias, a dedicated member of the European Alzheimer’s Alliance (EAA) since June 2010, also spoke of an upcoming meeting to proceed with the drafting of the National Alzheimer’s Plan, but it was with a touch of frustration that she reminded reporters that there had already been talk of this as early as 2009.

Urging Portugal to be a “good student” and keep things moving forward, Ms Matias stressed the need, not only to work towards curing dementia but also to respect the rights and dignity of people with dementia in Portugal as well as helping to alleviate the heavy workload currently borne by the families of people with dementia.

25 May: European Alzheimer’s Alliance grows in strength following EP elections

Alzheimer Europe would like to thank all candidates who signed our European Dementia Pledge in the run up to the European Parliamentary elections on 23-25 May.

By virtue of the coordinated campaign with and support from our national member organisations, 219 candidates showed their support for greater EU collaboration on dementia by joining the Alliance and/or signing the pledge, thus exceeding our original target of 200.

Of the 219 candidates, 83 were elected and have thereby committed themselves to remaining or becoming part of the European Alzheimer’s Alliance (EAA) in the new parliamentary term. 47 of the 83 successful pledgers are existing MEPs who were re-elected and the remaining 36 are new MEPs.

During the current parliamentary term the EAA had 72 members from 23 countries. At the start of this new term, the EAA will have 83 members from 26 countries, with only Estonia and Latvia not yet being represented.

We will of course continue our campaign to reach additional Members of the European Parliament.

AE would also like to say a big thank you to current members of the EAA who have worked hard to improve EU collaboration on dementia, but who were either unsuccessful in their election campaigns or chose not to stand and will therefore not be a part of the Alliance when the new parliamentary term begins.

EU Developments

2 May: EMA presents its first pharmacovigilance report to the Commission

On 2 May, the European Medicines Agency (EMA) presented the European Commission with its first report on the tasks undertaken during the first year of application of the EU’s new pharmacovigilance legislation. Pharmacovigilance is the process and science of monitoring the safety of medicines and taking action to reduce their risks.

Covering the period 2 July 2012 to 1 July 2013, the EMA says that this report reveals positive results regarding collection of key information on medicines, improved analysis and understanding of data and information, improved timeliness of procedures and greater transparency.

Some of the concrete results from this first-year reporting period are:

- An increase of more than 9000 in patient reports of suspected adverse drug reactions.
- Product information changes as a consequence of assessment of signals of new or changing safety issues with certain medicines.
- Initiation of a number of major public health reviews.
- Training thousands of individuals in pharmacovigilance and publication of a catalogue with training material for the implementation of the new legislation.

The EMA, the national competent authorities in the Member States and the European Commission have collaborated closely in implementing the new legislation.

6 May: EU Council approves IMI 2 legislation

On 6 May, the European Council adopted the IMI 2 regulation, following the Parliament’s approval on 15 April. The legislation is expected to come into force on 27 June 2014.

IMI 2 will build on the successes of IMI in advancing research and development in areas of unmet medical need. The Strategic Research Agenda (SRA) of IMI 2 has been shaped on the World Health Organisation’s “Report on Priority Medicines for Europe and the World” and input from more than 80 organisations, including regulators, patients, academia and learned societies.

The initial focus of IMI2 will be on fields such as neurodegeneration, metabolic disorders, immune-mediated diseases, infections and translational safety. Indicative summaries of the topics under consideration for inclusion in the Calls for proposals that will be
launched in 2014 under IMI 2 are now available on the Future Topics page of the IMI website. The EU funding for IMI 2 will come from Horizon 2020.

12 May: Dianne Gove attends EIP AHA Synergies meetings in Athens

Dianne took part in the EIP AHA synergies meeting in the sub-group patient empowerment. A smaller patient empowerment sub-group will be established to facilitate the creation of synergies between existing action groups addressing healthy ageing and in relation to patient empowerment. Dianne then attended the sessions of the EIP AHA organised in the context of the eHealth Forum 2014. These sessions focused on scaling up which involves learning from good and bad practices at a local level and spreading the good practices to a wider/regional level.

12-13 May: EPF AGM takes place in Brussels

EPF held its General Assembly Meeting and organised working sessions on ‘Access’, ‘Patient Empowerment’ and ‘Understanding Youth and strengthening the involvement of the Youth Group in EPF’. AE was represented by Jean Georges and Annette Dumas at these meetings.

Access to equitable access to healthcare is a key priority for EPF and part its work plan for 2014. EPF presented the organisation’s work on this topic and the setting up of an ‘Access’ working group within EPF. The aim of this group is to involve members from the outset in EPF policy formulation and activities and contribute to specific policy and projects work relating to access to health and social care (defining access from a patient’ perspective, develop indicators for monitoring and engage in activities to build evidence base on health inequalities). Annette Dumas will represent AE in this working group and will link up with EPF Public Affairs Group.

The ‘European Access Partnership’ was also introduced to the participants. This is an EPF-lead multi-stakeholder platform that will seek to facilitate the dialogue between the patients, European policy makers and institutions, healthcare professionals, member states and industry. The work of the Partnership was presented (Health inequalities Conference in Sofia followed by a resolution, a patients’ survey on access to healthcare, EP conference on ‘Health Inequalities in the ‘new’ EU Member States. Equity of Access to Quality Healthcare’ and the Vilnius Declaration for sustainable health systems for inclusive growth in Europe, adopted during the EU Presidency of Lithuania).

The ‘European Access Partnership’ and EPF working group on access will work closely to influence the European political agenda.

At the GAM, EPF presented its European elections Manifesto ‘Your vote for a healthier Europe’. EPF’s priorities are embodied in the Manifesto (patients views must be taken into account by the policy makers, patients must be empowered to be considered as equal partners with health professionals, patients must have equitable access to good quality healthcare, patients must be involved across the spectrum of health research and their rights must be recognised). 56 decision-makers have signed EPF Manifesto.

There was also a presentation of EUPATI (European Patients Academy on Therapeutic Innovation), an IMI-funded project led by EPF that will develop and disseminate objective, trustworthy, public knowledge about medicines R&D and facilitate patient involvement in R&D to collaborate in academic & industry research, authorities and ethics committees. The project will develop a web platform with education material targeted at different levels (EUPATI Certificate Training Programme for expert patients, EUPATI Educational Tool Box for patient advocates and a EUPATI Internet Library for the health-interestsed public). The material will be available in English, French, German, Spanish, Polish, Italian and Russian.

A new Board was elected. Anders Olauzon (Eurordis) who will continue as President of EPF, Susanna Balkonen (European Federation of Allergy and Airways Diseases Patients Associations) as Vice-President and Tomasz Szolagowski (Federation of Polish Patients) as Treasurer. Two new members join the Board: Brian West (European AIDS Treatment Group) and Dominik Tomek (Association for the Protection of Patients’ Rights in Slovak Republic). Current board members, Vida Augustinienë (Lithuanian Diabetes Association), Marco Greco (Federation of Crohn’s and Ulcerative Collitis Associations), Robert Johnstone (National Voice UK) and Stanimir Hasurdjiev (National Patients’ Organization - Bulgaria) will continue their mandate for a further year.

EPF benefits from a EU-funded operating grant in 2014. This covers its core activities and policy work (44%), projects (40%) and capacity building projects (16%). EPF now contemplates applying for a multi-annual operation grant that will span the next 4 years.

19 May: MEP Abela Baldacchino receives written reply from Commissioner Neelie Kroes

Following an article published in the Malta Independent newspaper on 25 February, which suggested that people living with dementia in Malta be electronically tagged to prevent undue anxiety if they go missing, Maltese MEP Claudette Abela Baldacchino wrote to the European Commission. She asked whether the Commission could inform her of which Member States have introduced technological devices of this kind to protect people suffering from dementia and also in which ways the Commission contributes to the development of such technological devices in its health strategies.

On 19 May, Ms Abela Baldacchino received the following written reply from Ms Neelie KROES, Vice President of the European Commission, leading the Digital Agenda:

“The Commission cannot give an overview about which Member States have introduced tracking devices to protect people suffering from dementia, since health policies can be determined at national, regional and local level. A collection of mental health and wellbeing initiatives by national and regional authorities across the EU is publicly available.
The European Commission is contributing to the development of a wide range of technological devices responding to the challenges of dementia as part of a larger strategy spanning health, demographic change and wellbeing. This includes support for research and innovation (R&I). The current work programme of Horizon 2020 calls for specific R&I actions to help people to live independently with cognitive impairment and to support their mental wellbeing.

Coordination and collaboration in this area of research is ensured by the Member State driven Joint Programming Initiatives on "More Years Better Lives" and "Neurodegenerative Diseases Research".

In addition to this longer term research, the Active and Assisted Living Joint Programme (AAL JP) supports market-oriented research for independent living and the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA) is fostering stakeholder-driven collaborative innovation to ensure the wider dissemination and scaling-up of best practices across Europe and to improve quality of life, among others, regarding dementia supportive environments, cognitive decline and independent living solutions.”

**22 May: EU Ombudsman receives EMA response to change of policy query**

In a letter dated 13 May to the European Medicines Agency (EMA), the European Ombudsman, Emily O’Reilly expressed concern about a change in policy concerning clinical trial data transparency. An approach which she said “very much differs from what I had understood to be EMA’s initial approach.”

Ms O’Reilly referred to documents sent to her on 7 May, which she was concerned showed that EMA was planning to limit access to clinical trial data by imposing strict confidentiality requirements and by allowing data only to be seen on screen using an interface provided by EMA, as well as imposing wide restrictions on the use of such data.

Against the backdrop of the EU vote of 2 April, in favour of more clinical trial data, the Ombudsman asked EMA’s Director, Guido Rasi, to inform her of how EMA intends to deal with requests for public access to existing clinical trial data. She also asked Mr Rasi to list the reasons and the legal basis for the change of policy.

On 22 May, Mr Rasi responded to the Ombudsman’s letter, stressing that the “perceived change of policy” is, in fact “intended to further increase transparency of clinical trial data” and that there is “no intention to introduce any hurdle to the implementation of EU legislation on access to documents.”

Mr Rasi assures Ms O’Reilly, in his letter, that the EMA’s new policy will mean that “all clinical study reports submitted to EMA in order to support an application for a centralised marketing authorisation, even those pertaining to trials performed outside the EU”, after the new regulation on data transparency enters into force, which is expected to be in mid-2016, “will be made public once a final decision on the application has been taken.”

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**26 May: Commission’s 2014 Health Programme work plan adopted**

The Commission has announced that its annual work plan for 2014 in the framework of the third Health Programme (2014-2020) was adopted on 26 May 2014.


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**28 May: Commission rejects appeal to ban stem cell research funding**

On 28 May, the European Commission announced that it will take no further action on the ‘One of Us’ citizens’ initiative. The initiative, a petition-based campaign, sought to halt all EU funding for embryonic stem cell research and IVF treatments involving the use of human embryos.

The European Parliament discussed the ‘One of Us’ initiative in April, before it was passed to the European Commission who made the final decision on whether to proceed with it. In a statement made on 28 May, EU research commissioner Marie Geoghegan-Quinn ruled out a policy change by the EU executive:

“We have engaged with this Citizens’ Initiative and given its request all due consideration, however, Member States and the European Parliament agreed to continue funding research in this area for a reason. Embryonic stem cells are unique and offer the potential for life-saving treatments.”

In April, the Wellcome Trust coordinated a joint statement on the continued support of stem cell and reproductive research under Horizon2020. Alzheimer Europe’s board supported the joint statement made by the trust, which was fully in line with the position that AE adopted on this issue in 2007.

In response to the Commission’s announcement, Gregor Puppinck, Director of the European Centre for Law and Justice (ECLI), an NGO based in Strasbourg and one of the key groups behind the initiative thought it likely that they would appeal the decision at the EU’s highest court, European Court of Justice in Luxembourg.

Wellcome trust statement and signatories: [www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_peda/documents /web_document/wp056637.pdf](www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_peda/documents /web_document(wp056637.pdf)


“One of Us” initiative: [www.oneofus.eu/](www.oneofus.eu/)

[www.alzheimer-europe.org/Donation](www.alzheimer-europe.org/Donation)

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**Newsletter: May 2014**


Members’ News
1 May: “Dementia: then what?” documentary released on DVD

Over a period of two years Dutch documentary maker, Ireen van Ditshuysen teamed up with Alzheimer Nederland to follow the lives of five people with dementia in The Netherlands. The resulting film, “Dementia: then what?” which aired on Dutch national television in late 2013 has now been released on DVD, with English subtitles.

Telling the stories of its five protagonists from diagnosis until they move into care homes, the film touches on symptoms, the course of the disease, various clinical features of the disease and the stages (of young and older onset) as well as examining roles of GPs and specialists. It also aims to give an insight into what it was like to participate in research and the impact of the disease and its progression on the five people with dementia and their loved ones.

To find out more and to purchase the dvd, please send an e-mail with your contact name and full address to: info@alzheimer-nederland.nl

Trailer (English subtitles): www.vimeo.com/84388261 (Password: DenD)

7 May: ASI calls for water prices to be capped for people with dementia

On 7 May, Alzheimer Society of Ireland called on Ireland’s Minister for Health to include dementia in the list of medical conditions for which water charges will be capped in Ireland.

The society cautiously welcomed news that carers, pensioners and those with a disability will be given an allowance to cover increased water usage needs, but drew the Minister’s attention to the fact that 63% of people with dementia in Ireland live at home in the community and many have high physical care needs requiring higher than average water use.

Gerry Martin, the society’s CEO said “People with dementia and their carers must not be at risk of having their water supply severely diminished as this could worsen existing medical conditions. We are calling on the Minister for Health to include Alzheimer’s and dementia on the list of medical conditions for which charges will be capped to enable the almost 50,000 people currently living in Ireland with dementia to continue to have a steady water supply as a basic necessity for their health and wellbeing”.

15 May: Spominčica invited to participate in “Brain” exhibition

“Brain- the inside story” an exhibition from the American Museum of Natural History in New York, all about the human brain, is visiting Slovenia’s capital, Ljubljana from 15 May until 24 August. The opening speech, on 15 May, was delivered by Slovenia’s US Ambassador, Joseph Mussomeli.

Spominčica was invited by the CEO of Ljubljana Convention Centre to actively participate in the exhibition.

Ljubljana was one of only three cities in Europe (Milan and Granada being the other two) chosen to host the exhibition, which has been organised in the context of 2014 - Year of the Brain.

During the exhibition, Spominčica will give three public lectures about dementia and have also set up an Alzheimer Cafe Pavilion.

http://en.brains.si/about-exhibition

20 May: National support network in Portugal grows

Alzheimer Portugal (APFADA) has sought, through the establishment of agreements with several entities, to extend the network of support, both for people with dementia and for their caregivers. The intention is to promote information, training and local support in order to increase awareness for the cause.

In addition to the already existing offices in Azeitão, Campo Maior and Fatima, new offices in Portimão, Beja and Viseu were recently given the go-ahead. The Office of Portimão opened on 15 May and the Beja one on 20 May. The Cabinet of Viseu has been operating since 1 April.

The Northern Delegation of APFADA has also established a new protocol for the creation of two new offices, one in Fafe and another in Cabecceiras de Basto, in operation since 7 March.

This means that APFADA now has 10 units and 11 support offices spread across 12 of the 18 districts of continental Portugal and the Madeira Archipelago.

23 May: Alzheimer Society of Ireland on local elections campaign trail

In the run-up to the Irish local elections, which took place on Friday 23 May (same day as the European Parliament elections in Ireland), the Alzheimer Society of Ireland was involved in a lot of grassroots lobbying, asking all local candidates to work towards making their communities more dementia-friendly.

Specifically, candidates were asked to:

- Support their local Alzheimer Society of Ireland services.
- Raise awareness of dementia in their area.
- Ensure the voice of people with dementia is heard by decision-makers.
- Ensure people with dementia are included in arts and recreation activities.
• Recognise the needs of people with dementia and their carers.
• Respond to the needs of people with dementia who are under 65.

A local election newsletter was developed to outline how local government can support people with dementia and their family carers. Voter prompt cards were also distributed across the country for voters to use when any canvassing parties called. The prompt card aimed to help voters outline the concerns facing people with dementia and their carers.

There was a positive response to the campaign from candidates. Some incorporated The Alzheimer Society of Ireland’s asks into their own election manifestos, while others pledged their support once elected.

“We must make our communities Dementia Friendly now…I am calling on Meath County Council to take on the challenge as put by the Alzheimer’s Society of Ireland and work with them to achieve this and if re-elected I will fight to make this happen” (Local Election Candidate).

You can read more about their local election campaign here:

26 May: Muistiliitto says Finland is taking care!

In 2013, the Alzheimer Society of Finland, Muistiliitto started its TAKE CARE! campaign. The motto stems from a true story: a woman with Alzheimer’s disease wandered outside her home and got lost during a freezing winter day. She walked around for hours, but nobody stopped her and no one asked her if she needed help; she died later the same day in a hospital. The Alzheimer Society of Finland wants to build a safer life for people with memory-related diseases and is raising awareness about safety issues and basic human rights.

On 26 May a young woman from Western Finland, Pauliina Koitto, was awarded a “Helping hand statue” by the Finnish National Rescue Association. In the middle of the night, Ms Koitto took care of a stranger, an older lady suffering from disorientation due to a memory disorder. Ms Koitto did not want to leave her outside to freeze in 17 degrees below zero! As another fine example, a serviceman in the armed forces, Aleksi Mäkelä, was recently given a military award for rescuing a person with a memory disorder.

The Finnish society is pleased to note that the Finnish media has been covering stories of people helping disoriented fellow citizens and is grateful for all the Finns who TAKE CARE! of themselves and of the people around them. “We all need each other occasionally and no one should have to survive alone”, says the society.

27 May: Swiss Confederation hosts national dementia plan kick-off meeting

On 27 May a kick-off meeting for Switzerland’s national dementia plan was organised by the Swiss Confederation and the cantons. Seven projects have been accorded high priority status and their implementation was launched at this meeting.

The first four projects to be tackled imminently are:
• Information and sensibilisation (the Swiss Alzheimer’s Association has the lead)
• Diagnostic (access, network of centres of excellence, guidelines)
• Monitoring
• Financing.

31 May: Alzheimer Society has a campaign-heavy month

May has seen a flurry of activity in the UK, with the launch of Public health England and Alzheimer Society’s new star-studded television campaign, followed by Dementia Awareness Week from 18 to 24 May with events across England, Wales and Northern Ireland. All of this was set against a backdrop of campaigning to sign European Parliamentary candidates up to Alzheimer Europe’s EU Dementia Pledge in the run up to the European elections on 23 May.

The Dementia Friends’ televised campaign, launched on 6 May features celebrities including singer Lily Allen, Discworld series novelist Sir Terry Pratchett and Coldplay’s Chris Martin. The advert encourages people to become Dementia Friends and was shown regularly on national television throughout May, as well as being disseminated on the internet.

Dementia Awareness week from 18 to 24 May kicked off with the results of a poll showing that more than 40 per cent of people affected by dementia keep concerns about the condition to themselves and are too ashamed, afraid or worried about being a bother to discuss their concerns with anyone. Off the back of this poll Alzheimer’s Society ran its “don’t bottle it up” campaign throughout the week, hoping to get people to open up about dementia. They encouraged people to talk to them and, in the spirit of the campaign, ran a Twitter Q and A session with Dr Dawn Harper from Channel 4’s “Embarrassing Bodies” on 18 and 19 May, encouraging people to ask Dr Harper any questions they had previously felt unable to ask.

There was national and regional press coverage throughout the week and the society also announced a new celebrity supporter, Alice Eve, star of last year’s blockbuster film “Star Trek: Into Darkness”.

On 20 May, the Society also held its first ever Dementia Friendly Awards.

The winners can be found here: www.alzheimers.org.uk/dementiafriendlyawards

The Dementia Friends campaign video can be found on: www.dementiafriends.org.uk
31 May: Board for the Norwegian Dementia Research Programme appointed

The Norwegian Health Association has recently appointed the board for the upcoming Dementia Research Programme. Former Minister of Education Tora Aasland is to head up the board. The other four elected board members are Professor Menno Witter, Kavli Institute for Systems Neuroscience, Ole Andreassen, Professor of Psychiatry at the University of Oslo, Peter Johannsen, Associate Professor at Copenhagen University and Wenche Frog Sellig, former Minister and Member of Parliament and current head of Norway’s Senior Citizens Advisory Board.

The board will allocate research funding, work towards broader international cooperation and stimulate interdisciplinary cooperation within dementia research. The funding for the programme was obtained by way of last year’s telethon that focused on the increase dementia awareness in Norway. In September this year, the programme’s first allocations will be announced.

31 May: Monaco’s Kate Williams takes on the Ironman challenge

On 29 June, Kate Williams from AMPA Monaco will take part in the 226 km “Iron Man France” competition in order to raise public awareness and funds for the cause.

An Ironman Triathlon is one of a series of long-distance triathlon races organised by the World Triathlon Corporation consisting of a 3.9 km swim, a 180 km bicycle ride and a marathon (42.1 km) run, raced in that order and without a break.

Kate has set up a blog and will appreciate any and all support!


Policy Watch

30 April: World Dementia Council holds inaugural meeting

Following the 2013 G8 dementia summit, a World Dementia Council was appointed to support World Dementia Envoy, Dr Dennis Gillings CBE. The 13-member council met for the first time in London on 30 April.

With the summit objective being to find a cure or disease-modifying therapy by 2025 and with the global cost of dementia at an estimated USD 604 billion (EUR 443 billion), the Council proposed plans to remove barriers to innovation, improve investment conditions and to encourage new research into dementia globally, working with governments, regulators and industry.

Dr Gillings said “We are determined to be radical but practical in the proposals that we bring forward. We will speak plainly to governments, regulators and industry about the changes we need to see happen quickly.”

Along with Dr Gillings, the members of the Council are:

- Sir William Castell, Chairman of the Wellcome Trust
- Dame Sally Davies, Chief Medical Officer at the Department of Health, England
- Dr Tim Evans, Director for Health, Nutrition and Population at the World Bank
- Dr Franz Humer, Chairman of Roche
- Dr Yves Joannette, Scientific Director, Canadian Institutes of Health Research, Institute of Aging
- Professor Martin Knapp, Director of Health, the London School of Economics
- Dr Kiyoshi Kurokawa, Professor of the National Graduate Institute for Policy Studies and Chair, Health and Global Policy Institute
- Yves Leterme, Deputy Secretary General of the Organisation for Economic Co-operation and Development
- Raj Long, Senior Regulatory Officer – Integrated Development, Global Health at the Bill & Melinda Gates Foundation
- Professor Pierluigi Nicotera, Scientific Director and Chairman of the Executive Board, German Centre for Neurodegenerative Diseases
- Professor Ronald Petersen, Director, Mayo Alzheimer’s Disease Research Center
- Dr Paul Stoffels, Global Chair of Johnson & Johnson
- George Vradenburg, President and Chairman of the Vradenburg Foundation and USA against Alzheimer’s

8 May: UN appoints Independent Expert on human rights of older people

On 8 May, the United Nations Human Rights Council in Geneva appointed Rosa Kornfeld-Matte as the new Independent Expert on the full enjoyment of the human rights of all older persons. Ms Kornfeld-Matte brings a wealth of experience to the position, having served as the National Director of the Chilean National Service of Ageing and a long career as an academic in the areas of gerontology, social policy and human rights. This is the first international UN mechanism dedicated to the human rights of older people.

As well as assessing how existing international human rights instruments have been implemented in relation to older people’s rights, Ms Kornfeld-Matte’s mandate will involve fact-finding missions, thematic studies on norms and standards and raising public awareness through the media. She will work in close coordination with the UN Open-Ended Working Group on Ageing (OEWG) and will report to the Human Rights Council on an annual basis, with the first report in September 2014.

www.ohchr.org/EN/Issues/OlderPersons/Pages/IOlderPersons.aspx
20 May: Ex-ballerina forces ‘landmark’ ruling in social care

Former star of Scottish Ballet, Elaine McDonald, OBE, has been locked in a six-year legal battle with Kensington and Chelsea Council in the UK over their decision to stop providing her with a night-carer to help her visit the bathroom. In November 2008, the 71 year-old’s local authority told her she would instead be provided with incontinence pads.

Ms McDonald, despite losing her case at the European Court of Human Rights (ECHR) on a separate issue, has forced an unprecedented ruling which could encourage social workers to consider the dignity of the elderly when assessing care provision needs.

Kensington and Chelsea Council withdrew the carer in order to save £22,000 a year, a decision the ECHR supported because it found the council’s right to pursue the “economic well-being of the State” at a time of austerity outweighed the rights of Ms McDonald.

“Therefore, despite the very distressing situation Ms McDonald was facing, the Court held that from 4 November 2009 onwards the interference with her right to respect for private life had been both proportionate and justified as ‘necessary in a democratic society’ and rejected this part of her complaint as inadmissible,” the judgement said.

Caroline Abrahams, charity director at Age UK, said: “While today’s ruling is very disappointing for Mrs McDonald as it does not provide her with the round the clock care she needs, legally it is a landmark ruling which potentially could have a significant effect on decisions around the provision of care in the UK.”

30 May: World Dementia Council publishes statement of purpose

The World Dementia Council published its statement of purpose on 30 May, setting out an ambitious 10 year plan, with the aim of “mobilising a global assault on dementia, in the way we attacked HIV/AIDS in the 1980s and 90s” by working on “accurate and early diagnosis, effective treatment and better care and support.”

“We believe current research and development is not making sufficiently rapid progress...the current ratio of risk to reward in dementia research and development is not attractive to investors. The lead times are long and the chances of failure are very high. We need to change that equation”.

Members of the Council come from different backgrounds and different nations but are united in their passion “to make an urgent and fundamental breakthrough in the diagnosis, treatment and care of people with dementia.”

“We will speak freely and clearly as to what we believe needs to change. We will be radical in our thinking, but always based on the best evidence and sound science.”

The Council encourages responses to its statement of purpose.

www.dementiachallenge.dh.gov.uk/2014/05/30/world-dementia-council-publishes-statement-of-purpose/

Science Watch

4 May: Young blood improves cognitive function in older animals

A new study from Stanford University shows that exposure of an aged mouse model to blood from a young animal can counteract and reverse pre-existing effects of brain aging at the molecular, structural, functional and cognitive level.

Dr Tony Wyss-Coray, study leader and Professor of Neurology at Stanford, contends that the plasma of young people may carry elements that diminish with age, leading to Alzheimer’s and many other diseases. If this “young” plasma is given to older people with dementia, these elements may be able to rejuvenate synaptic plasticity and improve cognitive function.

Dr Wyss-Coray is planning a Phase 2a clinical trial that could begin in late 2014 at the Stanford facilities. Some 20 participants with Alzheimer’s disease will be given plasma from young individuals and the researchers will use functional imaging to monitor the results.

The ultimate objective of the new study is to slow the onset of dementia rather than cure it. According to Dr Wyss-Coray, “if you can delay aging by a few years, you take care of most of the patients, because they will die of another cause.”

The study was funded by the U.S. Department of Veteran Affairs, the National Institute of Aging and the California Institute for Regenerative Medicine.

www.nature.com/nn/journal/vaop/ncurrent/full/nn.3569.html

7 May: FABP5 protein enhances cognitive function

Researchers at Case Western Reserve University (Ohio, USA) have shown that the FABP5 protein enhances cognitive function and that its deficiency impairs learning and memory functions in the hippocampus. FABP5 (fatty acid binding protein 5) is present in many body tissues and is especially highly expressed in the brain.

The research team led by Dr Noa Noy, Professor of Pharmacology at the School of Medicine, found that FABPS performs two different functions in neurons. First, it facilitates the degradation of endocannabinoids, which are neurological modulators controlling appetite, pain sensation, mood and memory. Second, the protein regulates gene expression, the process that controls cellular structure, appearance and function.

Dr Noy said: “FABP5 improves learning and memory both because it delivers endocannabinoids to cellular machinery that breaks them down and because it shuttles compounds to a transcription factor that increases the expression of cognition-associated genes.”

Essentially, FABPS acts as a truck that delivers endocannabinoids to individual neurons. Upon arrival, the endocannabinoids are degraded and the resulting product is moved – again by FABPS - to the nucleus. The degraded
product causes activation of a transcription factor that in turn launches production of various genes. Finally, these genes “instruct” the neurons to take steps that promote learning and memory.

Dr Noy concluded that: “we believe if we could find a way to upregulate (increase) the expression of FABP5 in the brain, we might have a therapeutic handle on cognitive dysfunction or memory impairment in some human diseases.”

8 May: Study of KLOTHO gene shows that it may enhance cognition

The effects of a variant of the gene KLOTHO, known to have anti-ageing effects in people fortunate enough to carry one copy, has been the subject of a study by researchers at the Gladstone Institute and the University of California in the US. The Gladstone Institute’s director, Dr Lennart Mucke led the study alongside Dr Dena Dubal from the UCSF Memory and Aging Center at the University of California. Their report, which concludes that the gene has added benefits with regard to brain function, was published in the Journal Cell Reports on 8 May.

Together with a large group of collaborators, Drs Muckle and Dubal examine three separate groups of people participating in ageing studies of various kinds, totalling over 700 people. Their published results showed that people with one of the life-extending variants of the KLOTHO gene scored better on cognitive tests. Since these effects seemed to be linked with higher circulating levels of klotho in the brain and bloodstream, they turned their focus to genetically engineered mouse models expressing higher-than-normal levels of the substance.

Elevating klotho levels in the mouse models enhanced their cognitive function as well as increasing the formation and flexibility of neural connections, the researchers say. The effects of klotho were evident in young and ageing mouse models and humans alike, according to the researchers.

The report also states that in healthy, ageing humans the positive cognitive effects of carrying one copy of the KLOTHO variant may override the effect of carrying the APOe4 gene variant, shown in previous research to increase incidence of developing Alzheimer’s disease.

12 May: AC Immune and Piramal will develop Tau protein diagnostics

AC Immune SA and Piramal Imaging announced on 12 May that they have entered into an exclusive worldwide license agreement for the research, development and commercialisation of AC Immune’s Tau protein positron emission tomography (PET) tracers which they say could help with the diagnosis and clinical management of Alzheimer’s disease (AD).

The formation of Tau tangles in the brain is recognised as one of the hallmarks of AD pathology, making it a potential target for diagnostic approaches. The availability of a Tau-PET tracer for imaging Tau tangles in the brain of patients could also be of value in clinical trials for disease-modifying therapeutics.

AC Immune will work in collaboration with Piramal Imaging to try to advance several lead candidates through late pre-clinical radio-pharmacology development. Piramal Imaging will have global rights for clinical development, manufacturing and commercialisation of a Tau-PET Tracer resulting from the collaboration.

13 May: Inovio acquires early stage DNA therapies for AD

Inovio Pharmaceuticals announced on 13 May that it has acquired worldwide rights (excluding China) for early preclinical therapies addressing Alzheimer’s disease and multiple sclerosis, thanks to the academic research of Professor Bin Wang of Fudan University’s Shanghai Medical College.

These newly licensed technologies are based on patent-protected and published discoveries from Prof. Wang and his collaborator, Dr David Weiner of the University of Pennsylvania. The scientists claim to have found a new method for generating inducible regulatory T cells (iTreg). These cells are involved in shutting down immune responses after they have successfully eliminated invading organisms, as well as in preventing autoimmunity or inflammatory diseases.

These new approaches could be used to develop therapies targeting major inflammatory diseases like multiple sclerosis and may also be useful in treating Alzheimer’s disease.

14 May: New research published into effects of antidepressants on Amyloid plaques

A commonly prescribed antidepressant can reduce production of amyloid-β (Aβ) plaques in mice and humans, according to new US research completed at Washington University School of Medicine in St. Louis and at the University of Pennsylvania. The study, led by Dr John Cirrito, assistant professor of neurology at Washington University and Dr Yvette Sheline of the University of Pennsylvania was published in the journal Science Translational Medicine on 14 May.

The research team used an antidepressant, citalopram to stimulate serotonin signaling in aged transgenic AD mouse models. Using a technique called two-photon imaging, they then tracked the growth of plaques similar to those found in brains affected by Alzheimer’s disease, over the
course of 28 days. The results showed that the growth of existing plaques had halted and the formation of new plaques were reduced by 78%.

In a second experiment, the team gave a single, concentrated dose of citatopol to 23 people aged 18 to 50 years who were "not cognitively impaired or depressed". Samples of cerebrospinal fluid (CSF) taken from the participants over the next 24 hours showed a 37% drop in amyloid beta production as compared with placebo. The researchers noted, however, that the drug could not cause existing plaques to shrink, or decrease in number.

Although the findings seem encouraging, Dr Cirrito cautioned that the risks and side effects associated with anti-depressants mean that until there is more definitive proof that these drugs help slow or stop Alzheimer's disease in humans, the risks aren't worth it. He insisted that "there is still much more work to do."

Dr James Pickett, head of research at the Alzheimer's Society also advised caution. He said that it was "an interesting paper" and was impressed that the team had managed to take their study from mice to humans, which can be problematic, but that the sample size was small and that the researchers had not carried out the study on people with Alzheimer’s, nor people over the age of 50.

www.stm.sciencemag.org/content/6/236/236re4

14 May: Eisai and Biogen to co-develop new Alzheimer's disease drugs

On 14 May, Eisai Co. Ltd. Announced that it will exercise its option to jointly develop and commercialise its clinical candidates for Alzheimer's disease (AD), together with US biotechnology firm Biogen Idec. The option was included as part of Eisai's collaboration agreement with Biogen Idec announced in March 2014.

Based on the agreement, Eisai and Biogen Idec will co-develop Eisai’s investigational AD treatment candidates E2609 and BAN2401 for major markets such as the United States, the European Union and Japan.

E2609 is believed to inhibit BACE, a key enzyme in the production of amyloid beta (Aβ). BACE inhibition decreases Aβ proteins in the brain, potentially improving symptoms and AD progression. BAN2401, an Aβ protofibril antibody, is believed to selectively bind to and eliminate soluble, toxic Aβ aggregates that are thought to contribute to the neurodegenerative process in AD.

A phase two clinical trial is already underway for BAN2401, while E2609 is currently undergoing preparations for a phase two clinical trial.


14 May: Further research published on role of calcium in familial AD

A team of researchers at the Perelman School of Medicine, University of Pennsylvania, US has completed a study into the effects of calcium in familial Alzheimer’s disease (FAD). The study was published on 14 May in the Journal of Neuroscience.

The team, led by Dr J. Kevin Foskett, chair of Physiology, had found in an earlier study that mutations in presenilin 1 and 2 (PS1 and PS2) disrupt the flow of calcium ions within neurons and result in exaggerated calcium signalling in the cell. PS1 and PS2 are proteins associated with FAD.

Using two FAD mouse models, the team found that PS1 and PS2 interacted with a calcium release channel, the inositol trisphosphate receptor (IP3R), in the endoplasmic reticulum. Mutant PS1 and PS2 increased the activity of the IP3R, in turn increasing calcium levels in the cell. Reducing the expression of IP3R1 - the dominant form of the IP3R receptor in the brain - by 50% was found to normalise the exaggerated calcium signaling observed in neurons of the cortex and hippocampus, thus alleviating FAD-like symptoms.

Dr Foskett believes that the research shows that increased calcium signaling, as a result of the presenillin-IP3R interaction is involved in the development of familial Alzheimer’s disease symptoms, including dementia and cognitive deficits. He also believes that, following these observations, approaches based on modulating calcium signaling should be explored for new AD therapies.

www.jneurosci.org/content/34/20/6910.short?sid=3d23c763-b4fd-442e-8a56-08c1f3ed73c9

21 May: Transthyretin protein may provide new therapeutic target for AD

A group of researchers, who have conducted a study at the Scripps Research Institute in California, US say that Transthyretin (TTR) - a protein implicated in producing aggregates normally harmful to the body - plays a part in warding off Alzheimer’s disease (AD). Their study, which was published on 21 May in the Journal of Neuroscience, has led them to start working towards a new drug for the disease.

TTR acts as a transporter for vitamin A and thyroxine (T4) in the body via cerebrospinal fluid and the bloodstream. It is mostly found in the liver and in cerebrospinal fluid production centres in the brain, but can also be produced at low levels in neurons.

In earlier research conducted by study co-author Prof. Joel N. Buixbaum, from the Institute’s Department of Molecular and Experimental Medicine, TTR had been found to bind to amyloid-beta in transgenic mouse models. The conclusion was that TTR may help to prevent AD.

In this new study, the team analysed DNA near the TTR gene and tested whether “transcription factors” - proteins that bind to specific DNA sequences, thereby controlling the flow of genetic information from DNA to messenger RNA - might increase activity of the TTR gene. One of these, Heat Shock Factor 1 (HSF1), was able to bind to the promoter of the TTR gene, boosting TTR production. Surprisingly, this boost in TTR production could only occur in neuronal-type cells and not in the liver cells where the bulk of the body’s TTR is produced.

The team is now in the early stages of developing a small molecule compound that could be delivered in pill form.
Dementia in Society

25 April: "Expressions – the Journey" arts festival features work by people with dementia

Milestones Trust, a charity based in Bristol, England, held an arts festival from 25 April to 1 May involving work from people with a variety of learning disabilities and mental health needs as well as people living with dementia.

Local residents of the Bristol Dementia Care Centre helped in the production of works for the “Expressions – the Journey” festival, which featured a creative indoor landscape of installation art, including colourful, knitted streets and shops.

The exhibition was formally opened on 25 April by award-winning author Nathan Filer, whose book "The Shock of the Fall" follows a young man with schizophrenia.

www.milestonestrust.org.uk/expressions

7 May: NHS England to provide more support for unpaid UK carers

The new CEO of NHS England, Simon Stevens, has committed his organisation to do more to support the millions of people providing unpaid care in the UK. His pledge to "care for the carers" was made on 7 May, to coincide with the carers UK annual “State of Caring” conference, in London.

At the conference, the 2014 “State of Caring” survey results were presented: 80% of survey respondents said that they suffer from negative effects on their physical health as a result of their caring activities. 73% also said that caring had a significant impact on their mental health, chiefly impacting on their anxiety and stress levels.

Mr Stevens made his pledge as he launched a new NHS document containing eight priorities and 37 commitments, drawn up in collaboration with carers, charities and partner organisations. It promises a national event for young carers, a carers’ champion on the board of NHS England and working with carers on personalised care planning, end of life care and dementia care.

www.england.nhs.uk/2014/05/07/commitment-carers/

29 May: Karlheinz Böhm dies aged 86 with Alzheimer’s disease

As an actor, Böhm was primarily known for his role as Emperor Franz Joseph in the “Sissi” films alongside Romy Schneider.

Böhm was also the founder of the aid organisation Menschen für Menschen, (People for People). The charity helps people in need in Ethiopia and has been led for some years by Mr Böhm’s Ethiopian wife, Almaz. In December 2013, she gave up her position as CEO of the organisation in order to care for her husband.

New Publications & Resources

14 May: Care UK releases dementia-friendly communication guide

Families, carers and dementia specialists have contributed to a new guide published by Care UK on 14 May. “Listen, talk, connect” aims to help families and friends of people with dementia to overcome communication hurdles and have more positive and meaningful interactions with their loved ones.

Dementia experts involved in the report explain that it is key to talk about the period that the person with dementia is “living in right there and then”. They also stress that “more importantly, it is essential to accept the person living with dementia for who they are now, rather than how you may have known them.”

Challenging a person living with dementia, or trying to force them to acknowledge the modern world is strongly discouraged in the guide. Instead, it urges people to understand how effective and therapeutic it can be to “walk with them down memory lane”.

Central to this guide is: “understanding that for someone with dementia, their thoughts, opinions and perceptions, which may be distorted, is the only reality they know.”

The guide is available to download (see below link) and printed copies are complimentary at any Care UK care home.

www.careuk.com/sites/default/files/CareUK_Dementia_Guide.pdf

Job opportunities

27 May: Bournemouth University seeks Post-Doctoral Research Fellow

A full time, permanent position for a Post-Doctoral Research Fellow at Bournemouth University Dementia Institute (BUDI) opened for applications on 27 May.

The Institute’s aim is to develop research, follow this through in education and explore the wider communication of ideas to policy makers, practitioners, carers, people with dementia and other interested parties.

The successful applicant would work closely with Professor Anthea Innes - Director of BUDI and duties would include data collection, data analysis, writing for publication and dissemination. In addition, making a contribution to the education and training portfolio under
development in BUDI. Applicants must have a PhD in a health or social science or related area, experience of data analysis and ideally be experience in using one or more of the well-known software packages as well as being a highly motivated researcher with a genuine interest in working in the dementia field. A satisfactory enhanced DBS is also required for this post.

Applications close on 19 June.

For an informal discussion please email Professor Anthea Innes at annies@bournemouth.ac.uk

www.jobs.ac.uk/job/AH53/post-doctoral-research-fellow-dementia/
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Dignity and autonomy in dementia
Glasgow, Scotland, UK
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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.