This newsletter is due to go out just before our Annual Conference in Berlin. We are delighted that we have close to 750 registered participants from 41 countries. The conference will bring together 181 speakers, as well as 216 poster presenters to share their research, projects and experiences.

As always, September was a particularly busy month with many of our national organisations marking World Alzheimer’s Month or World Alzheimer’s Day on 21 September. Our members’ section has a whole range of innovative meetings, initiatives, projects and campaigns coordinated by AE members across Europe. A number of our national organisations also used World Alzheimer’s Day to lobby their national governments and I am delighted that the health ministers of Sweden and Portugal both announced that their countries would be developing a national dementia strategy. It is great to see that the number of countries prioritising dementia as a national priority continues to grow.

My colleague Vanessa Challinor represented Alzheimer’s Disease International (ADI) at the recent Meeting of the Committee for Europe of the World Health Organisation (WHO). After the successful adoption of the Global Action Plan on Dementia by WHO, ADI and Alzheimer Europe called for the development of regional action plans and it was positive to hear that this idea seems to gather support from Member States.

On the policy front, Alzheimer Europe also followed the discussions at EU level about the future of EU action on health. We had supported the statement of a number of pan-European organisations calling for continued #EU4health activities. On 12 September, a number of Members of the European Parliament signed a similar call and I was particularly grateful to the significant number of members of our European Alzheimer’s Alliance who supported this call.

As always, we cover a number of recent research developments in this newsletter. Just as we were finalising this newsletter, we heard the disappointing news that Axovant’s phase III MINDSET trial of interpirdine failed to meet its co-primary endpoints. Thankfully, research into the development of medicines for the treatment and prevention of Alzheimer’s disease and dementia continues and we will continue to report on these scientific news.

Alzheimer Europe also continues its involvement in a number of European research projects and we have a particular focus in this month’s newsletter on EPAD, SMART4MD and ROADMAP.

Happy reading and I hope to see many of you in Berlin next week.

Jean Georges
Executive Director
ALZHEIMER EUROPE

21 September: Alzheimer Europe publishes new Dementia in Europe magazine including special supplement on the PredictND project


In issue 25, Marianne Thys sen from the European Commission, Employment, Skills, Social Affairs and Labour Mobility discusses the European Pillar of social rights and how it is addressing old age and dementia. Our colleagues from the European Disability Forum (EDF) explore how the Accessibility Act is an opportunity to improve the lives of people with disabilities and persons with dementia and AE’s Executive Director, Jean Georges looks at the impact of Brexit on dementia.

At a global level, Shekhar Saxena from the World Health Organisation (WHO) presents the new WHO global action plan on the public health response to dementia and explains how WHO will be supporting countries in implementing strategies and plans. Tania Dussey-Cassavini describes the hidden diplomatic work required to get the consensus of 194 Member States for this new action plan and we include additional comments from Paola Barbarino, CEO of Alzheimer’s Disease International (ADI) and Stefanie Becker, Director of Alzheimer Switzerland, on the new action plan.

At national level, Maureen Watt, Minister for Mental Health, Scotland talks about the third Scottish dementia strategy and Ed Bridges of Alzheimer’s Society Cymru about the consultation process on the soon to be launched new dementia strategy for Wales.

In our own news, you can take a look at our recent lunch debate at the European Parliament in Brussels where we discussed present and future treatment options on dementia and launched a new Alzheimer Europe report, the Dementia Monitor which highlights inequalities in access to care and treatment across Europe. We also give an update on Alzheimer Europe’s Clinical Trial Watch which provides accessible information on clinical trials.

We are pleased to showcase EU projects in which we are involved: The Smart4MD project is developing an app to improve the quality of life to people with dementia and their carers and we showcase the involvement of our European Working Group of People with Dementia in the INDUCT, SYDAD and MIND research projects.

In the society section, we focus on the national dementia working groups in Scotland, Netherlands, Ireland, Finland and Norway. The Alzheimer Association of Luxembourg shares its 30th Anniversary celebrations and José Carreira, Alzheimer Portugal’s new chair talks about his involvement in Portugal’s Memory Cafés. From Denmark we learn about involving people with dementia in Danish folk schools. Finally we take a look “behind the headlines” with Professors Alexander Kurz and Nicola T. Lautenschlager on recent studies linking physical activity and dementia risk reduction.

Last but not least, there is a special “spotlight” section of the magazine dedicated to activities of the German Alzheimer Association (DAzG) highlighting the upcoming Alzheimer Europe Conference (27AEC) in Berlin to be held from 2-4 October 2017.

The magazine this time also includes a special 16 page supplement showcasing the work of the PredictND project “From Patient Data to Clinical Diagnosis in Neurodegenerative Diseases”. Alzheimer Europe (AE) is a partner in the dissemination and outreach activities of this four-year project (2014–2018), co-funded under the European Seventh Framework Programme (FP7). This special supplement includes a general overview of the PredictND project, along with interviews with each of the project leaders, as well as some information about each of the project’s work packages and their remits.

27AEC - MEET THE SPEAKERS

27th Alzheimer Europe Conference - Meet the speakers: Thomas Klie

Thomas Klie, PhD is a lawyer and Professor of gerontology at the University of Klagenfurt, Austria, and the Protestant University for Applied Science in Freiburg, Germany. Until 2010, he was President of the German Association of Gerontology and Geriatrics, a member organisation of the International Association of Gerontology and Geriatrics (IAGG).

His main topics in the research work in the Institute Age Society Participation Freiburg (AGP) are demographic and social changes in modern society, elder abuse and social planning for the elderly on the municipality level. Since 2010, he is visiting Professor at the University of Namibia (UNAM) and, together with Janet Ananias, is responsible for the project “aging in Namibia”.

Thomas Klie is one of the speakers in Plenary 1, on 3 October.

27th Alzheimer Europe Conference - Meet the speakers: Lieve van den Block

Lieve Van den Block is Professor of Aging and Palliative Care Research at the Vrije Universiteit Brussel (VUB) and chair of the Ageing and Palliative Care Research Programme at the End-of-Life Care Research Group of the Vrije Universiteit Brussel (VUB) and Ghent University in Belgium. She holds a PhD in Medical Social Sciences and a Master’s degree in Clinical Psychology.

Her work focuses on national and international public health and interventional research aimed at monitoring and improving palliative and end-of-life care for older people and people with dementia.

She currently coordinates the EU funded FP7 project PACE (Palliative Care for Older People) and is partner in the EU funded H2020 project INDuct (Interdisciplinary Network for Dementia Utilising Current Technology).

She has received several scientific awards for her work including the prestigious Early Researcher Award of the European Association for Palliative Care. She published over eighty papers in leading peer-reviewed journals in medicine, public health and palliative care, and is editor of the Oxford University Press book “Palliative Care for Older People: a public health perspective”. Lieve van den Block is one of the speakers in Plenary 2, on 3 October.

http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Lieve-Van-den-Block

27th Alzheimer Europe Conference - Meet the speakers: Frank Jessen

Frank Jessen received his MD degree from the University of Saarland, in 1995. After residencies in neuropathology at the University of Düsseldorf, and neurology and psychiatry at the University of Bonn, he was board certified as a psychiatrist and psychotherapist in 2002. He served from 2002-2010 as a consultant psychiatrist and head of clinical Alzheimer’s disease research at the Department of Psychiatry, University of Bonn. In 2010, he was appointed Professor of clinical dementia research and deputy director of the Department of Psychiatry, University of Bonn. In 2015, he was appointed as a professor of psychiatry and psychotherapy and director of the Department of Psychiatry, University of Cologne. Since 2010, he is an associate researcher at the German Center of Neurogenerative Disorders (DZNE). Frank Jessen’s research focusses on early diagnosis and clinical trials in Alzheimer’s disease with expertise in neuropsychology, neuroimaging, epidemiology and genetics. He is a member of the DZNE clinical board, the European Alzheimer’s Disease Consortium executive committee, the ISTAART advisory council and the NIA-AA working group on Alzheimer’s disease criteria. He is the chairman of the ISTARRT professional interest area on subjective cognitive decline (SCD) and the SCD-initiative (SCD-I). He is also the main author of the German national guideline on the diagnosis and treatment of dementia. Frank Jessen is one of the speakers in Plenary 3, on 4 October.

http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Frank-Jessen

27th Alzheimer Europe Conference - Meet the speakers: Lutz Frölich

Lutz Frölich was born in 1956 in Neumünster. He studied medicine in Kiel, Heidelberg and also at the University of Kentucky, Lexington, KY, USA. His occupational activities brought him to Heidelberg, Würzburg and Frankfurt. Since 2003, Lutz Frölich is head of the department for Geriatric Psychiatry at the Central Institute of Mental Health (ZI) in Mannheim. The scientific emphasis of his work lies in the development and evaluation of new therapies for dementia, the research of clinical process, neuropsychological and diagnostic procedures for dementia as well as functional-imaging methods for psychiatric, age related diseases. He is a member of the Executive Committee of the European Alzheimer’s Disease Consortium. Lutz Frölich is one of the speakers in Plenary 4, on 4 October.

http://alzheimer-europe.org/Conferences/Berlin-2017/Keynote-Speakers/Lutz-Froelich/(language)/eng-GB

27th Alzheimer Europe Conference - Meet the speakers: Iva Holmerová

Iva Holmerová is the Chair of the Czech Alzheimer Society, which she co-founded in 1997. A practicing physician since 1981, she is qualified in General and Geriatric Medicine and also holds a PhD in Social Gerontology. She is also the Chair of Alzheimer Europe, since 2016. She is the Director of the Czech Centre of Gerontology (since 1992), the President of the Czech Society of Gerontology and Geriatrics (since 1997) and a committee member of the International Association of Gerontology and Geriatrics (IAGG) since 1997. Iva is an Associate Professor of Humanities at Charles University (Prague) and was named Visiting Professor at the University of the West of Scotland in 2014. She has been a Board member of Alzheimer Europe since 2008 and served as Vice-Chairperson from 2010 to 2016, prior to being elected Chair. Iva Holmerová is one of the speakers in Plenary 4, on 4 October.

EU PROJECTS

4-5 September: Alzheimer Europe holds ROADMAP project consultation with people with dementia

On 4 and 5 September in Münsbach, Luxembourg, Alzheimer Europe (AE) organised and jointly facilitated a consultation with the European Working Group of People with Dementia (EWGPWD) and ROADMAP project colleagues from the University of Edinburgh, to consult on their project activities within the work stream “outcomes definition”.

During the two days, various discussions revolving around the potential usefulness of real-world research in dementia and Alzheimer’s disease (AD) were held. In order to gain insights into both the members’ and their carers’ own lived experiences, the attendees split into two groups (one consisting of the members of the EWGPWD and the other of their carers), with a couple of joint feedback sessions, which provided participants with an opportunity to share their thoughts about the consultation and their main conclusions for the ROADMAP researchers. The sessions entailed discussions on disease progression, addressing the usefulness of terms describing stages, as well as what changes indicate a progression in the context of AD. Other discussions focussed on treatment and research surrounding hypothetical drugs that could either delay the onset of dementia or slow down its progression. This was concluded by a recapitulation of what a meaningful delay in disease progression might entail and how meaningful real-world evidence could potentially be captured using measures not typically used in clinical trials.

On 5 September, both groups provided feedback on a survey that is being designed to unpick which outcomes are most important and most helpful in understanding Alzheimer’s disease (AD) progression. The consultation ended with a joint feedback session about the activities and the project in general, in which the EWGPWD identified the top five messages they would like to pass on to the researchers working on the ROADMAP project.

www.roadmap-alzheimer.org

4-6 September: SMART4MD project meeting takes place in Sweden, full study launch is imminent

From 4 to 6 September, members of the Support, Monitoring and Reminder Technology for Mild Dementia (SMART4MD) project consortium gathered for a General Assembly (GA) in Malmö, Sweden.

The ambitious SMART4MD project, launched in April 2015, is developing a computer tablet-based system app to improve the quality of life of people with mild dementia and of caregivers. The app is designed to help people with mild dementia adhere to treatment regimens, as well as allowing them to share health-related data with their carers and doctors. The app gives people more control over their care, and hopes to help slow cognitive and functional decline. It also aims to ease pressure on carers and reduce costs incurred by healthcare providers.

Project partners in attendance, alongside hosts BTH, were: Alzheimer Europe (Luxembourg), Anglia Ruskin University (United Kingdom), Athena ICT Limited (Israel), Consorci Sanitari De Terrassa (Spain), Dex Innovation Centre (Czech Republic), Pow Health (United Kingdom), SAS-IBIMA (Spain), UC Limburg (Belgium) and Universidad Politecnica De Madrid (Spain).

The next project GA will be held in early 2018. For more information about the project visit: http://www.smart4md.eu/

7 September: EPAD project participates at the EFPIA Rentrée 2017

On 7 September, the European Federation of Pharmaceutical Industries and Associations (EFPIA) held an event under the banner “Unlocking tomorrow’s cures” in Brussels, Belgium. The EFPIA Rentrée 2017 gathered six scientists working on ground-breaking, innovative and life-changing therapies.

Amongst them, Serge Van der Geyten (pictured), Director Neuroscience External Affairs at Janssen Pharmaceutical, presented EPAD with a talk entitled “Prevention of Alzheimer’s Dementia in Europe – the EPAD project”. He described the EPAD initiative, its aims and its progress to date.

18 September: EPAD bids farewell to Lennert Steukers

The EPAD project says fond farewells to Lennert Steukers. Lennert worked full time as project manager for Janssen on the IMI -EPAD project and helped in the overall management of the project. In his role, he notably supported the coordinator, Executive Committee and the work package leaders in day-to-day management. He was also involved in EPAD’s internal and external communication activities.

All the EPAD family would like to thank this #epadista for his many outstanding contributions and his dedication throughout the past 2.5 years. Lennert will be taking a new position of a Clinical Scientist, Experimental Medicine Neuroscience in Janssen. We wish him every success in the future.

19 September: EPAD gets great media coverage around World Alzheimer’s Day

In September 2017, two articles about the EPAD project appeared in the media.

On 19 September, the Italian newspaper “la Repubblica” published an article entitled “L’Alzheimer si combatte giocando d’anticipo” including an interview and quotes from Prof. Giovanni Frisoni from the University of Geneva. He highlighted the EPAD project and described it as “il più grande al mondo sull’Alzheimer”. The article can be read on the journal website http://ricerca.repubblica.it/repubblica/archivio/repubblica/2017/09/19/lalzheimersi-combate-giocando-danticipo26.html?ref=search

On 21 September, the Journal of mHealth released its latest issue (August/September 2017 Edition). Pamela Brankin, Head of Marketing and Communications at Aridhia, wrote an article entitled “Transforming trials – why data-driven drug development is critical to gaining competitive advantage” where EPAD was featured as a project exemplifying the benefits to use adaptive trials in research. The article can be read on the Journal website: https://t.co/WkJySoeG

26 September: SMART4MD project enters key phase

The SMART4MD project entered its key phase in September 2017. A feasibility study (conducted in Spain and Sweden) which has taken place over the last two months is almost finalised. The study was conducted to assess the newly developed SMART4MD application for people with mild dementia, their carers and healthcare professionals. This has been ground-laying work for the next stage in which an 18-month large scale clinical trial will be conducted with 1200 patients in 4 countries.

The application, which has been designed based on feedback during focus groups and interviews, covers functionalities revolving around personal health and memory, entertainment as well as psychoeducational materials.

http://dex-ic.com/smart4md-project-enters-its-key-stage---large-scale-clinical-trial-of-app-for-mild-dementia-patients

28 September: ROADMAP project reports on progress

The ROADMAP team has been busy this September.

The Coordination team has recently completed a performance assessment of all ROADMAP partners, and is taking the leading role in preparing for the next General Assembly Meeting (GAM), which will be held in Barcelona from 16-18th October, 2017.

The Outcomes Definition team has been involved in several stakeholder engagement activities towards defining better outcomes in Alzheimer’s disease (AD). Having devised a protocol for the systematic review, which has been approved by the ROADMAP executive committee, the double blind screening of titles and abstracts is now underway. The University of Edinburgh held a consultation with patients and carers from partner Alzheimer Europe’s European Working Group for People with Dementia. The interpretation and write-up of this stakeholder consultation is also underway. Finally, the pilot outcome definition survey for health professionals has been completed, and feedback from these is being used to modify the forthcoming survey for patients and carers, which will be piloted from October 2017.

The Real World Evidence identification team has developed a template for the inquiry of relevant scientific questions, which was circulated to the consortium in late August. They have also established contact with BIOFINDER for the purposes of negotiating and developing collaboration. Finally, Olin Janssen, a PhD student at University of Maastricht, has joined the ROADMAP team.

ROADMAP also has another new member, with the Disease Modelling and Simulation team. Andrey Kormilitzin, from Professor Simon Lovestone’s group at the University of Oxford recently joined, and will be assisting in modelling and simulation activities. The team’s recent focus has been on the use of the Tripod checklist to provide more details on the simulation models selected from Handels, Novartis,
PENTAG/Lilly, and Guo. Subsequent to this the team has begun preparation of a validation protocol for the Handels model. Systematic Literature Reviews have been the primary focus of the Health Economics team. These reviews are on: on quality of life of dementia patients and carers; resource utilisation and costs in dementia; quality of life and resource allocation – submitted for publication to BMJ Open in August; and pharmacoeconomic modelling.

The team responsible for Regulatory and Health Technology Assessment engagement has been occupied primarily with ROADMAP’s Expert Advisory Group, meeting with prospective new members of the Group, and preparing for its next meeting, which will take place in Barcelona on 18th October.

Next is an update about ROADMAP’s Ethical, Legal, and Social Implications (ELSI) team. Recently, they have completed a key activity of ROADMAP’s first year, producing the initial report on the requirements for an ELSI framework in the context of employing a “Real World Evidence approach in AD”. In addition to this, a meeting of the Ethics Advisory Board took place on 19th September, and during the same month they began a collaboration with the Real World Evidence identification team to analyse the ELSI aspect of using mobile devices for AD research.

Finally, as well as producing the third issue of the ROADMAP newsletter, the Communication team has been disseminating information about recent conference presentations and posters by other members of the ROADMAP team, as well as preparing communications activities such as video interviews with key members of the consortium to be conducted at the next ROADMAP GAM in October.

For more information visit www.roadmap-alzheimer.org and subscribe to their quarterly newsletter.

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**EU project acknowledgement**

A number of the projects in which Alzheimer Europe is a project partner receive funding from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon2020 research and innovation programme and EFPIA.

The projects in this newsletter, with IMI and IMI2 funding are:

- EPAD - grant agreement 115736
- ROADMAP - grant agreement 116020

Other projects are co-financed by the European Union under an EU Framework Programme for Research and Innovation – Horizon 2020).

The project in this newsletter, with Horizon2020 funding is:

- SMART4MD - grant agreement 643399.

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**Alzheimer Europe Networking**

On 3-4 September (Münsbach, Luxembourg) Ana and Dianne attended the EWGPWD meeting.

On 4-5 September (Münsbach, Luxembourg) Ana, Dianne and Chris carried out a consultation with the European Working Group of People with Dementia (EWGPWD for the ROADMAP project).

On 6 September (Luxembourg, Luxembourg) Dianne, Jean and Helen took part in the second expert meeting of the working group addressing the ethical issues related to dementia as a potential disability.

On 7 September (Lyon, France) Jean attended the Programme Board of the European Joint Action on Dementia.

On 8 September (Amsterdam, Netherlands) Jean and Ana participated in a meeting of AE survey of carers’ experiences of diagnosis of dementia.

On 10-14 September (Budapest, Hungary) Vanessa attended the 67th session of the WHO Regional Committee for Europe.

On 11 September (Florence, Italy) Dianne attended a continence care meeting in Florence.

On 14 and 15 September (Brussels, Belgium) Jean attended the interim review meetings of the EPAD (European Prevention of Alzheimer’s Dementia) project.


On 20 September (Brussels, Belgium) Ana attended a meeting for the preparation of an IMI project proposal.

On 21 September (Brussels, Belgium) Vanessa attended the EPF/ EPHA #EU4HEALTH Core Group meeting.

On 26 September (Esch/Belval, Luxembourg) Jean attended the kick off meeting of Centre of Excellence in Digital Health and Personalised Medicine.

On 27 September (Brussels, Belgium) Vanessa attended the European Parliament Research & Innovation for Europe. What after 2020?

On 28 September (Brussels Belgium) Vanessa attended the MSD “What If” Roundtable #1 – “The right to dignity”.

On 28 September (Amsterdam, the Netherlands) Dianne attended a meeting for the preparation of an IMI project proposal.

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Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 124, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

Austria: Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP). Belgium: Mark Demesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). Bulgaria: Andrey Kovatchev (EPP). Croatia: Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). Cyprus: Costas Mavrides (S&D); Eleni Theocharous (ALDE). Czech Republic: Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). Denmark: Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). Estonia: Uurma Paet (ALDE); Finland: Liisa Jaakonsaari (S&D); Anneli Jätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). France: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). Germany: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Costas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostas Kostas (ECR); Eleni Theocharous (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Ellissavet Vozemberg-Vrionid (EPP). Hungary: Ádám Kósá (EPP). Ireland: Lynn Boylan (GUE/NGL); MattCarthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke 'Ming' Flanagan (GUE/NGL); Marianne Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). Italy: Brando Benifei (S&D); Elena Gabbrielli (S&D); Stefano Mazzanti (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP); Philippe Juvin (EPP). Malta: Roberta Metsola (EPP); Alfred Sant (S&D). Netherlands: Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). Poland: Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). Portugal: Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). Romania: Cristian Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (S&D); Daciana Octavia Sârbu (S&D); Claudiu Ciprian Tanasescu (ALDE); Renate Zech (ALDE). Slovakia: Richard Shawcross (ECR); Vladimír Mečiar (EPP); Sergei Zymon (EPP). Slovenia: Sirpa Pietikäinen (EPP). Sweden: Yvette Guelard (S&D); Peter Lundgren (EFD); Cecilia Wikström (ALDE). United Kingdom: Martin Andersson (S&D); Jenhiston (GUE/NGL); Richard Ashworth (ECR); Theresa Griffin (S&D); Ian Hudghton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).

EUROPEAN ALZHEIMER’S ALLIANCE

12 September: 42 members of the EAA support a statement calling for continued EU engagement in health

We are delighted to note that 42 of the 70 plus Members of the European Parliament (MEPs), who have signed a “Statement on the future engagement of the EU in healthcare” are members of the European Alzheimer’s Alliance (EAA).

The Statement, dated 12 September 2017, expresses deep concern about the future of healthcare policy in the EU, in the wake of the publication of a “White Paper on the Future of Europe” earlier this year and calls for continued EU action in the field of health, as well as enhanced cooperation between EU Member States.

The 42 EAA signatories are (in alphabetical order): Georges BACH (Luxembourg), Vilija BLINKEVIČIŪTĖ (Lithuania), Biljana BORZAN (Croatia), Cristian Silviu BUSOI (Romania), Soledad CABEZÓN RUIZ (Spain), Nessa CHILDERS (Ireland), Deirdre CLUNE (Ireland), Carlos COELHO (Portugal), Tanja FAJON (Slovenia), Elena GENTILE (Italy), Nathalie GRIESBECK (France), Françoise GROSSETÈTE (France), Marian HARKIN (Ireland), Brian HAYES (Ireland), Anneli JÄTTENMÄKI (Finland), Karin KADENBACH (Austria), Manolis KEFALOGIANNIS (Greece), Seán KELLY (Ireland), Andrey KOVATCHEV (Bulgaria), Merja KYLLÖNEN (Finland), Marian-Jean MARINESCU (Romania), Costas MAVRIDES (Cyprus), Linda MCATANEO (United Kingdom), Mairead MCGUINNESS (Ireland), Miroslaw MIKOLÁŠIK (Slovakia), Elisabeth MORIN-CHARTIER (France), Dimitrios PAPADIMOULIS (Greece), Aljoz PETERLE (Slovenia), Sirpa PIETIKÄINEN (Finland), Marek PLURA (Poland), Sofia RIBEIRO (Portugal), Paul RÜBIG (Austria), Olga SEHNALOVÁ (Czech...
Republic), Igor ŠOLTES (Slovenia), Bart STAES (Belgium), Ivan ŠTEFANEC (Slovakia), Romana TOMC (Slovenia), Ivo VAJGL (Slovenia), Lambert van NISTELROOIJ (Netherlands), Hilde VAUTMANS (Belgium), Julie WARD (United Kingdom), Renate WEBER (Romania).

Alzheimer Europe thanks all 42 of these MEPs, as well as their peers who have also signed the statement, for taking action to ensure the health and wellbeing of all citizens remain priorities for the EU in the future.

Find out more about the EAA and how MEPs can join here: https://goo.gl/AykR8g

Read more about the Statement here: https://goo.gl/hYp28w

EU DEVELOPMENTS

12 September: MEPs call for continued EU engagement in healthcare

More than 70 Members of the European Parliament (MEPs), from all major political groups, have signed a statement expressing their deep concern about the future of healthcare policy in the EU, in the wake of the publication of a “White Paper on the Future of Europe” earlier this year.

The "Statement on the future engagement of the EU in healthcare", dated 12 September 2017, calls for continued EU action in the field of health, as well as enhanced cooperation between EU Member States. It can be downloaded below, in PDF format.

The prospect of reducing EU engagement in the area of healthcare, as outlined in the White Paper, dated 1 March 2017, stands in stark contrast to the results of the Eurobarometer survey 2017, which showed an overwhelming demand (70%) for the EU to do more, not less, in this area: “We need to counter populist rhetoric and deliver on the expectations of European citizens”, the signatories of the Statement assert.

Earlier this year, Alzheimer Europe and 38 other organisations representing EU health stakeholders addressed a joint letter to Jean Claude Junker, President of the European Commission, expressing grave concern about the future of health in European policies and programmes: https://goo.gl/RCKGb1

The Eurobarometer 2017 result on the question of EU involvement in health policy can be viewed here: https://goo.gl/fHRaK

The White Paper can be viewed here: https://goo.gl/d1XVZV

The full Statement (PDF) can be downloaded here: https://goo.gl/dgyUjd

14 September: European Parliament casts final vote on the European Accessibility Act

On 14 September Members of the European Parliament (MEPs) voted in the plenary session on the proposed amendments to the Accessibility Act.

The final report was adopted by 537 MEPs in favour, 89 abstentions and 12 against. The plenary vote gave the rapporteur of the Accessibility Act, MEP Morten Lokkegaard the mandate to start the negotiations with the Council as soon as possible.

People with disabilities and people with dementia face many challenges that hamper their daily life. This draft law aims to improve this. Key products and services, like phones, ticketing machines and banking services, will have to be made more accessible to people with disabilities.

Alzheimer Europe is a member of the European Disability Forum (EDF) who was strongly campaigning to convince MEPs to adopt an ambitious Accessibility Act.

The five top priorities campaigned for by EDF were:

- Applicability of the Accessibility Act to other Union acts such as public procurement or the EU Structural Funds
- Adoption of a strong, binding clause on the built environment
- Application of accessibility requirements by microenterprises and small and medium-sized enterprises (SMEs)
- Transport accessibility
- Inclusion of sector-specific accessibility requirements in Annex I

Morten Løkkegaard (ALDE, DK) rapporteur, said: “I am satisfied with the solid majority in Parliament today. More than 80 million people living with disabilities will benefit from today’s vote in Parliament. The final report naturally consists of both plusses and minuses and now we face difficult negotiations in Council. I will do my utmost to get the maximum out of it.”

More details of the EDF campaign can be read here: http://www.edf-feph.org/newsroom/news/european-parliament-crucial-vote-accessibility-act
MEMBERS’ NEWS

14 July: UK Alzheimer’s Society holds a workshop on Patient and Public Involvement in research

On 14 July 2017, an international group of people from research, healthcare, governmental and charity sectors attended a pre-AAIC one day conference on patient and public involvement (PPI) in research. The idea of PPI is that research is carried out alongside and involving members of the public rather than ‘for’ or ‘about’ them. PPI goes beyond merely communicating science to the public, and rather involves them in all aspects of research design and delivery.

The day included themed sessions on best practice and PPI impact, plenary talks and group discussions. Wendy Mitchell, a Research Network volunteer spoke on the right of people affected by dementia to be involved in research. Simon Denegri gave an overview of PPI in the UK, and how organisations NIHR and INVOLVE were influenced by progress in the dementia field. Jennifer Bethell and Kathy McGilton (University Health Network, Toronto, Canada) presented preliminary results from a systematic review of PPI impact reporting in dementia research and Anna Grinbergs-Saull (Alzheimer’s Society) presented on work to evaluate the impact of the Alzheimer’s Society Research Network. Marc Wortmann closed the day with a talk on international trends in PPI. We also hosted a marketplace where delegates could exhibit and share their work. Stalls included PPI in individual research projects and international charity sector initiatives.

There were a number of recurring themes in discussions throughout the day:

1) Partnership: For PPI to be successful, research should be viewed as a partnership between people affected by dementia and researchers.

2) Language: Choosing the right language and communication method supports group practice in PPI. There is also a lack of standardisation in the language we use to describe PPI: engagement/involvement, carers/supporters/people affected by dementia.

3) Inclusiveness: Meaningful involvement requires involvement at the earliest stage of research. This includes asking people how and when they want to be involved, and how much time they can give.

4) Impact: There is no standardised way to report PPI impact, and a lack of reporting in research. This event showed that we are building up an evidence base for the benefits of PPI, and

highlighted the importance of sharing it. A full report of the day is available at: www.alzheimers.org.uk/researchnetwork

18 September: Alzheimer Portugal attends the Alzheimer’s Global Summit 2017 in Lisbon

From 18 to 22 September the Alzheimer’s Global Summit 2017 on dementia was held in Lisbon at the Champalimaud Foundation with the support of the Queen Sophia Foundation. The summit was based on two main pillars: Social and Health Care Research (September 18-19), organised by the National Reference Centre for Alzheimer’s and Dementia Carers (CREA) of Imsero and the Scientific Summit (September 20-22) organised by the Center of Research in Neurological Diseases (CIEN) Foundation and the Center for Networked Biomedical Research in Neurodegenerative Diseases (CIBERNE).

Alzheimer Portugal was represented by Maria do Rosário Zincke dos Reis at the Scientific Committee of the Social and Health Care Research who also had the opportunity to give a presentation on the current situation of Alzheimer’s Disease in Portugal. Alzheimer Portugal’s President, José Carreira chaired a session on national plans which also included other members of Alzheimer Europe. Jesus Rodrigo, from La Confederación Española de Alzheimer (CEAFA), presented the situation in Spain and Charles Scerri, board member of Alzheimer Europe from the Malta Dementia Society (MSIDA), gave an overview about main achievements at European level.

At the opening ceremony participants had the great opportunity of listening to Queen Sophia, Leonor Beleza, the Champalimaud Foundation Chair, and Marcelo Rebelo de Sousa the President of the Republic of Portugal. All of them showed great commitment to the cause of people with dementia. We were very pleased because Leonor Beleza referred to the fact that Marcelo Rebelo de Sousa was the first Portuguese to join the campaign “Memórias para Guardar” (Memories to be kept in mind).

During the summit there was a debate chaired by the Director General of Health, Francisco George, with the participation of Adalberto Campos Fernandes Minister of Health, Portugal, Carlos Moedas, European Commissioner for Research, Science and Innovation and Shekhar Saxena, Director of the Department of Mental Health and Substance Abuse of the World Health Organization (WHO).

During the summit Alzheimer Portugal referred to the work of the European Working Group of People with Dementia (EWGPWD) as an example on how to involve people with dementia in the work of Alzheimer Europe and how they play an important role on dispelling stigma and misperceptions about dementia.

Alzheimer Portugal also took the opportunity to speak about the document named “Bases for the Definition of Public
Policies in the Field of Dementia", prepared by a working group which was created within the framework of the reform of the National Network for Integrated Continuous Care, including recommendations to the government on the main priorities to be included in a future National Dementia Plan. This document was in public discussion until 15th September. During this debate, the Minister of Health announced that the Portuguese government will launch a national dementia plan, highlighting 3 topics: 1) “intersectorial integration”; 2) – improve early diagnosis; 3) – access to treatment (drugs and rehabilitation).

18 September: Finland celebrates traditional memory Week

Memory Week is celebrated annually in Finland around World Alzheimer’s Day. The theme of the week was: “Many Faces of Memory Diseases”. The theme aims to highlight, that people are always individuals and that every story about living with memory-related disease unique.

During Memory Week, the Memory associations had organised all sorts of events. These included, the “dress in red” campaign organized by the Memory Association of Oulu. Further, the Memory Pilot of Southern Savonia provided brain training exercises and brain health smoothies. Numerous memory associations also held Memory Masses (church services) which pay particular attention to people with memory diseases and the whole family.

The Alzheimer Society of Finland also set up a panel discussion about self-determination rights for people with memory-related diseases. The panel consisted of experts by experience and by occupation. The society was pleased with the active discussion and the lively media attention of this event.

18 September: Alzheimer Society of Finland launches Awareness Campaign “Many Faces of Memory Diseases” as highlight of Finland’s Memory Week

The Finnish Alzheimer’s Society is very pleased to announce that a nation-wide campaign: “Many Faces of Memory Diseases” was launched on 18 September as a highlight of Finland’s Memory Week and World Alzheimer’s Day.

The core of the campaign is a website, where people with memory-related diseases and their families share their stories. The stories were gathered through interviews by the Communications Planner of Muistiliitto from all over the country providing insights from all age groups.

“Many Faces of Memory Diseases” gives a voice to the people with memory diseases and their families. It strengthens their voice in the society. It brings up the challenges that people with memory disease face. For example, how difficult it might be to get the right diagnosis. The aim of the campaign is to reduce stigmas and prejudices related to memory diseases.

The website also serves as a peer support: it emphasizes that no-one should be left alone. It invites people to join the campaign. The campaign site shows that every story of memory disease is different and unique.

Further, the website is linked to the website of the Alzheimer Society of Finland where people can find out more information and support. “Many Faces of Memory Diseases” tells the basic facts one should know about memory diseases and gives advice on how people can act to provide support and become volunteers.

https://www.muistini.fi

18 September: Bosnia and Herzegovina raise awareness and fight against stigma

With the main goal to raise awareness of dementia in Bosnia and Herzegovina the Alzheimer association (A&R) was part of two events during World Alzheimer’s month. Firstly, the „Girls on running” event where 700 runners participated and secondly in Sarajevo’s half marathon with 1.300 runners.

The „Girls on running” is a very popular event promoting running, and a healthy city life style for women and the fact that women support the whole family. Through this event A&R highlighted the facts that women have a bigger risk from dementia and women are care givers in 90% of cases. Also running is both good for prevention of dementia and good for treatment of dementia for both physical and mental health.

Every year the Sarajevo half marathon has more and more runners. This year A&R used this event to raise of awareness of dementia, fight against stigma and show how sport and recreation can help prevent dementia.

A&R had a team of 12 runners running under the moto "run4parents /running against dementia". The whole event was followed by a facebook campaign! The runners were selling kilometers and donating to the Alzheimer association All the kilometers were sold! This ia a great sign showing that people feel compassionate about people with dementia but there is still much more hard work more to do. During both races the Alzheimer Association gave away leaflets about "September - month of Alzheimer" and "Do not neglect
memory loss - 10 symptoms of dementia" and vitamins for better health.

21 September: Spominčica hosts multiple events for September's World Alzheimer's Month in Slovenia

On 21 September to highlight World Alzheimer’s Day the Ljubljana Castle was lit up in the blue 'Forget-me-not' colour.

Other events took place throughout the month too. On 15th September Spominčica held a 90 minute midnight club discussion with the title 'Forget me not'. Guests were Štefanija L. Zlobec, president of Spominčica, Dr. Milica G. Kramberger, neurologist and family carer of a husband with dementia, Mirka Debeljak and Slavica Biderman, author of a book about dementia. During the 90 minute discussion, topics included dementia and its related problems and how to live with a person with dementia. Spominčica talked about how they give support and their own activities. Such events are all about raising awareness of dementia in Slovenia. The bilingual collection of poetry »Forget-me-Not« and author Danijela Hliš, a Slovenian, living in Australia who is also a member of Alzheimer Australia was also read.

Spominčica is a partner in the Slovenian project ADAM with goal of early diagnosis of dementia. The ADAM project held a press conference on the 15th September and were happy to report they had tested 457 people, but they got more than 7,000 requests for testings.

On 21 September, World Alzheimer’s day, Spominčica organised a press conference with the support of the President of Chamber of Health: Prof. Zdenka Čebašek Travnik. The successful event was widely covered by Slovenian media. Spominčica President Štefanija L. Zlobec and Dr. Milica G. Kramberger, neurologist, were live on the evening news. Dr. Milica G. Kramberger, neurologist, leader of MOPEAD project, presented the project at the press conference and later on the TV.

On 23 September Spominčica organised the 6th Memory Walk in Ljubljana. In the third week of September another 28 Memory Walks were organised across Slovenia.

21 September: Alzheimer Portugal launches awareness campaign during World Alzheimer’s month

Alzheimer Portugal marked World Alzheimer’s Month with an awareness campaign, aimed at highlighting the problem of dementia which affects more than 180,000 people in Portugal and bringing it to the attention of the Portuguese population.

The campaign with the motto "The memory that I would like to keep ..." began on 1 September, with a video of the President of the Republic, Marcelo Rebelo de Sousa. Several public figures, actors, radio animators, deputies, journalists and bloggers also joined the invitation of Alzheimer Portugal and have been sharing their most important memory on various social networks.

The association invited all of Portugal to record a video in which they share a memory. The challenge is to record a video that begins with the phrase "The memory I'd like to save ..." and share it on social networks using the hashtags #memoriasparing and #passing memory and challenging three friends to do the same.

Throughout the month of September, Alzheimer Portugal have shared the various videos on its Facebook page and YouTube channel, appealing to all Portuguese who also record their own video and share it on social networks.

With this movement, Alzheimer Portugal, which marks its 30th Anniversary next year, intends to reinforce the importance of dementia as a public health priority and to create a National Dementia Plan that support to these caregivers.

The campaign "Memories to Save" also aims to mobilise Portugal for the annual Passeio da Memória solidarity walk of Alzheimer Portugal, which is traditionally held in September.

21 September: Fundación Alzheimer España reports on its World Alzheimer’s Day activities

As every year on World Alzheimer’s Day (WAD) 21 September, Fundación Alzheimer España (FAE) wanted to raise the voice of people affected by dementia as well as their families and caregivers, giving visibility to their everyday needs and promoting social awareness of a problem that affects us all.

This year, the FAE works under the slogan “I'm with you” highlighting the importance to avoid patient's and caregiver's isolation. It is also to raise awareness that Alzheimer's disease affects not only the elderly but also the second and third generation carers.

For this purpose, FAE wanted to be present at various events held on the occasion of the WAD:

- Solidarity Career "I'm with you". The aim was to raise awareness about the disease and support families. Runator, a running application, dedicated his month career in the Global circuit to support the Spanish Alzheimer’s Foundation. From 21 to 24 September, people had the opportunity to run (4 or 12 km) from anywhere in the world to help the Spanish Foundation.

- The race had a very special sponsor, “La Oreja de Van Gogh”. This Spanish pop band wanted to show solidarity with Alzheimer's patients and their families through the
theme “I’m with you”. They named the race #Estoy Contigo as the name of their last success also dedicated to this disease from their latest album entitled "The imaginary planet". This magical ballad expresses, in a poetic way, the accumulation of feelings (mix of anger, sadness, and bewilderment) of those who deal daily with the progressive loss of memory of loved ones. This song is currently in first position of downloads in iTunes.

Link to download: https://lov.g.lnk.to/EstoyContigo

21 September: Alzheimer’s Society UK reports on its World Alzheimer’s Month events

World Alzheimer’s Month (WAM) 2017 has been an exciting flurry of activity for Alzheimer’s Society.

Global Youth Animation: Alzheimer’s Society launched their brand new animation ‘Memories with Grandma’ to raise awareness of dementia and promote young people to take action against this global issue. The primary audience is 7 to 11 years old, although it can be watched more widely. School and youth organisations can use it alongside an activity pack to create Dementia Friends.

People living with dementia and young children helped to develop the animation’s story and script and even participated in its creation! This ensured that the animation’s messaging reflects what people living with dementia want young people to know, and that it’s what young people would like to watch. Grandma Mary is voiced by Dianne, one of their fantastic supporters who is living with dementia. An international version was also translated into Spanish, French, Arabic and Mandarin. Please contact dfinternational@alzheimers.org.uk if you’d like a copy.

Peter’s Story: On World Alzheimer’s Day, Alzheimer’s Society shared Peter Lyttle’s story across their blog and social media channels. Peter’s dementia journey was turned around when he met Dementia Adviser Elaine, and he’s now playing his part in the dementia movement by using his experience to help others with the condition. The story was released in three parts. You can view them all online.

Global Dementia Friends: Alzheimer’s Society also welcomed new members to the global Dementia Friends movement. 26 countries around the world are now delivering or developing their own Dementia Friends programmes and making a significant impact to the lives of people living with dementia. If you’d like to know more or discuss setting up a Dementia Friends programme please contact dfinternational@alzheimers.org.uk.

Media: The Global Dementia Friends Ambassador of Alzheimer’s Society, Carey Mulligan, helped to spread awareness of dementia by speaking of her own experience both in Huffington Post and on BBC World Service radio. This, alongside the Global Alzheimer’s & Dementia Action Alliance’s media work on women and dementia made for a powerful and thought provoking WAM.

27 September: World Alzheimer’s Month 2017 is also a highlight in Croatia

By blurring the data on photos of their biggest sports achievements, which were mega-screened during opening ceremony of the World Challenge Meeting in Zagreb by the end of August, world top athletes warned 150 million TV viewers around the world of the severity of Alzheimer’s disease. This event, supported by Alzheimer Croatia, started this year’s activities of the World Alzheimer’s Month 2017 in Croatia.

Croatian Parliament congratulated Alzheimer Croatia

During World Alzheimer’s Month, especially on World Alzheimer’s Day, numerous events were held in Croatia that promoted the need for early detection of Alzheimer’s disease and strengthened dementia awareness. For the first time, events took place in many cities of Croatia, which has greatly enhanced the media outcomes of Alzheimer Croatia’s efforts to create the better quality of living for people with dementia. For their successful work, on World Alzheimer’s day Alzheimer Croatia was congratulated by the Croatian Parliament, the Ministry of Health of the Republic of Croatia and the Municipal City of Zagreb.

The most prestigious event of the World Alzheimer’s Day in Croatia took place at the University Hospital Centre in Zagreb, which is also the Referral Center for Neurodegenerative Diseases, and was attended by high representatives of the Ministry of Health of Republic of Croatia and the City of Zagreb. On that occasion, advisory center with the Alzheimer Croatia was held, involving the neurologists of this clinic.

Support of future activities

With county and city support, roundtables and forums were held throughout Croatia, where health and social workers discussed problems of dementia. Direct meetings with citizens were traditionally carried out at the main squares of the cities, Alzheimer’s Cafés, on occasional lectures and one Memory Walk. These activities were complemented by events organized by other clinics, research institutes, schools and retirement homes, causing great media coverage.

Alzheimer Croatia has used these meetings with representatives of the institutions of society, that make key decisions on public health and social policies, to present plans to encourage early detection of Alzheimer’s disease and for development of the dementia friendly communities, for which it has been fully supported.
27 September: Alzheimer Uniti takes part in 3 days Alzheimer celebrations

Alzheimer Uniti was engaged in the celebration of Alzheimer’s World Day on several different levels: scientific, cultural and welfare. The Alzheimer Unity yearly meeting took place again in Campidoglio, collecting the most recent information about new ways of living with dementia. The meeting was an ideal opportunity to present the project of the Alzheimer’s Village of Fondazione Roma, inspired by the Dutch Hogeweyk. The project will be completed at the beginning of 2018 and will certainly be seen as a leader as far as innovation and training is concerned.

During World Alzheimer’s month of September an open air “3 Days Alzheimer Fest” was organised on a charming lakeshore in Lombardy. The event attracted families as well as experts and assistants wishing to reflect on problems and situations of dementia in Italy in a serene atmosphere. Alzheimer Uniti hopes that these kind of events will help bring dementia to the attention of key institutions and policy makers.

In addition, Alzheimer Uniti organised open events all over Italy in order to disseminate information on the necessity of protecting and defending dignity and rights of people with dementia and their families.

27 September: Norwegian Health Association campaigns to raise funds

Arendalsuka is an important political festival which takes place on a yearly basis in Arendal, southern Norway. During a whole week, hundreds of meetings and events involving politicians, non-governmental organisations and professionals are organised. In the light of the parliamentary elections in September, health and healthcare were even more prominent topics than during previous years.

For this occasion, the Norwegian Health Association took the initiative to host two important debates:

The first debate entitled; “Why have we still not found a cure for dementia?” was held by two leading dementia researchers; Professor Christian Doeller and Professor Tormod Fladby in addition to representatives from the pharmaceutical industry, a person with dementia, and two politicians; Mr Torgeir Micaelsen, representing The Labour Party, and Mrs Anne Grete Erlandsen from The Conservative Party.

The discussion revealed a further need for collaboration between the scientific, the political and the commercial field. The organisations message was that people cannot afford to be patient for much longer and that, there is an urgent need to find a way to solve one of society’s biggest healthcare challenges. There is no political controversy concerning this urgency. The two representatives both expressed their willingness to focus on dementia as a huge and important challenge.

The second debate concerned the need for day care services and activities for people with dementia. It was concluded, that organised activities and arenas for social gatherings can increase the quality of life for the person with dementia and make it possible for them to live longer in his/her own home. Further, it will also lighten the burden for caretakers. Kari-Ann Baarlid from the Norwegian Health Association highlighted, that people with dementia tell them that they need a reason to make them want to get up in the morning, and pointed out, that there is a urgent need for organised activities, available for the increasing number of people with dementia.

Each year in September, the Norwegian Health Association campaigns to raise funds for research in dementia. The slogan of this years’ campaign is: “One fine day, dementia will be forgotten”. The focus lies on the burden on carers, “when someone you love is diagnosed with dementia”.

The association reaches out to people throughout Norway, and asks them to support research and provide local support for people with dementia as well as their carers. 70 percent of the funds that are raised, will be dedicated to research and 30 percent to local work.

In order to collect funds, the organisations’ members and schoolchildren, walk through villages and knock on doors with collections shakers. Further, the organisation arranges stands and provides informational meetings. Apart from these engagements, a large social media campaign was also launched and reached a wide audience online. Another widespread approach is, that all households in Norway receive a postal DM, with information how they can support dementia research. To the joy of the organisation, the campaign has received a lot of media coverage, in local, regional and national media.
27 September: Scottish Dementia Working Group reports on its recent activities

September has been a busy month for the Scottish Dementia Working Group, with a number of meetings and events taking place as well as preparation for Alzheimer Europe’s Berlin conference next month.

In September, the Scottish Dementia Working Group worked hard on the use and exploration of new technology to support their work. They organised a North East General Meeting focused on technology, with presentations about assistive technologies and how the group has used technology to enhance involvement and spread the word about their work. Members also spoke at Alzheimer Scotland’s ‘Confident Conversations’ event about the impact technology has had on their lives and took part in a workshop to contribute to the development of a Digital Strategy for the organisation.

This month also saw one of the regular meetings with the Scottish Government’s Minister for Mental Health, Maureen Watt MSP (pictured). Many new members were able to join the meeting, asking questions about post-diagnostic support and the Dementia Strategy. The organisation is grateful to the Minister for her answers to all the questions and for continuing to meet them regularly.

To mark World Alzheimer’s Day on 21st September, a number of their members also attended the Scottish Dementia Awards, which many members had been involved in judging. They were delighted to hear about the innovative and exciting work happening around Scotland and to celebrate the winners, including their own committee member and former Chair Henry Rankin who deservedly received a Lifetime Achievement Award.

Elsewhere, members have been busy preparing for Alzheimer Europe Conference in Berlin which will be attended by Chair Archie Noone and Vice-Chair Carol Hargreaves, in her capacity as a member of the European Working Group. Both Archie and Carol will be presenting at the conference: Archie on a partnership between the Scottish Dementia Working Group and Occupational Therapy Interns, and Carol on how she maintains a sense of humour in spite of her dementia diagnosis. Both Archie and Carol are looking forward to the trip and hope to meet many of you there.

27 September: Two new Alzheimer Cafés open in Hungary during World Alzheimer’s Month

The Social Cluster Association of Hungary is proud to announce, that in September two new Alzheimer Cafés have started in Hungary, one is at the biggest and most frequented district of Budapest, the XI. District, and the second is in one of the most significant cities of West-Hungary, Székesfehérvár.

On 8 September, under the umbrella of World Alzheimer’s Month a major event took place in the XV District of Budapest, aimed at bringing attention to initiatives that can not only provide help and support for the people living with Alzheimer and the people taking care of them, but future solutions for society as well. Among the many participants were Dr. Miklós Menyhárt practitioner and Tamás Tatai, the originator and manager of the project „Dementia friendly Mosonmagyaróvár”. The Social Cluster of Hungary was represented by the association’s vice president, Dr. Győző Pék, and the secretary-general, Dr. Norbert Vajda. The event attracted huge interest, and gave the opportunity to address many important topics and questions related to Alzheimer and dementia.

On 23 September, a comprehensive health screening programme for dementia (part of the INDA project) took place at Nagykovácsi where well-prepared professionals had a talk about dementia and its effect on society with the interested and voluntary audience, and had them fill out a Mini Cognitive Test for the purpose of bringing attention to the importance of screening. Aside from the participants, press and media were also present to maximise the opportunity to raise awareness.

POLICY WATCH

5 September: Scotland’s First Minister Nicola Sturgeon announces introduction of ‘Frank’s Law’

On 5 September Nicola Sturgeon announced, the introduction of “Frank’s Law” in Scotland in response to a high-profile public campaign. The law will see free personal and nursing care extended to under-65s who have degenerative conditions including dementia.

The proposed legislation is named after former Dundee United footballer Frank Kopel who was living with dementia before his death in 2014. Mr Kopel was diagnosed with vascular dementia and Alzheimer’s in 2008, aged 59. His family had to pay out about £300 a week on personal care towards the end of his life, as he was not entitled to free care until he was 65. He died just after his 65th birthday, having had just 19 days of free personal care.

Ms Sturgeon told MSPs that a study into the proposed implementation of Frank’s Law had now been published. “I am pleased to announce that we will now begin work to fully implement Frank’s Law,” she said.

Mrs Kopel said in an interview that it was a “momentous day” for the campaign team. “Somewhere along the line I kept thinking that Frank’s Law is a battle that is winnable,” Scottish Tory MSP Miles Briggs had taken up the cause,
securing support from Labour and the Liberal Democrats, and Scottish Greens for a member’s bill.

Mr Briggs said “It’s clear that ministers have been forced into this position by public and political pressure, but in the end they have finally done the right thing and decided to remove age discrimination”

12 September: Swedish Prime Minister announces dementia strategy for Sweden

On 12 September at the recent opening of Parliament Swedish Prime Minister Stefan Löfven, announced a dementia strategy for Sweden in his opening address. Karin Westerlund of Alzheimer Sweden says “It will have positive effects on the Swedish health system and Swedish research concerning neurodegenerative diseases. Those that take part in the advocacy work for persons with dementia in Sweden see this decision as a long-awaited turning point that will not only aid people with dementia but also the discourse of quality of life for caregivers to persons with dementia”.


15 September: Alzheimer Europe represents ADI at 67th meeting of the World Health Organization (WHO)

On 15 September Alzheimer Europe’s Policy Officer Vanessa Challinor, on behalf of Alzheimer’s Disease International (ADI) delivered a statement to 53 governments attending the 67th meeting of the World Health Organization (WHO) Committee for Europe meeting in Budapest, Hungary.

The statement highlights the need for every country to prioritise the development of a national response to dementia, including, mainstreaming data on dementia and enhancing prevention in-line with focus on all non-communicable diseases.

There are over 10 million people living with dementia in Europe. In 2030 it is predicted there will be 13.42 million people in Europe living with dementia.

Alzheimer Europe and Alzheimer’s Disease International (ADI) have both urged the 67th meeting of the World Health Organization (WHO) Committee for Europe to respond to the Global plan of action on the public health response to dementia 2017-2025 and make Dementia a European priority.

The global plan was adopted in May 2017 and is the single biggest opportunity to dramatically enhance the response to dementia globally and in Europe. The plan calls for every member state to meet targets to reduce the impact of dementia through awareness, treatment and research, dementia friendliness, risk reduction, information and care and support.


Statement of Alzheimer’s Disease International

This statement is submitted by Vanessa Challinor of Alzheimer Europe, on behalf of Alzheimer’s Disease International (ADI), the umbrella federation of over 90 national Alzheimer’s Associations around the world and 47 million persons living with Alzheimer’s disease and other irreversible dementias. ADI has been in official relations with the WHO since 1996, has ECOSOC consultative status at the UN and its Chief Executive, Paola Barbarino, is on the board of the NCD Alliance.

We are pleased to note the recognition by the Regional Committee Meeting of the unanimous adoption of a global action plan on the public health response to dementia http://apps.who.int/gb/ebwha/pdf_files/WHA70/A70_28-en.pdf?ua=1. We also note the initial list of regional implications in your agenda item 3 and that prior to the Global Plan this region took steps in its Healthy Ageing Plan 2012-2020 to include certain quality of care strategies for older people including dementia care and palliative care for long-term care.

The Global Plan provides a framework with priorities and targets that are ambitious in respect of a comprehensive Public Health Response to Dementia. There is broad agreement on what policies to adopt. But as the OECD observed in Addressing Dementia in 2015 “ensuring that these policies are consistently implemented remains a challenge and there is still much uncertainty about which policy approaches are most effective”. With that in mind ADI suggests there are four priority challenges within many.

- The Global Plan calls for comprehensive national level government plans and though many European countries have taken this step to review their own data, situation and strategy, many have not. And the evidence suggests plans need to be regularly updated. ADI would be very willing to be a knowledge partner should the Secretariat or Committee organise some form of knowledge exchange aimed at supporting national plan development.

- The plan moves forward the establishment of a Global Dementia Observatory (GDO), which has several European pilot sites and engagement of European institutions in the consultations that led up to its initial work. It is a matter of frustration to policy makers and advocates alike that data on dementia is not mainstreamed in national data sets and is of uneven quality. ADI welcomes the potential of the GDO to improve this situation if European nations and the Secretariat take full and rapid advantage of the
tools and knowledge from the GDO work stream. We look forward to the reviews of the Global Plan in 2020, 2023 and 2026 as part of an important learning process.

- The Global Plan, recognises that dementia shares risk factors with other NCD’s and calls for more complete integration of brain health and dementia risk reduction messaging and action into NCD prevention efforts. This is important and could help to reduce people’s risk of getting dementia. But there is a need to go further and to make the public aware of the link between physical health and brain health and to prioritise dementia prevention within a greatly increased dementia research budget.

- Lastly the Plan recognizes in proposed actions for member states the importance of systematically shifting the locus of care “towards community and home-based care settings and multi-disciplinary, community based networks that integrate social and health systems and provide quality care and evidence based interventions”. This has been a major challenge in many countries and could usefully be a focus for sharing knowledge in respect of approaches to system change to improve the quality of dementia in primary and acute care as well as in respect of new models of community and home-based care.

20 September: Health Minister promises national dementia plan for Portugal

On 20 September at the Alzheimer’s Global Summit, Lisbon, the Minister of Health announced that the Portuguese government will launch a National Dementia Plan, highlighting 3 topics:
- “intersectorial integration”;
- improve early diagnosis;
- access to treatment (drugs and rehabilitation).

The minister did not give any further details, such as: when the plan will be finished, who will coordinate its creation and implementation, which governmental and nongovernmental entities will be involved in, and the budget that will be allocated to it.

A document already prepared by a working group created within the framework of the reform of the National Network for Integrated Continuous Care called “Bases for the Definition of Public Policies in the Field of Dementia” is already in the hands of the government and includes recommendations which will be the framework for the steps towards a National Dementia Plan in Portugal.

The document defines 3 main strategic areas:
- Better collaboration and intersectorial coordination between health services and social services in order to avoid that their activities don’t run in parallel but are converging;
- Timely and correct diagnosis and access to pharmacological and non-pharmacological treatment, by strengthening the role of primary care and its collaboration with hospital care;
- Continuity of formal care in the community and support to the families, with the involvement of residential and institutional care.

To put these strategic areas into practice the document states that it is important to have:
- Public awareness;
- Training of health care and social care professionals;
- Access to new Technologies, mainly information and communication new Technologies;
- Research.

Alzheimer Portugal recommends that the creation of a national dementia plan should be a national priority and this plan should be based on the strategic proposals already included in the document “Bases for the Definition of Public Policies in the Field of Dementia” and should define and put into practice a care pathway including as main axes:
- better quality of life of people with dementia and their carers;
- research on the different areas that concern dementia;
- the definition of a legal framework on the rights of people with incapacity (specifically for people with dementia), including the legal framework of care, intervention and research.

20 September: AGE Platform Europe (AGE) calls on governments to use Madrid International Plan of Action on Ageing (MIPAA)

On 20 September on the eve of the UNECE Ministerial Conference on Ageing in Lisbon AGE Platform Europe (AGE) issued a press release calling for national governments to use the Madrid Plan (MIPAA) over the next five years to enhance the protection of older people’s human rights in view of improving their economic and social participation in society and to uphold the full spectrum of civil, political, social, economic and cultural rights of older persons! Anne-Sophie Parent, AGE Secretary General said “We witness a gap between what governments think they are delivering and the real-life experiences of older people in those countries and therefore would like to reiterate our support to the recommendation by the UN Independent Expert on the rights of older persons, Rosa Kornfeld-Matte for establishing a binding legal instrument.

The full press release can be read here:
21 September: The World Health Organisation launches new materials on global plan

The World Health Organisation (WHO) marked this year’s World Alzheimer’s Day on 21 September with the publication of new materials on the global plan on dementia, produced in partnership with ADI. The resources are for policy-makers, health- and social-care providers, civil society organizations and people living with dementia and their carers. They recommend action in a number of areas including advocating for policy change, raising public awareness, creating dementia-friendly communities, and catalysing research and innovation. The information sheets are based on the Global action plan on the public health response to dementia, endorsed by the World Health Assembly in May 2017. Original files can be downloaded from the WHO Programme for Neurology and Public Health.

SCIENCE WATCH

15 August: Is there an increase in late-life dependency?

On 15 August, research published in The Lancet investigated how the proportions of dependency states have changed between 1991 and 2011.

The Newcastle University study estimated years lived in dependency states in people of 65 years and older. The scientific team compared two studies with information of people from three areas of the United Kingdom (Cambridgeshire, Newcastle, and Nottingham).

The information of both studies that were used by the team, provided prevalence estimates of dependency in four states: high dependency (24-h care), medium dependency (daily care), low dependency (less than daily), and independent. Results of the statistical analyses showed that, on average men now spend 2.4 years and women 3.0 years with substantial care needs, as well as that a larger proportion receives care at home (by family and friends as well as formal home-based services).

In comparison to 1991, the results showed that a 65-year old person in 2011 spent on average almost a year longer requiring 24-h care than in 1991.

http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31575-1/abstract

23 August: Study suggests that increasing lithium in drinking water could prevent dementia cases

In a study published in the journal JAMA Psychiatry on 23 August, researchers from the University of Copenhagen found that a high level of lithium in drinking water may prevent dementia. Previous findings have demonstrated the preventative levels of lithium in mouse models as well as some clinical studies. In the published study, researchers investigated for the first time the association between lithium in drinking water and the incidence of dementia. They conducted a Danish large population-based study and analysed more than 800,000 people (aged between 50 to 90). They found that people with dementia had significantly lower levels of lithium exposure compared to the healthy controls.

The incidence of dementia was decreased among people exposed to 10.1 µg/L and more than 15 µg/L compared with exposure to 2 to 5 µg/L. However, an exposure to 5.1-10 µg/L of lithium was associated with an increase of the incidence of dementia compared with exposure to 2 to 5 µg/L.

http://jamanetwork.com/journals/jamapsychiatry/article-abstract/2649277

28 August: Biogen announces Phase 1b results for its experimental AD drug aducanumab

The biotechnology firm Biogen is developing an experimental treatment for use in early Alzheimer’s disease (AD). For this purpose, a human monoclonal antibody called aducanumab against Amyloid Beta was generated.

The Phase 1b study is a randomized, double-blind, placebo-controlled, multiple-dose trial evaluating the safety, tolerability, pharmacokinetics, pharmacodynamics and clinical effects of aducanumab in people with prodromal or mild Alzheimer’s disease. 143 participants who completed this 54-week Phase1b study had the opportunity to continue in a 3 year extension trial.

On 28 August, Biogen announced results from the analysis of the long-term extension of its ongoing Phase 1b study of aducanumab. The major adverse events observed were headache, fall, and amyloid-related imaging abnormalities. The company reported that aducanumab reduced deposits of Amyloid Beta in the brain in a dose- and time-dependent manner. The data of this long-term extension study supports the ongoing Phase 3 studies, EMERGE and ENGAGE, aiming to evaluate the safety and efficacy of aducanumab in people with early Alzheimer’s disease.

1 September: Risk of head injuries might be associated with antidepressant use in AD

In a recent study published in the journal Alzheimer's Research & Therapy, researchers from the University of Eastern, Finland, suggested that antidepressants might be associated with head and traumatic brain injuries among people with Alzheimer’s disease (AD).

Antidepressant use has previously been linked with an increased risk of falling in people with AD but the risk of head injuries in these people had never been studied. In the published study, researchers investigated the association between antidepressant use and risk of head injuries in people with AD. They conducted a large, nationwide study population with 32,730 participants diagnosed with AD and among them 10,910 participants took antidepressants. They found that antidepressant use was associated with an increased risk of head injuries, especially during the first 30 days of use. The risk was also shown to persist for over two years of use. In addition, some traumatic brain injuries were observed in the study population taking antidepressants.

https://alzres.biomedcentral.com/articles/10.1186/s13195-017-0285-3

9 September: The use of artificial intelligence for the identification of Alzheimer's disease

On 9 September, scientists from the University of Bari (Italy) have published recent research on the potential use of artificial intelligence (AI), to better identify structural changes caused by Alzheimer’s disease (AD).

Through the use of a newly developed algorithm that analyses magnetic resonance imaging (MRI), the team was able to reach an accuracy in prediction of over 80%. MRI is an imaging technique to visualise physiological changes in the body.

During development, the researchers used a training set of 67 whole-brain MRI scans, including 29 normal controls and 38 samples of subjects with AD. The scans used for the research were retrieved from the Alzheimer’s Disease Neuroimaging Initiative (ADNI) and belonged to a larger dataset selected to obtain a representative sample of ADNI.

Further, the team also employed an independent test set, including altogether 148 subjects, which was composed of 52 normal controls, 48 samples of subjects with AD and 48 subjects with mild cognitive impairment converting to AD (cMCI).

The software was able to distinguish between normal controls from those with cMCI with an accuracy of 84%. Further, it was able to reach an accuracy of 86% in differentiating between the scans of the normal controls and those with AD.

https://www.biorxiv.org/content/biorxiv/early/2017/06/27/156331.full.pdf

15 September: Biohaven and ADCS initiate Phase 2 trial for trigriluzole in people with mild to moderate AD

Biohaven Pharmaceutical Holding, a clinical-stage biopharmaceutical company developing neuroscience drugs, is testing trigriluzole as a potential treatment for Alzheimer’s disease (AD). This experimental drug modulates glutamate, which its dysfunction is known to be implicated in AD.

On 15 September, Biohaven announced its collaboration with Alzheimer’s disease cooperative study (ADCS), an initiative developed to promote the testing and discovery of new AD drugs. They jointly launched a randomised, double-blind, placebo-controlled Phase 2 trial aiming to determine the safety and efficacy of trigriluzole in people with mild to moderate AD.

18 September: Preliminary 90+ Study results suggest a healthier lifestyle may keep dementia at bay even though amyloid plaques are present

Twenty years ago, David A. Snowdon, director of the Nun Study, published a ground-breaking article about the longitudinal study; Aging and Alzheimer’s disease: Lessons from the Nun Study. The archetype for this study was a nun who died at the age of 101. The extraordinary finding was, that despite having abundant neurofibrillary tangles and senile plaques - the classic lesions of Alzheimer’s disease - she maintained a high cognitive status. On 18 September, during the World Congress for Neurology in Kyoto, Japan Professor Claudia Kawas from the University of California, who is lead researcher of the 90+ Study, introduced preliminary findings of their longitudinal investigation which started in 2003. Every six months, the research team carries out neuropsychological tests on 1,700 participants to monitor their cognitive performance. Upon death of participants, post-mortem samples are conducted. The striking finding was that, although half of the post-mortem examined participants had plaques, they did not show signs of dementia in the neuropsychological tests. At the same time, half of the people with dementia that took part in the study developed symptoms of memory loss without the pathological hallmark of plaques. Professor Claudia Kawas, highlighted that one of the reasons for the so called ‘cognitive resilience’ in those who unexpectedly remained free of dementia, was the healthy lifestyle the people led. She further explained that, this group of “resilient participants”, among others, exercised more and watched less TV. These findings support the early assumption Snowdon was proposing when the article was published.

Although the results point out that cognition could be protected through physical and mental activity, these preliminary results of the report do not form a suitable basis for deriving public health strategies to counter dementia. Further studies are needed in order to be able to better assess the effect of potential measures.

26 September: Axovant’s experimental AD drug fails to meet its co-primary endpoints in Phase 3 study

On 26 September, Axovant Sciences, a clinical-stage biopharmaceutical company developing novel therapeutic solutions to treat dementia, announced results of its MINDSET Phase 3 clinical trial for the treatment of mild to moderate Alzheimer’s disease (AD). This Phase 3 study was a randomised, double-blind, placebo-controlled trial evaluating the efficacy, safety and tolerability of intepirdine as an adjunctive therapy to donepezil in people with mild to moderate AD. More than 1 300 participants received orally the investigational drug once-daily. Although the drug was well tolerated, it failed to demonstrate a statistically significant improvement in cognition and measures in daily activities at 24 weeks compared to participants treated with placebo. Currently, the company is advancing the HEADWAY Phase 2 trial evaluating intepirdine in people with dementia with Lewy Bodies. The results are expected at the end of the year.

27 September: Alzheimer’s Society provides overview of the connection of hormones and dementia in women

Statistics show that women are at a higher risk to develop dementia, but the full picture of factors that influence this risk has not yet been elucidated.

In order to provide the public with an overview, the Alzheimer’s Society has put together an article with factors that could partially explain why the development of dementia may be more likely in elderly women than men. As a starting point, one of the main theories revolves around the influence of a hormone called oestrogen, which is the role for ApoE4. It was suggested to affect tau pathology, the other major hallmark of AD. In the published study, researchers revealed that mouse models presenting ApoE4 exacerbated more brain damages and had significantly higher tau level whereas the absence of ApoE4 was neuroprotective. Indeed, when ApoE4 was absent, tau tangles were not harmful and mouse models did not exhibit brain damages. In addition, no inflammatory response was observed in mouse models lacking ApoE while a strong one was described when ApoE4 was present. Furthermore, researchers examined autopsy samples from 79 people who had died from tau pathologies. They noticed more severe damages in people with ApoE4 compared to those that lacked ApoE4.

http://www.90study.org

primary female sex hormone. Although, both women and men produce it, its levels are far more elevated in women. In late adulthood, women enter the menopause and levels of oestrogen drop radically.

Research has indicated that oestrogen interacts with neuronal networks at many different levels, and may affect some of the risk factors for Alzheimer’s disease (AD). At the same time, oestrogen also affects how other chemicals work in the brain. One of these is acetylcholine, which has an important role in the communication of brain cells. A study with rats has indicated that oestrogen might also help to maintain the connections in the hippocampus, an area of the brain which is associated with memory.

Another interesting influence is that, the energy producing cells of women are better warded against damage caused by the AD associated plaques, and their toxicity. However due to the aging process, the decrease of oestrogen and estrogenic compounds which may protect against the toxicity, could be an explanation why this advantage is lost in old females.

In this context, research on the influence of hormone replacement therapy (HRT) becomes more and more interesting for scientists. Despite their efforts, the results of studies that try to evaluate whether or not replenishing oestrogen levels to reduce the risk of developing dementia have been ambiguous or did not show significant evidence.

In this context there are currently no recommendations for the use of HRT in order to prevent dementia and elevated potential risks due to HRT such as heart disease, stroke and certain types of cancer remain a reason for caution.


DEMENTIA IN SOCIETY

6 September: Prince Henrik of Denmark has been diagnosed with dementia

Prince Henrik of Denmark, husband of Queen Margrethe, has been diagnosed with dementia, following a medical examination at Copenhagen’s university hospital, Rigshospitalet, the Danish royal household announced on 6 September. Doctors concluded that “the extent of the cognitive failure is greater than expected”, considering Prince Henrik’s age of 83. The palace confirmed that the French-born prince, who retired from public life last year, will further downgrade his activities following his diagnosis.

JOB OPPORTUNITIES

19 September: Edinburgh University’s Usher Institute is recruiting for the ROADMAP project

Closing Date: 03-Oct-2017

Edinburgh University’s Usher Institute is seeking to appoint a Research Assistant to contribute to the ROADMAP project, a European private-public consortium established to build a European-wide data access and analysis platform for ‘real-world evidence’ on Alzheimer’s disease (AD) across the spectrum.

You will join Professor Cathie Sudlow’s team, based at Edinburgh University’s Usher Institute in the Bioquarter, Little France. You will produce high quality evidence of stakeholder views on the outcomes of AD and its progression by conducting a systematic review and stakeholder engagement activities. You will identify and critically appraise relevant research studies, extract and synthesise data and conduct qualitative research. You will collaborate with partners in several European countries and disseminate research findings.

They are looking for someone with:

- A good undergraduate degree in a relevant subject (e.g. medicine, psychology, neuroscience, epidemiology, information science), or able to demonstrate equivalent experience
- Knowledge and experience of critical appraisal of peer-reviewed publications & other research reports, including an understanding of the risks of bias in scientific reporting and how to identify & minimise their impact
- Excellent data management, organisational and archiving skills to robustly and accurately deal with large amounts of programme information using appropriate tools
- The ability to communicate clearly and work well within a multi-disciplinary team
- Familiarity with neuroscience or mental health

This post is full-time, to start as soon as possible and available for twelve months.

Line manager: Professor Cathie Sudlow

Further details about the post, role specification and how to apply can be found at the following link: https://goo.gl/7cntX

DONATE NOW!
Help us make dementia a priority
NEW PUBLICATIONS & RESOURCES

20 September: Global Alzheimer’s and Dementia Action Alliance (GADAA) releases new video: Women & Dementia: A Global Challenge

To mark World Alzheimer’s Month, GADAA has released the short film, ‘And Then I Looked Up Dementia Women Speak Out’. The film shows the impact of dementia is much greater for women than men worldwide.

The video illustrates the issue of women and dementia and highlights that the prevalence, care burden and stigma of dementia disproportionately affects women, making it a global women’s health, social care and rights challenge that can no longer be ignored. Of the 29 countries in the world with a national plan to tackle dementia, only 12 acknowledge what it really means for women. The film can be seen here: https://www.gadaalliance.org/filmlaunch/

26 September: EPF issues a new policy factsheet on clinical trials

In September, the European Patients’ Forum (EPF) has issued a new policy factsheet on Clinical Trials. It explains what clinical trials are, why this topic matters to patients, what the role of the European is, and what EPF is advocating for. Access the new EPF factsheet here: http://www.eu-patient.eu/globalassets/library/factsheets/epf_clinical_trials_final.pdf

28 September: Alzheimer’s Disease International (ADI) publishes its first report on the impact of dementia in sub-Saharan Africa (SSA)

Alzheimer’s Disease International (ADI) has published its first report on the impact of dementia in sub-Saharan Africa (SSA), at its 4th Sub-Saharan African Regional Conference. The report, co-authored by researchers from the Global Observatory for Ageing and Dementia Care at King’s College London, calls for a transformation in the response to dementia, citing a 63% increase in the number of people expected to be living with dementia in the region by 2030 – and an increase of 257% by 2050.

Launched during World Alzheimer’s Month, the report highlights new data on the impact of dementia in SSA, the experiences of those living with dementia in the region and the urgent need for governments to act to encourage improved understanding, access to health services and social protection.

Paola Barbarino, CEO of Alzheimer’s Disease International, says: “This report provides important evidence of the huge scale of the challenge we face on multiple fronts in sub-Saharan Africa. Not only is dementia hidden socially, but governments must do more to enhance the infrastructure needed to support those affected. We are calling on governments in the region to take the issue up urgently and to follow the recommendations of the World Health Organization’s Global Plan of Action. The full report can be read here: https://www.alz.co.uk/africa

AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>1 October</td>
<td>European Working Group of People with Dementia (Berlin, Germany)</td>
<td>EWGPWD members, Dianne, Ana</td>
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<tr>
<td>2 October</td>
<td>AE Board (Berlin, Germany)</td>
<td>AE Board and staff</td>
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<tr>
<td>2 October</td>
<td>INTERDEM meeting (Berlin, Germany)</td>
<td>Dianne and Ana</td>
</tr>
<tr>
<td>2 October</td>
<td>AE Annual General Meeting (Berlin, Germany)</td>
<td>AE members, Board and staff</td>
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<tr>
<td>2-4 October</td>
<td>26th Annual Conference “Care today, cure tomorrow” (Berlin, Germany)</td>
<td>AE members, Board and staff</td>
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<tr>
<td>4-5 October</td>
<td>MOPEAD Consortium meeting (Berlin, Germany)</td>
<td>Dianne and Chris</td>
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<tr>
<td>5 October</td>
<td>PredictIND Management Board (Berlin, Germany)</td>
<td>Jean</td>
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<tr>
<td>10-11 October</td>
<td>AMYPAD General Assembly (Amsterdam, Netherlands)</td>
<td>Jean and Cindy</td>
</tr>
<tr>
<td>16 October</td>
<td>ROADMAP General Assembly (Barcelona, Spain)</td>
<td>Jean, Dianne and Chris</td>
</tr>
<tr>
<td>18 October</td>
<td>European Patients Forum Access Working Group Meeting (Brussels Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>18-19 October</td>
<td>IMI Stakeholder Forum 2017 (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>19-20 October</td>
<td>Alzheimer’s Association workshop “Aging and Alzheimer’s disease” (Vara, Bulgaria)</td>
<td>Jean</td>
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<tr>
<td>24-25 October</td>
<td>Council of Europe International Conference, 20th anniversary of the Oviedo Convention (Strasbourg, France)</td>
<td>Ana</td>
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<tr>
<td>26-27 October</td>
<td>European Alzheimer’s Disease Consortium (Lisbon, Portugal)</td>
<td>Jean</td>
</tr>
<tr>
<td>Date</td>
<td>Meeting</td>
<td>Place</td>
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<tr>
<td>2-4 October</td>
<td>27th Alzheimer Europe Conference “Care today, cure tomorrow”, <a href="http://www.alzheimer-europe.org/Conferences/Berlin-2017">http://www.alzheimer-europe.org/Conferences/Berlin-2017</a></td>
<td>Berlin, Germany</td>
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<tr>
<td>16-18 October</td>
<td>9th International Conference on Alzheimer’s Disease &amp; Dementia, <a href="http://alzheimers-dementia.conferenceseries.com/">http://alzheimers-dementia.conferenceseries.com/</a></td>
<td>Rome, Italy</td>
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<tr>
<td>16-17 October</td>
<td>17th Global Neuroscience Conference, <a href="http://neuroscience.conferenceseries.com/">http://neuroscience.conferenceseries.com/</a></td>
<td>Osaka, Japan</td>
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<td>17-20 October</td>
<td>Alzheimer’s Australia National Conference, <a href="http://dementia2017.org/">http://dementia2017.org/</a></td>
<td>Melbourne, Australia</td>
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<td>20-21 October</td>
<td>9th Dementia Conference, ASK 2017 for dementia friendly society, <a href="http://www.spominica.si">www.spominica.si</a></td>
<td>Terme Čatež, Slovenia</td>
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<td>1-4 November</td>
<td>Clinical Trials on Alzheimer’s Disease (CTAD), <a href="http://www.ctad-alzheimer.com/">http://www.ctad-alzheimer.com/</a></td>
<td>Boston, USA</td>
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<td>3-5 November</td>
<td>20th Asia Pacific Regional Conference of Alzheimer’s Disease International, <a href="http://www.alz.or.id">www.alz.or.id</a></td>
<td>Jakarta, Indonesia</td>
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<td>11-15 November</td>
<td>47th Annual Meeting of the Society for Neuroscience, <a href="https://goo.gl/6nWvl">https://goo.gl/6nWvl</a></td>
<td>Washington DC, USA</td>
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<td>27-30 November</td>
<td>CNS Summit, <a href="http://cnssummit.org/">http://cnssummit.org/</a></td>
<td>Florida, USA</td>
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<tr>
<td>15-16 Feb 2018</td>
<td>8th International Conference on Pharmacoeconomics of Alzheimer’s Disease (IPECAD), <a href="http://www.ipecad.org/">www.ipecad.org/</a></td>
<td>Paris, France</td>
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<tr>
<td>22-23 Feb 2018</td>
<td>11th International Conf. on Vascular Dementia, <a href="http://vasculardementia.conferenceseries.com/">http://vasculardementia.conferenceseries.com/</a></td>
<td>Paris, France</td>
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<tr>
<td>1-3 March 2018</td>
<td>Nutrition and maintaining functions with aging (IANA 2018)</td>
<td>Miami, USA</td>
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<tr>
<td>15-18 March 2018</td>
<td>AAT-AD/PDTM Focus Meeting on Advances in Alzheimer’s and Parkinson’s Therapies</td>
<td>Torino, Italy</td>
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<tr>
<td>22-25 March 2018</td>
<td>12th World Congress on Controversies in Neurology (CONy)</td>
<td>Warsaw, Poland</td>
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<tr>
<td>3-6 October 2018</td>
<td>Croatian Congress on Alzheimer’s Disease with International participation, CROCAD-18</td>
<td>Novigrad, Croatia</td>
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<tr>
<td>29-31 October 2018</td>
<td>28th Alzheimer Europe Conference “Making dementia a European priority”</td>
<td>Barcelona, Spain</td>
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<tr>
<td>22-25 October 2019</td>
<td>29th Alzheimer Europe Conference “Making valuable connections”</td>
<td>The Hague, Netherlands</td>
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Contact Alzheimer Europe:
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