Let me start this welcome with some fantastic news! On 24 October, we heard that Alzheimer Europe was one of the 13 organisations which will be awarded a Framework Partnership Agreement (FPA) from the European Union’s health programme to cover our operations for the years 2018-2021. Thanks to this support, we will be able to continue key initiatives such as our European Working Group of People with Dementia, our European Dementia Ethics Network and our Annual Conferences.

Talking of which, this year’s Annual Conference in Berlin attracted close to 750 participants from 41 countries and this newsletter provides detailed reports on the three conference days. The different days were packed with interesting plenary presentations and participants were hard put to select which of the many interesting parallel sessions to attend. In addition, over 200 posters were presented during the coffee breaks.

I wanted to take this opportunity to thank all the presenters and participants for sharing their research, projects and initiatives and turning our Annual Conference into a truly unique networking opportunity. We are currently in the process of analysing the responses of people who participated in our evaluation survey of the conference and I was delighted to see that 96% of participants would recommend our conference to their colleagues.

Our collaboration with INTERDEM is also going from strength to strength. The network of psychosocial researchers held their annual meeting in Berlin and were actively involved in our conference. The two organisations signed a memorandum of understanding in Berlin outlining their commitment to collaborate in future.

We also chose our Annual Conference to present the top line results of our five country survey on carers’ perceptions of diagnosis which made for interesting reading. Thanks BoB Woods for an interesting overview and Roche for their support to this project.

October was also a very busy month on the EU project front with the AMYPAD, MOPEAD PredictND and ROADMAP projects having their general assembly meetings to check on progress and decide on priorities for the coming months. It is truly fantastic that Alzheimer Europe is a recognised and valued partner in all these innovative research projects. In these projects, we support the dissemination activities, contribute to ethical discussions and represent the views of people with dementia and their carers.

Let me therefore finish this welcome by thanking the members of our European Working Group of People with Dementia this month for their incredible contributions to our conference and their invaluable insights to our research projects.

I hope you will enjoy this newsletter with our many October highlights.

Jean Georges
Executive Director
ALZHEIMER EUROPE

1-4 October: European Working Group of People with Dementia plays an active role in AE’s Conference in Berlin

AE’s European Working Group of People with Dementia (EWGPWD) played a very active role and contributed in many different ways to the success of the AE Conference in Berlin “Care today, cure tomorrow”.

On the day prior to the conference, the EWGPWD met in Berlin. All members of the group were present in the meeting. The group welcomed a new member from Finland and, during the meeting, prepared and rehearsed their contributions to the Conference, including the special symposium and their stand.

On Monday 2 October, members of the group participated in the AE Annual General Assembly, and its Chairperson, Helen Rochford-Brennan spoke about the relevance of involving people with dementia at national and European level.

Then, the vice-chairs of the group together with the other members and AE staff, welcomed delegates with dementia registered for the conference and had a tour of the venue. This year 39 delegates with dementia participated in the conference in Berlin – which is a new record!

On day two of the conference one of the main highlights was a symposium organised by the EWGPWD “Living well with dementia We are still here, I am still… “. During the symposium four people with dementia participated and shared their perspectives and lived experience: Helga Rohra (Germany) spoke about: Employment I am still able to work. Amela Hajrič (Bosnia and Herzegovina), spoke about: Stigma, I am still experiencing stigma. Idalina Aguiar (Portugal), talked about: Social Media: I am still active on social media. Carol Hargreaves (Scotland, UK) spoke about Humour: I am still a person with a sense of Humour.

The positive message conveyed by all four speakers was that, although they meet with losses of competence and skills, they “continue to be themselves”, persons still able to contribute to society, still able to do things for themselves, still able to feel, laugh, work, take part in everyday life. In order to be able to do so, they felt that people with dementia need appropriate and timely support and a more inclusive society.

Helen Rochford-Brennan (Chair), and Chris Roberts (Vice-chair) together with his wife, participated in different plenary sessions on the topic of the impact of dementia in the family (Chris and Jayne) and in the current and future research priorities (Helen). Their speeches were very much welcomed by the audience and provided valuable insights into their experiences of living with dementia.

Also, Helga Rohra, member of the EWGPWD from Germany, and Jayne Goodrick (Chris’s wife), chaired parallel sessions on the topic of living with dementia and on dementia care training respectively.

The active participation of the members of the EWGPWD, and of delegates with dementia and carers and supporters, makes AE Conferences truly unique. We would like to thank all members of the EWGPWD and their supporters for their work and involvement in this event.

2 October: Alzheimer Europe and INTERDEM sign memorandum of understanding

The INTERDEM network of researchers interested in psychosocial interventions held its Annual Meeting prior to the AE Conference in Berlin with a record number of close to 100 researchers attending. Alzheimer Europe and INTERDEM used the opportunity to sign a memorandum of understanding highlighting their willingness to collaborate.

In the memorandum, both organisations confirmed that they share a common vision of “changing perceptions, practice and policy in order to improve the quality of life of people with dementia and their carers” and affirmed the following rights of people with dementia:

- The right to a timely diagnosis;
- The right to access quality post diagnostic support;
- The right to person-centred, coordinated, quality care throughout their illness;
- The right to equitable access to treatments and therapeutic interventions;
The right to be respected in their community as an individual with capacities and limitations.

**2 October: AE Annual General Meeting unanimously approves 2016 Reports and 2018 Work Plan**

On 2 October, Alzheimer Europe (AE) held its 2017 Annual General Meeting in Berlin. The meeting was attended by Alzheimer Europe representatives from its national member associations as well as various guests.

Honorary Secretary Jim Pearson presented the 2016 Annual Report and Honorary Treasurer Maria do Rosário Zincke dos Reis gave an overview of the financial report. The delegates reviewed and unanimously adopted AE’s 2016 annual and financial reports.

The Annual Meeting also decided to accept NGO Futura (Montenegro) as a provisional member organisation and welcomed Udruženje AIR (Bosnia and Herzegovina) as a full member organisation of Alzheimer Europe. Delegates also reviewed AE’s 2018-2021 Work Plan and gave their unanimous backing to the plans presented by the organisation’s Executive Director Jean Georges.

During the meeting Helen Rochford Brennan, Chair of EWGPWD gave an overview of the activities of the group during 2017.

The next Annual General Meeting will take place in Barcelona, Spain which is also the venue for the 28th Alzheimer Europe Conference from 29 October to 31 October 2018.

**2-4 October: 27th AE Conference in Berlin “Care today, cure tomorrow” brings together close to 750 participants from 42 countries**

The Alzheimer Europe Conference “Care today, cure tomorrow” was formally opened by Iva Holmeverová, Chairperson of the organisation who welcomed close to 750 participants from 42 countries. The conference brought together 181 speakers, as well as 216 poster presenters to share their research, projects and experiences.

Together with Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft and Bernd Heise, a member of the German association’s Advisory Board of people living with dementia, she extended a special welcome to the 38 people with dementia attending the conference, as well as their carers and supporters: “We are delighted that we do not just speak about people living with dementia at our conference, but speak with them and fully involve them as speakers and in the planning process of our events.”

During the opening ceremony, dementia was highlighted as one of the key public health challenges at European, national and local level. Matthias von Schwanenflügel, Ministry for Family Affairs, Senior Citizens, Women and Youth and Regina Kraushaar, Ministry of Health gave an overview of the activities of Berlin and Germany to support people with dementia and their carers, raise awareness, combat stigma and support greater research in the field. The German “Allianz für Menschen mit Demenz” and the „Demenz Partner” campaign were showcased as examples of good practice.

In his keynote presentation “Time is on our side”, Prof. Alexander Kurz from the Technical University in Munich gave an overview of the challenges and opportunities which future treatments for Alzheimer’s disease could raise. He expressed his hope that treatments currently under development will slow down the progression of the neurodegenerative process, particularly if administered at the early stage. Such a novel scenario could imply more years of life, more time and better capability to adapt to and cope with cognitive and functional impairment, more years spent at mild and moderate rather than at more advanced stages of the disease, and possibly even an escape from severe dementia and dependence. He called on Alzheimer associations, health care professionals and society at large to collaborate and assess how best to use this extra time provided by early diagnosis and novel treatments.

The opening ceremony was brought to an end with a surprise rendition of a number of Berlin songs by the Board and staff of the conference co-host, the German Alzheimer’s association.

**Second day of AE Conference “Care today, cure tomorrow” focuses on living with dementia and care approaches**

The focus of the second day of the Alzheimer Europe Conference was on the experience of living with dementia and the importance of innovative care in supporting people with dementia and their carers.

The first plenary session “The impact of dementia on the whole family” was delivered by Chris Roberts and his wife Jayne Goodrick (Wales, United Kingdom). They shared their experience of receiving a diagnosis and how this diagnosis impacted Chris, his wife and his family and how they all had to learn how to “live with dementia”. They highlighted that dementia seriously challenges the whole family dynamic and relationships and can...
cause total breakdown, as well as a lot of guilt and blame. They shared how they learned to overcome these challenges and how important their advocacy work on behalf of other people with dementia has become. As a fitting conclusion, they highlighted: “We continue to do what we know best: be husband and wife rather than patient and carer”.

The importance of “Home care in dementia – relief for caregivers and support for care-receivers” was introduced by Prof. Elmar Grässel from the University Hospital Erlangen (Germany). He highlighted that more than 50% of carers are at risk of reduced physical health because of their caregiver role. He presented the range of support and respite services which are available for carers but stressed that carers need to be motivated to use these services. The implementation of non-pharmacological therapies in different settings was another important priority presented by Prof. Grässel.

The third speaker, Imogen Blood (United Kingdom) gave an update on “The European Joint Action on Dementia and its focus on dementia-friendly communities and initiatives”. She presented the findings and key conclusions of the report commissioned by the UK Department of Health. According to her, the focus of dementia-friendly community initiatives should be on removing barriers in order to promote the inclusion of people with dementia in the ordinary day-to-day life of their communities. People with dementia involved in her research said that it was important for them to “continue to be me” by doing “normal” things. Having opportunities to make a contribution and having a say in the design, delivery and evaluation of dementia-friendly initiatives is also important. Key to the success of these initiatives is a broad alliance – a “social movement” which gathers and responds to the experiences and priorities of local people with dementia and their supporters, and builds on local resources and networks to raise public awareness and improve the physical environment.

Prof. Thomas Klie from the University of Freiburg (Germany) concluded the first plenary session with his presentation on the “Ethical and legal considerations in the care of people with dementia at home”. Although life and care at home are preferred by most individuals, this exposes people with dementia and carers to particular strains. As a result, questions regarding human rights issues in care and fairness in the distribution of care tasks arise. To address these, Prof. Klie advocated for a “Caring Community” with a mix of informal, professional and voluntary help focusing on providing efficient care and case management.

The second plenary session entitled “Dementia care in the 21st century” started with an overview by Dr. Anders Wimo from Karolinska Institutet (Sweden) on “The cost of dementia care”. According to him, 47 million people in the world lived with dementia (about 10.5 million in Europe) in 2015 and these numbers are expected to increase to 75 million in 2030 and 132 million in 2050. The socioeconomic impact is enormous with global costs estimated at USD 818 billion in 2015 of which 40% are due to informal care.

Prof. Knut Engedal from the University of Oslo (Norway) gave his presentation on “Care guidelines and national dementia strategies” and stressed that such strategies should be based on important ethical principles such as autonomy and dignity and the framework of person-centred care. In countries with strategies, the awareness of dementia in the public has been improved, more people with signs of dementia have received a diagnosis and more people have had access to services according to their needs. Another way of developing high-quality care for people with dementia is to establish national care guidelines, based on the best evidence from the literature. However, it is of importance that care guidelines and dementia strategies are anchored at national social and health authorities and that politicians are willing to finance public services that are recommended by the care guidelines and strategies.

Prof. Bob Woods from Bangor University (United Kingdom), presented top line results from a five country survey on “The experience of carers of a diagnosis of dementia”. Over 1,400 carers of people with dementia in the Czech Republic, Finland, Italy, the Netherlands and Scotland (UK) responded to a survey which was supported by an educational grant from Roche to Alzheimer Europe. The survey looked at first indications that led to carers seeking help, the role of different
healthcare professionals in the diagnosis, existing barriers to diagnosis, the disclosure of the diagnosis to the person and carers and the provision of information and signposting to other services and post-diagnostic support. More details on this survey are available in a press release issued during the conference.

Prof. Lieve Van den Block from the Vrije Universiteit Brussel (Belgium) presented the “PACE project and its implications for palliative care for people with dementia” and stressed that the provision of high-quality palliative care should be a priority for nursing and care homes in Europe. The EU-funded PACE project studying palliative care in Belgium, the Netherlands, England, Finland, Poland and Italy found that the quality of end-of-life care for people with dementia in nursing homes and nursing home staff’s knowledge of palliative care must be improved.

**European Working Group of People with Dementia (EWGPWD): “We continue to be ourselves”**

An additional highlight of the day was a symposium organised by AE’s European Working Group of People with Dementia at which four people with dementia participated and shared their perspectives and lived experience: Idalina Aguiar (Portugal), Amela Hajrič (Bosnia and Herzegovina), Carol Hargreaves (Scotland, UK) and Helga Rohra (Germany). The positive message conveyed by all four speakers was that, although they meet with losses of competence and skills, they “continue to be themselves”, persons still able to contribute to society, still able to do things for themselves, still able to feel, laugh, work, take part in everyday life. In order to be able to do so, they felt that people with dementia need appropriate and timely support and a more inclusive society.

**Focus on prevention, timely diagnosis and innovative treatments**

In his plenary presentation, Dr Horst Bickel from the Technical University of Munich (Germany) provided “An overview of current epidemiological trends in dementia”. He stressed that up to one third of dementia disorders could probably be prevented by controlling risk factors. The most promising in terms of prevention were a reduction of vascular risk factors (smoking, obesity and hypertension) and an increase in physical and mental activity. A number of studies suggested a secular trend towards a decline in dementia risk in Western countries.

“Reducing dementia risk by targeting modifiable risk factors in mid-life: the lessons of the In-MINDD project” was also the focus of the presentation by Prof. Kate Irving from Dublin City University (Ireland). In-MINDD sought to take the best available evidence and integrate this within a communication and support tool to help communicate reliable and important messages to the public and the health and social care community via a website designed with this purpose. Although the intervention did not demonstrate a significant change in behaviour in participants, lessons were learned concerning the process of normalising new complex interventions into existing care and the role of technology in supporting behaviour change to support cognitive health. Prof. Irving concluded by calling for a balance between investment in prevention, care and cure.

Prof. Wiesje van der Flier from the VU Medical Centre in Amsterdam (Netherlands) focused on “Advances in Alzheimer’s diagnosis; implications for clinical practice?” Her positive assessment of the research over the past decades was that it had resulted in great progress in our knowledge of Alzheimer’s diagnosis. One of the challenges is how to combine the available information in a way that is both meaningful for the individual patient and doable for the individual doctor. According to Prof. van der Flier, there is room for shared
decision making and improved communication between patients, carers and professional. E-tools may be of help for this purpose. The question “Are we getting closer to better treatments for Alzheimer’s disease?” was addressed by Prof. Frank Jessen from the University of Cologne (Germany). He highlighted the enormous challenge of developing a new treatment for Alzheimer’s disease, since, so far, all promising drugs for disease modification, but also new compounds for symptomatic treatment have failed to show clinical efficacy. Amongst the reasons for these failures, he cited difficulties with treatment targets, mode of action and selection of patients. Despite these negative results, a number of important learnings were gained: Very early treatment and combination therapies are the upcoming next steps. Importantly, recent studies also showed promising results in the field of non-pharmacological interventions with regard to prevention of dementia. In addition, there is development in the treatment of behavioural symptoms at the stage of dementia.

Identifying current and future research priorities
A final round table brought together key stakeholders at a European level to discuss and identify current and future research priorities. Moderated by Sabine Jansen, the Executive Director of the German Alzheimer’s association, the panel included:

- Lutz Frölich (European Alzheimer’s Disease Consortium, Germany)
- Iva Holmerová (Alzheimer Europe, Czech Republic)
- Andreas Holtel (European Commission)
- Pierre Meulien (Innovative Medicines Initiative)
- Helen Rochford-Brennan (European Working Group of People with Dementia, Ireland)
- Winfried Teschauer (Deutsche Alzheimer Gesellschaft, Germany)
- Myrra Vernooij-Dassen (INTERDEM, Netherlands).

The participants highlighted the growing support for dementia research at both a national and European level, with a number of programmes including the Innovative Medicines Initiative (IMI), the Joint Programme for Neurodegenerative Diseases Research (JPND) and Horizon2020 programme dedicating significant funds to all aspects of dementia research. The need for a better coordination of these different programmes was discussed, as well as the importance of promoting a holistic approach to dementia research. Pierre Meulien presented the example of IMI which addresses all aspects of Alzheimer’s disease research, from knowledge creation to developing new treatments.

Andreas Holtel from the European Commission emphasised that beyond H2020, research on Alzheimer’s disease, dementia and neurodegenerative diseases in general will remain a prime focus, targeting the full breadth of research efforts from understanding the disease to implementation and public health research. According to Winfried Teschauer, strengthening research in nursing and care sciences would support primary and secondary care. For the European Alzheimer’s Disease Consortium, the development of sensitive and specific biomarkers for an early diagnosis of AD and other dementias, which can be used in general practice and the development of effective disease-modifying therapies for Alzheimer’s disease constitute priority areas for research. Social health is a priority for the INTERDEM network and its chairperson Myrra Vernooij-Dassen expanded: “Social health, including social engagement is underused in prevention and treatment of dementia. Research could focus on its working mechanisms and on developing, evaluating and implementing interventions to enhance social health.”

Patient engagement and involvement in co-developing new strategies to combat Alzheimer’s disease was seen as critical to the success against the disease, according to Pierre Meulien, whilst Helen Rochford-Brennan said: “Every person with dementia has human rights, and should be entitled to receive information about research and, if willing, be enabled to take part in research on dementia. This gives us hope.”

The quick translation of research results into clinical practice was another important recommendation from the discussions and was highlighted by Iva Holmerová and Lutz Frölich: “Scientific advances have to be evaluated with respect to their clinical relevance and applicability in the practice of medicine”. Echoing the motto of the conference, participants stressed the importance of “Care today, cure tomorrow” to ensure that we provide hope for the future for better treatment and prevention strategies, whilst recognising the need to improve the quality of life, support and care of people living with dementia today.
Good bye Berlin, welcome Barcelona

The three-day conference was formally closed by Iva Holmerová who thanked the 181 speakers and 216 poster presenters for their active contributions to the success of the conference and for sharing their research, projects and experiences. She also paid a special tribute to the various sponsors of the conference, including the health programme of the European Union as well as Abbvie, Alzheimer Europe Foundation, Axovant, Eisai, Lilly, MSD, Otto und Edith Mühlschlagel Stiftung in der Robert Bosch Stiftung, Roche and Visit Berlin.

She invited all participants to already take note of the date of the next Alzheimer Europe Conference “Making dementia a European priority” in Barcelona from 29 to 31 October 2018.

3 October: Five-country survey of carers highlights continuing delays in dementia diagnosis across countries

At the 27th Alzheimer Europe Conference in Berlin, Prof. Bob Woods (Bangor University, Wales, United Kingdom) presented the top line results of a five-country survey on the experience of 1,409 carers of a diagnosis of dementia. Amongst the key reported findings:

- The majority of participating carers were women (82.8%) in all participating countries (ranging from 75.8% in the Netherlands to 88.4% in Scotland)
- Differences existed with regard to the relationship of the carer to the person with dementia with a majority of participating carers in the Netherlands being spouses or partners (53.7%) whereas the largest group in all other participating countries were the children of the person with dementia (ranging from 45.8% of carers in Scotland to 64.8% in Italy)
- On average, 47% of carers felt that the diagnosis would have been better earlier (ranging from 36.5% in the Netherlands to 52.1% in Italy)
- Amongst the key identified barriers to earlier diagnosis, carers reported the first professional seen not considering that anything was wrong (33%) or believing it was not worth pursuing a diagnosis (6.6%) and the refusal of the person with dementia to seek help (37.9%)
- Carers reported that in a number of cases (19.2% in the Netherlands to 31.8% in the Czech Republic and 31.9% in Italy), another condition was diagnosed before the diagnosis of dementia was made.
- The role of healthcare professionals involved in the diagnosis of dementia differs between European countries with the percentage of carers reporting that they first sought help from GPs/primary care ranging from 31.9% in Italy to 83.9% in Scotland.
- Carers also reported differences as to the assessments which are carried out as part of the diagnosis with memory tests being reported by 78.7% of carers in the Czech Republic to 92.8% of carers in Finland, interviews with the person with dementia from 62.3% in the Czech Republic to 86.7% in Italy, blood tests from 31.8% in Italy to 64.2% in Finland, brain scans from 56.1% in the Czech Republic to 84.3% in Finland and lumbar punctures from 1.7% in Scotland to 18.3% in the Netherlands.
- Significant differences exist across European countries as to the percentage of people with dementia being informed about their diagnosis with 59.3% of Italian carers reporting that the person had not been informed about their diagnosis and this percentage falling to 23.2% in the Czech Republic, 8.2% in the Netherlands, 4.4% in Scotland and 1.1% in Finland.

When presenting the findings, Prof. Bob Woods highlighted: “Over 1,400 carers provided invaluable insights into their experiences of the diagnosis of dementia. We were particularly interested to see whether there were differences between people who had been diagnosed more recently (after 2013) compared to those who had been diagnosed earlier. Several countries have dementia strategies and there is growing public and professional awareness. It was encouraging to see that medical professionals were less likely to be a barrier to diagnosis in all countries with the number of professionals considering that nothing was wrong decreasing from 36.8% to 28.7%. We will of course further analyse these results and present them in a scientific paper later this year.”

Welcoming the results, Jean Georges, Executive Director of Alzheimer Europe said: “Thanks to the participating carers, we are better able to understand the existing barriers which still exist across Europe which delay people with dementia and their carers getting a timely diagnosis. The differences across Europe show however that each national system will need to identify specific measures to improve diagnosis rates”.

24 October: Alzheimer Europe’s bid for core funding under the EU health programme is successful

On 24 October, CHAFEA (Consumer’s, Health, Agriculture and Food Executive Agency) published the award decision with the results of the call for proposals for operating grants launched under the 2017 Annual Work Programme. 38 organisations had submitted their proposals and based on the budgetary availability, 13 organisations will be awarded a Framework Partnership Agreement (FPA), covering their operations for the years 2018-2021. Alzheimer Europe is delighted to announce that it was amongst the 13 successful applicants.
EU PROJECTS

15 September: The MinD project works with healthcare experts

For Visit 16, the main design phase of the project, MinD colleagues met at the Alexianer Hospital in Berlin and at TU Dresden. The guest researchers and various hosting colleagues worked together on the development of design proposals in response to three ‘transition areas’ – areas where people with dementia and their carers are most concerned with adapting to change and which had been derived from data analysis in prior secondments. Each transition area covers different potential options to increase wellbeing and social interaction of people with dementia.

In the first week, 14 design ideas were developed and prepared for presentation in posters, offering a visualisation as well as participant quotes and descriptions of the designs, which had been translated into German for the local experts. An expert workshop with local medical and healthcare staff was held in order to gain feedback and advice on the suitability and other aspects of the 14 design ideas.

For the second week, the MinD team established a number of criteria to help with assessing the relevance, significance and feasibility of the design ideas to help with selecting the most promising ideas for further development. Four of the design proposals were selected for further refinement: two of them have an emphasis on changing routines and communication in order to allow for more mindfulness in dementia care, and two of them are more experimental and technologically challenging. One example is a personalised ‘guide to my future (self)’ which contains self-help guidance and exercises for managing life with dementia. Another example is a smart device, which helps people with dementia to focus on conversation partners when taking part in social events.

The four design proposals have been developed and documented to allow better understanding of the ideas. This will be valuable for further assessment by experts in the following secondments, where further selections will have to be made.

21 September: i~HD and EMIF organise joint meeting in Madrid

On 21 September, the European Institute for Innovation through Health Data (i~HD) and the European Medical Information Framework (EMIF) hosted a two-day joint meeting entitled; “Realising the Value from Health Data - Improving Care and Research” in Madrid (Spain).

The meeting at the Hospital Universitario 12 de Octubre attracted over 200 delegates. During the first session, representatives from the Spanish and the Estonian health ministries discussed the importance of reusing clinical data for the improvement of health care and clinical research. The politicians acknowledged the need to provide a basis for dialogue with patients in this process. Further, goals and challenges of a transition towards “value-based” and “outcomes-based” health care were discussed. During the afternoon, discussions revolved around possibilities of empowerment of patients and the development of solutions that lead to a healthy data ecosystem with quality data.

The agenda for the second day, included an overview of the results of EMIF’s work to date. In addition, technical aspects such as the harmonisation of Alzheimer’s disease cohort data to a “Switchbox common data model” (developed within EMIF) were presented.

The meeting was rounded off by a panel discussion, including Michel van Speybroeck, (Janssen Data Sciences), Simon Lovestone (EMIF Co-Coordinator and Professor of Translational Neuroscience, Oxford) and Nigel Hughes (EMIF-Platform Co-Coordinator and Janssen Pharma R&D) highlighting the overarching goal of their work towards improved health outcomes and the need for patient involvement.

25-29 September: INDUCT consults with Alzheimer Europe’s dementia working group

On 25-29 September, members of INDUCT (Interdisciplinary Network for Dementia using Current Technology) attended the second INDUCT School that took place in Salamanca, Spain. The School was organized by IDES (Social Innovation & Assistive Technologies)/Intras Foundation, the Spanish Centre of reference in Alzheimer (CREA), the University of Salamanca, the University of Maastricht and the INTERDEM Academy Network. The school helped all the project members to learn about the progress that early stage researcher (ESR) have made in their projects since the first INDUCT school in January. In this School, the INDUCT Fellows were encouraged to recognise future collaboration opportunities by using an ‘interactive wall’ where ESR could place a label with their ‘learned abilities’ and ‘calling for help’ to their colleagues for the next steps of the projects.

Once again, the members of the EWGPWD from Alzheimer Europe (Chris Roberts, Nina Balackova and Idalina Aguilar alongside their family supporters) provided valuable insights on how to better involve people with dementia in research. The members emphasized the importance of avoiding dehumanization in dementia research, by listening and taking into account the research participant opinions, treating them not as subjects of research, but as persons. The members also highlighted the need for researchers to appreciate
participants’ lived experiences, as it could be an ‘added value’ in psychosocial research.

During their stay in Spain, the INDUCT members and the EWGPWD visited different facilities related to dementia care, such as the CREA (which is the largest Alzheimer research centre in Spain), as well as the Intras foundation headquarters, where they had the opportunity to try in situ all the technologies currently used in their Memory Clinic. The week was closed with a two-day symposium about ‘New perspectives in dementia care’, held at the University of Salamanca.

https://www.dementiainduct.eu/

29 September: MinD project works with partners in Barcelona and consults with healthcare experts

The main design phase of the MinD project continues and the project met at Eurecat, Universitat Politecnica de Catalunya and Pich Architects offices in Barcelona for “Visit 17”. The design team worked on the development of design proposals in response to the three “transition areas”: Coming to terms with emotions; Maintaining social participation; Negotiation and communication.

In the first week, the team focused on idea generation for each of the transition areas, resulting in 7 to 10 ideas per area. Based on a list of criteria assessing the relevance, significance and feasibility of the design ideas, 3 of the ideas for each area were selected to be developed into more detailed concepts over the second week.

These concepts were presented to a round table discussion with mental health experts specialising in dementia from Sant Joan de Déu Hospital and Alzheimer Catalunya, organised by the Cluster Salut Mental Catalunya. The expert review provided valuable insights and supported analysis and development of the concepts, these will also inform the decision making process about which ones will be developed into prototypes.

30 September: INDUCT project is looking for opinions of people living with dementia about surveillance technologies

The Interdisciplinary Network for Dementia Using Current Surveillance Technology (INDUCT) is studying surveillance technologies which can consist of technological devices used on and by people with dementia to monitor their location. Recently, Yvette Vermeer (pictured), an early stage researcher (ESR) discussed the growing awareness of the role that surveillance has on addressing the needs of people with dementia and their caregivers at the conference of the British Society of Gerontology, entitled: “Do not go Gentle – Gerontology and a good old age”. This presentation is available on the Aging Bites Youtube channel.

INDUCT is currently looking for people living with dementia to provide their opinion on surveillance technologies and whether or not they see potential empowerment through the use of these products. If you are living with dementia and would you like to know more about this research, please send an e-mail to: y.vermeer@ucl.ac.uk.

4 October: PredictND showcases its progress at the 27th AE Conference in Berlin

The PredictND project chose the 27th AE Conference in Berlin to showcase its progress. Participants were greeted with a conference bag which included a special supplement of AE’s Dementia in Europe magazine which provided a high level overview of the PredictND project.

On 4 October, an interactive and educational session was also dedicated to this project and allowed the researchers to present the results of the project focusing on the important role that information technology and the PredictND clinical decision support tool could play in improving the diagnosis of Alzheimer's disease and other dementias in clinical practice.
Chaired by Wiesje van der Flier (VUMC, Netherlands), the symposium was started with a short introduction by Mark van Gils (VTT, Finland) about the PredictND project that aims to develop computer tools to aid in differential diagnosis of neurodegenerative diseases. Next, Steen Hasselbalch (Righshospitalet, Denmark) provided a description of the characteristics of different types of dementia and highlighted a number of challenges for the clinician. Marie Bruun (Righshospitalet, Denmark) continued with a hands-on introduction to several neuropsychological tests and visualised the rating of brain MRI with a focus on memory clinic decision making.

Hilkka Soininen (University of Eastern Finland, Finland) outlined different approaches that could be used in the future to detect cognitive disorders earlier with a focus on primary care. Hanneke Rhodius-Meester (VUMC, Netherlands) demonstrated the PredictND tool and showed its added value in a truly interactive session where she discussed difficult cases for clinicians to evaluate. The symposium was brought to an end by Jyrki Lötjönen (Combinostics, Finland) who presented an overview of the key outcomes of the PredictND project.

On 5 October, the PredictND team met for a project and Management Board meeting to discuss the priorities for the final months of the project which will end in February 2018.

4 October: Symposium explores ways for MOPEAD, EPAD and ROADMAP projects to engage with Alzheimer associations

The 27th Alzheimer Europe Conference was a great occasion to get to know three of the IMI (Innovative Medicines Initiative) projects Alzheimer Europe is involved in.

At a symposium convened by Eli Lilly, entitled: “Engaging with patient organisations within IMI consortia to inform quality, relevance and value in Alzheimer’s research – insights from MOPEAD, EPAD and ROADMAP”, the attendees were able to explore how these three initiatives are tackling Alzheimer’s disease across the disease continuum.

The symposium was moderated by Jean Georges Executive Director of Alzheimer Europe. The panellists provided their perspectives regarding the rationale for each project, engaging in a discussion on the concrete multipronged actions to improve timely diagnosis through citizens’ participation, pioneering novel approaches to clinical trials and providing evidence regarding the value of new medications. The first panellist was Mercè Boada, she is co-founder of Fundació ACE and Project Coordinator of the MOPEAD (Models of Patient Engagement for Alzheimer’s Disease). Her presentation was followed by an introduction to the EPAD (European Prevention of Alzheimer’s Disease) project by Craig Ritchie, Director of the Centre for Dementia Prevention. The presentations were rounded off by Catherine Reed, principal research scientist at Eli Lilly, who introduced ROADMAP (Real world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform) and how real-world evidence may be used to address specific healthcare challenges. One of the highlights of the following discussions was the engagement of Pierre Meulien Executive Director of the IMI at the end of the symposium.

4-5 October: MOPEAD project holds 3rd Consortium Meeting in Berlin

On 4 to 5 October, members of the Models of Patient Engagement for Alzheimer’s Disease (MOPEAD) project met with members of their External Advisory Board from the EPAD and ROADMAP projects in Berlin.

During the two days, they discussed ongoing work and potential areas to explore with the advisors. During a working dinner on the first day, project coordinators Laura Campo and Mercè Boada presented the overall project and the participants introduced themselves to the advisors.

On the second day, the leaders of the clinical work packages presented progress reports and highlighted outstanding issues and next development stages. These work package discussions were enriched throughout with feedback from the team and advisors. At the end of the meeting, Elisabetta Vaudano (Project Officer, Innovative Medicines Initiative) provided feedback on the projects’ progress. Potential future synergies of MOPEAD, ROADMAP and MOPEAD were examined. Laura Campo then recapitulated the days’ discussions and closed the meeting, wishing all attendees a safe return.

9 October: AETIONOMY partners meet in Stockholm to discuss progress

On 9 October 2017, project partners of the AETIONOMY project met in Stockholm at the Karolinska University Hospital to discuss progress with the project in general. Much of the day was taken up with discussions about the data analytics strategy and validation plan. The meeting ended with a discussion about the next steps and plans for the General Assembly which will take place at the end of November in Basel (Switzerland). Dianne represented Alzheimer Europe at this meeting.
10 October: AMYPAD project holds its General Assembly meeting in Amsterdam

On 10 and 11 October, the “Amyloid imaging to Prevent Alzheimer’s disease” (AMYPAD) consortium gathered for their General Assembly (GA) meeting in Amsterdam, The Netherlands. The event was sponsored by VU University Medical Center (VUmc).

On the first day, the GA meeting officially started with a welcome by the chairs of the meeting Frederik Barkhof (VUmc) and Gill Farrar (GE Healthcare). They introduced the meeting objectives and reported the one year progress. After that, the diagnostic study was presented by Giovanni Frisoni (Université de Genève) followed by the prognostic study presented by Craig Ritchie (The University of Edinburgh). There was also a presentation on the tracer delivery by GE Healthcare and Piramal and the scanner certification process by IXICO. Marthe Smedinga (RUMC) reported then the ethics in AMYPAD for both the diagnostic and prognostic studies. Andrew Stephens (Piramal) continued with a talk on TAU PET imaging. Finally, each WP had the opportunity to present its remit and progress so far.

On the second day, Veronique Dekker and Sandra Pla (Synapse) gave an overview of the project management and the upcoming administrative tasks. A presentation was delivered on the regulatory strategy by Gill Farrar. During the morning of 16 October, the GAM started with a break-out session of WP4 (Disease Modelling and Simulation) during which the model validation was discussed internally. After that, the meeting was officially opened by Principal Investigator John Gallacher and discussions followed on the data cube (a theoretical model which will encompass linked information on disease progression, outcomes/variables and data sources) by Johan van der Lei. In pursuit of this, parallel workshops were launched, focussing on an overview on the data platforms, ROADMAP has direct access to through its partners (DPUK, EMID-AD and EMIF-EHRs). On the second day, Alba Jené from Synapse gave an update on financials of the project and IMI reporting after a short welcome introduction by John Gallacher. This was followed by short WP updates on their respective progress. Further, the data access procedures were presented by Antje Hottgenroth and Stephanie Vos. The meeting was then wrapped up and upcoming actions were recapitulated by John Gallacher.

16 October: The first MOPEAD project newsletter is out!

On 16 October, the MOPEAD communication work package released its first ever newsletter: https://goo.gl/Ya8jDM

The “Models of Patient Engagement for Alzheimer’s Disease” project aims to contribute to redress the situation: the project will assess different Patient Engagement models across Europe that will help identify subjects with mild and prodromal AD at an early stage. MOPEAD has the potential to contribute to move the AD Environment towards earlier diagnosis to improve identification of appropriate patients for disease modifying therapies.

19 October: EPAD Research Participant Panel invited to speak at the IMI Stakeholder Forum 2017

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Forum, two parallel tracks focused on examples of IMI’s open innovation in practice. The first track was co-developed by IMI and the European Patients’ Forum (EPF) and was focused on patient engagement and collaboration. The second track was on the microbiome, with a view to seeing how IMI could best work in this area.

The EPAD project is very thankful that Eileen, a Member of the EPAD Research Participant Panel, was willing to come along to the IMI Stakeholder Forum to talk about her actual involvement in the research and her contribution via the EPAD panel.

Alzheimer Europe Networking

On 1 October (Berlin, Germany) Dianne, Ana and Jean attended the meeting of the European Working Group of People with Dementia.

On 2 October (Berlin, Germany) the Alzheimer Europe Board met.

On 2 October 2017, Berlin (Germany) Ana attended an INTERDEM meeting.

On 2 October (Berlin, Germany) Alzheimer Europe organised its Annual General Meeting with its member organisations.

On 2-4 October (Berlin, Germany) Alzheimer Europe organised its 27th Annual Conference “Care today, cure tomorrow”.

On 4 to 5 October 2017 (Berlin, Germany) Dianne, Jean and Chris attended the 3rd Consortium Meeting of the MOPEAD project.

On 5 October (Berlin, Germany) Jean attended a project and management team meeting of the PredictND project.

On 9 October (Stockholm, Sweden), Dianne attended an AETIONOMY project meeting.

On 10-11 October (Amsterdam, Netherlands) Jean and Cindy attended the General Assembly of the AMYPAD project.

On 16-17 October (Barcelona, Spain) Jean, Dianne and Christophe attended the 4th General Assembly Meeting (GAM) of the ROADMAP project.

On 18-19 October (Brussels, Belgium) Cindy attended the IMI Stakeholder Forum 2017.

On 18 October (Brussels, Belgium) Vanessa attended the EPF Working Group on Access meeting.

On 18 October (Barcelona, Spain), Dianne attended the EXAG ROADMAP project meeting.

On 19 October (Brussels, Belgium) Vanessa attended the Eurocarers launch event of the White Paper on Cancer Carers.

On 19-20 October (Varna, Bulgaria) Jean participated in a meeting “Aging and Alzheimer’s disease: Opportunities for therapeutic interventions” organised by the US Alzheimer’s Association.

On 24-25 October 2017 (Strasbourg, France) Ana attended an international conference about the Oviedo Convention organised by the Council of Europe.

On 27 October (Brussels, Belgium) Cindy attended an EFPIA Patient Think Tank Meeting.

On 30 October (Cambridge, United Kingdom), Dianne attended a meeting in connection with the ethics work for the MOPEAD project.
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 Tomasić (ECR). Cyprus: Costas Mavrides (S&D); Eleni Theocharous (EPP). 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: Urmas Paet (ALDE); Finland: Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Merja Kyllönen (GUE/NGL); Sirpa Pietikäinen (EPP). France: Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); Françoise Grossetête (EPP). Germany: Angelika Niebler (EPP); Udo Voigt (NI). Greece: Costas Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulis (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyra (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg-Chrysogonos (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Nessa Childers (EPP); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL); Patrizia Toia (S&D); Damiano Zoffoli (S&D). Hungary: Ádám Kósa (EPP). Ireland: Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D); Deirdre Clune (EPP); Brian Crowley (ALDE); Luke ‘Ming’ Flanagan (GUE/NGL); Marian Harkin (ALDE); Brian Hayes (EPP); Seán Kelly (EPP); Mairead McGuinness (EPP); Liadh Ni Riada (GUE/NGL). Italy: Brando Benifei (S&D); Elena Gentile (S&D); Stefano Manifesto (S&D); Simonetta Sommaruga (S&D); Pier Antonio Panzeri (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (S&D); Patrizia Toia (S&D); Damiano Zoffoli (S&D). Lithuania: Vilija Blinkeviciute (S&D). Luxembourg: Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (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 (S&D). Romania: Mirceasavţă (S&D); Aldo Patriciello (EPP); Remo Sernagiotto (S&D); Patrizia Toia (S&D); Damiano Zoffoli (S&D). Slovakia: Miroslav Mikolášik (EPP); Ivan Stefanec (EPP); Anna Zábořská (EPP). Slovenia: Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romana Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (ALDE). Spain: Íñigo Errejón (GADAA); and the European Disability Forum (EDF). The event was chaired by MEP Deirdre Clune (Ireland) and MEP Heinz Becker (Austria) also attended and gave some closing remarks. The event was sponsored by MSD.

The key objective of the roundtable was to put the experience of people with Alzheimer’s disease at the heart of the discussion on a rights-based approach to Alzheimer’s. Alzheimer Europe was invited to give a presentation on the “European Dementia Monitor 2017” and Helen Rochford-Chartier (EPP); Katzina Udom (NI); Elke Tiefensee (S&D); Peter Tschäppät (S&D); Mechtild Roeder (S&D); Ursula Godehardt-Dürr (ALDE); Nathalie Griesbeck (ALDE); Charles Goerens (ALDE); Viviane Reding (EPP).

EUROPEAN ALZHEIMER’S ALLIANCE

28 September: MEP Deirdre Clune hosts roundtable discussion at the European Parliament on the right to dignity for people with Alzheimer’s disease

On 28 September in Brussels at the European Parliament, Deirdre Clune hosted a discussion called “What if” roundtable on “The right to dignity: Overcoming the stigma, discrimination and inequalities faced by people with Alzheimer’s”
EU DEVELOPMENTS

10 October: EDF reports highlights number of people with disabilities excluded from voting

According to the European Disability Forum (EDF) millions of Europeans with disabilities are excluded from this fundamental right.

The right to political participation and the right to vote are fundamental rights for all citizens. They are at the heart of democracy and citizenship. They are also rights enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) that the European Union (EU) and all its Member States (except Ireland) have ratified, meaning they are obliged to make it happen for all their citizens with disabilities.

In reality, millions of people with disabilities in Europe are deprived from exercising this fundamental right. Women with disabilities, people with disabilities living in institutions and people with less visible disabilities, such as people with dementia or intellectual or psychosocial disabilities, are at even higher risk of being excluded.

EDF is working closely with the European Economic and Social Committee (EESC) providing input for a EESC report on the subject of the right to vote for people with disabilities. The report will be adopted in early 2018.

11 October: European Commission publishes mid-term evaluation of the 3rd Health Programme 2014-2020


11 October: MEPs and stakeholders discuss ‘Benchmarking access to healthcare in the EU’

On 11 October, the European Parliament Interest Group on Access to Healthcare hosted a hearing in relation to the Expert Panel on Effective Ways of Investing in Health’s Opinion entitled ‘Benchmarking access to healthcare in the EU’. The hearing, organised by the European Commission, was attended by stakeholders representing a wide variety of interests and backgrounds, with all professional associations working in the fields concerned present.

The hearing aimed to provide those attending with an opportunity to express their commitment to join efforts in closing gaps in access to healthcare, to learn about possible approaches, to set benchmarks in access to healthcare and about policy levers guiding Member States to close these gaps and to learn how the Opinion could be used.

12 October: European Commissioners for Health, Agriculture, and Sport and Education agree on a roadmap for healthy lifestyles

In the “Tartu Call for a Healthy Lifestyle” Commissioners Andriukaitis, Navracsics and Hogan have outlined concrete actions to help promote healthy lifestyles, especially among children and young people. Healthy lifestyle is also important for older people and people with dementia. Exercise can contribute to a healthy brain and could be a factor in dementia risk reduction. Much more research needs to be done in this field but it seems logical that physical activity does indeed have a positive impact on the brain structure and function.

24 October: The Human Brain Project reports on its progress in building Europe’s new platform for understanding the brain

Over 500 scientists and engineers from 19 countries met in Glasgow on 17-20 October at the 5th Summit of the Human Brain Project (HBP) to discuss results and perspectives on their quest towards...
building a unified platform for a comprehensive understanding of the human brain and its diseases.

Understanding the multilevel organisation of the brain requires bridging the different scales in time and space, from the molecular to the level of large scale organisation and behavior. This challenge is so extraordinary that not the even best-funded single research project could claim to provide the full picture. Therefore, a unique lasting contribution the HBP can make is to integrate and focus precious resources to build a collaborative platform: a genuine European research infrastructure driven by innovative supercomputing and neuromorphic systems. On the platform, experimental and theoretical approaches are combined with models, simulation and data analytics. This provides neuroscience and brain medicine with a new path to meet the brain’s complexity, linking insights, methods and large datasets from many areas of brain research. This shared platform will serve excellent research groups to leverage and multiply the impact of the available funding, the brightest ideas, and the best scientific talent.

The HBP has spearheaded a new approach in basic and clinical brain research. Its strategy of systematically combining neuroscience, robotics and high computing is yielding promising early results. The Glasgow Summit showed that Europe’s plans for understanding the brain are on track and marked the start into the next year of the HBP’s journey with a positive and exciting outlook.

On the occasion of the 20 years of the Biomedicine convention, an international conference was held on 24-25 October 2017 in Strasbourg, under the auspices of the Czech Chairmanship of the Committee of Ministers. The conference aimed at analysing the relevance of the Convention in the light of the developments in the biomedical field and the perspectives with a view to define the elements of a “strategic action plan” for the work of the Council of Europe’s (CoE) Committee on Bioethics (DH-BIO) for the 2018-2019 biennium. During these two days, delegates heard presentations from a number of high-level profile speakers. During the first day of the conference, there were keynote speeches on the history and principles that informed the development of this important Convention. The Convention was open for signature on 1997 and was the first international legally binding instrument on the protection of human rights in the biomedical field.

Dr Quintana and Prof Honnefelder, both members of the drafting committee of the Convention, referred to the challenges the committee faced when writing it. In particular, for finding substantial agreement in many sensitive and uncertain topics, and explained the Convention was thus conceived as a “framework instrument”, with broad, general principles, which could be developed in the years to come by additional protocols.

The main topics addressed during the conference included: (1) autonomy, consent and privacy with particular attention to the challenges raised by the evolution of practices for children rights and older people; (2) equity of access to health care; and (3) new scientific and technological developments (i.e. genetics and genomics, new scientific and technological developments, brain technologies, information technologies and big data).

Other relevant presentations included the outcomes of the high level seminar on “International case-law in bioethics: insight and foresight” hold on 5 December 2016, and the findings of two recent studies about children’s rights carried out in Sweden and the Netherlands (“The rights of Children in biomedicine: challenges posed by scientific advances and uncertainties” Uppsala University and "From law to practice: towards a roadmap to strengthen children's rights in the era of biomedicine" Leiden University). Another highlight of the event was the signing ceremony of the Additional Protocol to the Convention on Human Rights and Biomedicine concerning genetic testing for health purposes by the Czech Republic.

The main general conclusions of the conference were around the need for recognising the pluralism of narratives and values on biomedicine; finding ways to integrate political, expert and public opinions into a mature deliberation which should be as inclusive as possible; and guaranteeing access to the benefits of science and technology to all, whilst, at the same time, protecting human rights and dignity.

The main discussions on the specific topic of older people revolved around decision making and legal capacity which should be understood as time and task specific; the need for revisiting informed consent forms in biomedical research to ensure these forms are suited to the needs of older people; finding ways of maximising the participation of older people in research and breaking down barriers to digital inclusion of older people. Ana Diaz, AE Project Officer, attended the conference.

MEMBERS’ NEWS

13-14 September: The Czech Alzheimer’s Society organises the annual “Prague Days of Gerontology” conference

In September, the annual ‘Prague Days of Gerontology’ conference organised by the Czech Alzheimer’s Society brought together multiple perspectives from researchers and professionals working across various sectors, from pharmacology to policy.

Professor Bob Woods opened the conference with a lecture presenting results from a recent European survey on the experiences of informal caregivers of people with dementia. The findings were particularly poignant for the audience as the Czech Republic was one of the five countries who had participated in the survey, and participants were able to gain a greater insight into the experiences of Czech caregivers.

Professor Iva Holmerová, Chairperson of Alzheimer Europe and the Czech Society of Gerontology and Geriatrics, also delivered a presentation on the work of the largely unknown Czech physician Oskar Fischer, who in 1907, published a ground-breaking article describing the changes in the brain of 16 patients with dementia.

Participants were able to learn more about the role of the pharmacist in the care of people with dementia, as well as hear from Petr Veleta on how dance can improve the quality of life for those with dementia. Various care providers discussed current practice in the field, and an update from the policy sector provided the audience with a perspective on the future priorities for dementia care. Furthermore, on the second day of the conference, three interactive workshops focusing on memory testing, Namaste Care and the experiences of family caregivers were offered to attendees.

21 September: Alzheimer’s Society’s Memory Walk on track to raise £9m

Memory Walk is Alzheimer’s Society’s largest fundraising event – a series of sponsored walks taking place in the autumn across England, Wales & Northern Ireland. Families and friends are encouraged to come together, and unite against dementia to raise funds. At each event there are two walk lengths to choose from - a shorter accessible route around 2km, and a longer, more challenging walk up to 10km. Memory Walk supports some of Alzheimer’s Society’s vital work, including essential research and life-changing local services for thousands of families affected by dementia.

In the last 5 years, the events have gone from strength to strength. This year, Memory Walk was held in 34 locations, bringing together 110,000 people - 100,000 more people than in 2012. Memory Walk is on track to raise £9 million by the end of the financial year, and this year the event entered the top 5 of the UK’s largest mass participation events. The walks are supported by over 2,500 essential volunteers, who selflessly give up their time to welcome, cheer and thank the walkers for taking part, as well as supporting the event team in running each Memory Walk.

The unique thing about Memory Walk is the emotional yet uplifting atmosphere generated by the walkers. Each walker wears a ‘walking for’ label on their t-shirt to tell their fellow participants why they are taking part, and has the opportunity to hang a personal tag on the memory tree in memory of a loved one. With thousands of people attending each event, seeing the crowds gather and take steps together to raise vital funds makes for a very special day.

With 2018 events already open for registration, and more exciting developments to come, Memory Walk looks to continue to grow over the coming years. To find out more, visit www.memorywalk.org.uk.

21 September: Alzheimer Association Cyprus holds yoga session to mark World Alzheimer’s month

The branch of the Cyprus Alzheimer Association in the eastern end of the island marked September with two free events.

On the 21 September, patients, friends and supporters were invited to an evening at the Alzheimer’s local support centre. The title of the event was to learn how to relax along with breathing techniques. Maggie Ridge a local yoga teacher who holds the British Wheel of Yoga Teaching Diploma and has been teaching for about 16 years kindly hosted the evening.

The centre was full and everyone that came felt that the talk was very helpful, especially for those who were carers.

The second event on 29 and 30 September was held at Lidl Supermarket where the Cyprus Alzheimer Association distributed leaflets in Greek and English and gave advice to anyone that asked for help. Monika Hannoun, the association’s nurse, checked blood pressure and supporting members of the voluntary committee came for two hours at each session throughout the two days.

The general public were very interested in the activities of the Association who received many kind words thanking them for the help they give.
29 September: The Alzheimer Society of Finland celebrates volunteers

In 2016 The Alzheimer Society of Finland organized its first national celebration for organization’s volunteers. For the second time the celebration was held in September 2017 as part of the Memory Week activities and it rounded up nearly a hundred volunteers from all over Finland. During the event participants got to enjoy dance performances, stand-up comedy and presentations about volunteering. The Alzheimer Society of Finland also rewarded two distinguished memory associations’ volunteers with society’s badges of merit. The aim of the national celebration is to gather together and draw attention to the vital work that’s being done by the volunteers. In Finland the local memory associations coordinate volunteer work and offer plenty of opportunities to participate. Volunteers can for example become “Memory friends” for persons with memory disease, lead peer groups, help to organize events or host memory cafes.

29 September: The Panhellenic Association of Alzheimer’s Disease and Related Disorders reports on its World Alzheimer’s Day activities

In order to celebrate the World Alzheimer’s Day 2017, the Alzheimer’s Associations, members of the Panhellenic Association of Alzheimer’s Disease and Related Disorders, organised various events in Greece. These events were opened to the public and free of charge.

- The 6th Educational Seminar of Health Professionals, Outpatients and Professional Carers of People with Dementia took place on 16 and 17 September 2017 at the Chamber of Commerce and Industry of Heraklion Crete by the Alzheimer’s Disease and related disorders Heraklion Prefecture “ALLILENGII” (SOLIDARITY).
- Informative speech and memory tests were given by personnel of “Karelleio Alzheimer’s Institution, NGO Apostoli of the Holy Archdiocese of Athens”, in Argostoli, Kefalonia.
- On 20 September, people of all ages ran in the “Run For Memory-Walk For Memory” at the Old Venetian Harbour of Chania, Crete, to raise awareness of the disease.
- On 24 September, the Athens Alzheimer Association celebrated its’ 15-year anniversary with a whole day event hosted at Stavros Niarchos Foundation Cultural Center. More than 4000 people attended the event and participated in memory games. They also shared one of their memories at the Memory Wall and visited the art exhibition «forget me not». In addition, 250 people underwent memory testing and 450 dementia caregivers met dementia experts. The main celebration took place in the afternoon and more than 1000 people attended Dr. Paraskevi Sakka’s speech about Athens Alzheimer Association milestones during the last 15 years, followed by speeches about prevention, diagnosis and treatment of dementia and the role that new technologies have in dementia.
- On 17 September, the Thessaloniki Alzheimer Hellas operated an all-day information stand where specialized personnel of the association gave reliable information to our fellow citizens about the disease. On 21 September, the Alzheimer Hellas theater team performed the play of a famous theater writer at the Royal Theater of Thessaloniki. The event was attended by 500 people who were delighted with the play performance and also had the chance to hear our associations’ choir perform! On that day a song created for people with dementia and their caregivers was also performed for the first time! On 30 September in a Shopping Center, children participated in an all-day event called “My Grandparents and me”. They expressed their feelings and thoughts about the Disease through experiential techniques and expressive means (i.e. painting, collage, and memory games). All our activities reached our aim to raise awareness and reduce social stigma!
- On 29 September, the Messinian Association for Alzheimer disease, “MESENA”, organized an informative day on Alzheimer disease for people of all ages. More than 600 people attended the event where screening of videos and discussion with teenagers, mini-mental tests to aged people, advices to caregivers and lectures were given by medical doctors Dr. Tsolaki and Dr. Sakka.

30 September: Association Luxembourg Alzheimer reports on its recent activities

September has been a busy month for the Association Luxembourg Alzheimer (ALA), with a number of meetings and events taking place on the occasion of World Alzheimer’s Month.

On 21 September, the “Beim Goldknapp” nursing home/day care centre hosted its 10th birthday party in Erpeldange-sur-Sûre (Luxembourg). Guests were Lydie Mutsch, Minister of Health, Romain Schneider, Minister of Social Security and Corinne Cahen, Minister of Family. All staff, residents and their families attended the event to celebrate the 10th anniversary of the
nursing home and day care centre “Beim Goldknapp”. After some speeches, everyone gathered around a birthday cake. On 22 September, the nursing home and day care centre “Beim Goldknapp” organised an open day. Visitors were able to take a look behind the scenes of the center that offers an infrastructure and concepts of care adapted specifically to the people with dementia. Several topics were presented including aromatherapy, biographical work, art studio, use of service dogs and also the different living units.

On 23 September, the Luxembourg’s annual Memory Walk took place, starting from the Place Clairefontaine in Luxembourg City. It was the 16th time that ALA organised the event to mark World Alzheimer’s Day. The principal aim of the Memory Walk is to raise awareness among the general public concerning Alzheimer’s dementia and to show solidarity with people living with dementia, their families and caregivers. ALA also used the event as an opportunity to propose various stands and animations.

This year, ALA celebrates its 30th birthday. To mark this momentous year, the association released a calendar to raise awareness of the disease among the general public. The calendar was presented to the general public on 23 September during the Memory Walk. It illustrates the life in our centers (e.g. everyday situations as well as wonderful moments with our residents and customers).

4 October: Global Dementia Friends Network Meet in Berlin

This year’s Alzheimer Europe Conference in Berlin offered an ideal opportunity to meet with colleagues from around Europe involved in the Global Dementia Friends movement. Alzheimer’s Society UK were joined by colleagues from Austria, Denmark, Germany, Finland, Ireland, Israel, Italy, Malta, the Netherlands and Portugal on Wednesday 4 October for a session packed full of updates, success stories and mutual learning.

Twenty seven countries around the world are now developing and delivering their own Dementia Friends programmes, working to change the way the world thinks, acts and talks about dementia. The Global Dementia Friends network is a platform through which countries can share best practice and learn from one another, together ensuring that we are creating the greatest impact for people living with dementia globally.

In the session, Denmark, Germany, the Netherlands and the UK all provided country-specific updates on recent progress and achievements of their programmes. The remainder of the session focused on corporate engagement; the benefits to organisations of becoming dementia-friendly and how Dementia Friends provides a good introduction to this. We heard from members who have successfully engaged with pharmacies, supermarkets and transport companies and discussed the wider opportunities that partnerships of this kind present. The UK shared its experience of developing tools to engage with organisations and explored ways in which other countries could adapt these processes to better suit their own contexts.

If you are interested in learning more or would like to join the Global Dementia Friends movement then please contact us on dfinternational@alzheimers.org.uk.

17 October: Alzheimer Switzerland moves to Bern

The national office of Alzheimer Switzerland has moved to Bern, the capital of Switzerland.

The new address and contact details are:

Gurtengasse 3
3011 Bern
Switzerland
Telephone: +41-58 058 80 00

20-21 October: Spominčica organises the 9th Alzheimer Slovenia Conference

From 20 to 21 October, Spominčica - Alzheimer Slovenia organised an international dementia conference entitled “ASK 2017 - For dementia friendly society”. The conference celebrated the 20th anniversary of Spominčica, established in 1997 by Dr. Aleš Kogoj, a well known Slovenian psychiatrist. There were more than 300 registered participants who were extremely satisfied by the event. Delegates from the field of dementia from Slovenia and abroad presented their recent findings, novelty treatments and therapies. Lectures were held by Helga Rohra, a member of The European Working Group of People with Dementia, Annette Dumas, Dr. Ezio Giacobini, Dr. Nori Graham, Dr. Bengt Winblad and many other renowned professionals. Moreover, people with dementia from Slovenia presented their personal experiences with the disease. The event was very well covered by the media.

30 October: The Alzheimer Society of Finland organises seminars in the Finnish Parliament

The Alzheimer Society of Finland has organised three seminars this year with the Parliamentary Memory Club in the Finnish Parliament. The association was extremely
The association discussed about the role of nutrition among community-dwelling individuals with Alzheimer’s disease and their spouses, how to maintain their functional ability and memory disorders and dementia.

The Harvard Aging Brain study undergone positron emission tomography (PET) imaging to measure Tau and Aβ levels in two brain regions of interest: the entorhinal cortex and the inferior temporal cortex. Researchers showed that SCD was associated with tauopathy and Aβ burden only in the entorhinal cortical region. In addition, they found that the association between SCD and entorhinal cortical tauopathy was much stronger than the association between Aβ and SCD.

4 October: Acadia Pharmaceuticals starts a phase III trial for Dementia-Related Psychosis

On 4 October, the company Acadia Pharmaceuticals, which develops innovative therapies in the nervous system area, announced the launch of a Phase III trial of pimavanserin in Dementia-Related Psychosis. This study, called Harmony, is investigating pimavanserin, which is the only drug approved for the treatment of hallucinations and delusions associated with Parkinson’s disease psychosis.

The purpose of this trial is to evaluate the efficacy and safety of pimavanserin for the treatment of hallucinations and delusions associated with dementia-related psychosis including psychosis in people with Alzheimer’s disease, dementia with Lewy Bodies, Parkinson’s disease dementia, vascular dementia and frontotemporal dementia. Approximately 360 participants will be assigned to receive pimavanserin (34 mg) or placebo once daily. The company did not mentioned where the trial will be conducted.

https://jamanetwork.com/journals/jamaneurology/article-abstract/2656323

4 October: Study reveals that hypertension in mid-adulthood is a risk factor for dementia only for women

In a study published on 4 October in the journal Neurology, US researchers from Kaiser Permanente in California, revealed that women who developed high blood pressure in their 40s did have an increased risk of dementia.

Hypertension is a known risk factor of dementia in late middle age, usually the 50s. In the published study, scientists analysed the effects of gender in the link between blood pressure and dementia risk in early adulthood (average age 32.7) and mid-adulthood (average age 44.3).

The study involved 5646 participants of the Kaiser Permanente Northern California health care system, who had clinical examinations when they were in their 30s and then again in their 40s.

532 participants (298 women and 234 men) were diagnosed with dementia. Scientists found that participants with high blood pressure in their 30s did not appear to have any increased risk of dementia. Although, they reported that high blood pressure in men in their 40s didn’t appear to increase...
their risk of developing dementia, women who developed high blood pressure in their 40s had a 73 percent higher risk of developing dementia in later years.

http://www.neurology.org/content/early/2017/10/04/WNL.0000000000004602

4 October: Three scientists earn the Nobel Chemistry Prize for developing cryo-electron microscopy

On 4 October, the Swiss Jacques Dubochet, the German-born US citizen Joachim Frank and the Scottish-born Richard Henderson awarded the prestigious Nobel Chemistry prize for developing cryo-electron microscopy. This process, using electron beams, allows researchers to better understand viruses and study the 3D structures of proteins in living organisms. The structure of cells in their natural form, without the use of dyes, can now be examined at very low temperatures. This method has been used to study the Zika virus as well as the structure of the amyloid and tau fibrils, two proteins implicated in Alzheimer’s disease.


9 October: Researchers suggest a link between LSD1 gene and brain changes seen in AD and FTD

In a study published in the journal Nature Communications on 9 October, US researchers from the Emory University School of Medicine, Atlanta, found that a gene called Lysine specific histone demethylase (LSD1) is linked to Alzheimer’s disease (AD) and frontotemporal dementia (FTD). In the published study, researchers generated a mouse model lacking the LSD1 gene. These mouse models had lost neuronal cells in specific regions of the brain. The brain function was impaired with paralysis as well as learning and memory defects. In addition, scientists described changes in gene expression similar to those seen in people with AD and FTD. They continued by examining brain tissue samples of people with AD and FTD and found that the LSD1 gene was accumulated in tau tangles, one of the biological hallmarks of both diseases.

http://www.nature.com/articles/s41467-017-00922-9

9 October: Study suggests that delayed word processing could predict MCI conversion to AD

In a study published in the journal Neuroimage Clinical on 9 October, researchers from the University of Birmingham in the United Kingdom found that delayed word processing in people with mild cognitive impairment (MCI) could be an indicator of their risk of developing Alzheimer’s disease (AD). Scientists used an electroencephalogram, a test detecting electrical activity in the brain, to study the brain activity of 25 participants including healthy people, people with MCI and people with MCI who had developed AD within three years of diagnosis of MCI. They discovered anomalies in the brain activity during language processing in the group of MCI participants who would go on to convert to AD compared to healthy controls and MCI participants who did not convert to AD.


10 October: Menopause may increase the risk for AD

US researchers from Weill Cornell Medical College, New York, reported that menopause causes metabolic changes in the brain that may increase the risk of developing Alzheimer’s disease (AD). The study published on 10 October in the journal Plos One analysed 43 female participants of age 40-60 years, who were cognitively healthy. The consumption of glucose, the main brain energy source, was evaluated using positron emission tomography imaging. Findings showed that women who had undergone menopause or were in the process of menopause had lower levels of glucose compared to pre-menopausal women in the same brain regions as clinical AD patients.

http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0185926

13 October: Ionis Pharmaceuticals launches Phase 1/2 trial of IONIS-MAPT Rx in people with mild AD

On 13 October, Ionis Pharmaceuticals, a pharmaceutical company developing antisense drugs for the treatment of severe and rare diseases, announced the start of a Phase 1/2 clinical trial investigating IONIS-MAPT Rx for Alzheimer’s disease (AD). IONIS-MAPT Rx is a drug aiming to reduce the production of tau protein in the brain, one of the hallmarks of AD. The Phase 1/2 study is a three-month randomized and placebo-controlled evaluating the safety and activity of IONIS-MAPT Rx in 44 participants with mild AD.

13 October: New mechanism suggests a link between RBFOX proteins and AD

On 13 October, a study published in the journal Nature Communications described how RBFOX proteins contribute to the loss of synaptic transmission, which is the process of communication between nerve cells, in Alzheimer’s disease (AD).

Scientists from McGill University, Montreal, Canada, analysed the stability profiles of RNA molecules and found that specific RNAs were significantly reduced in the brain of individuals with AD than in healthy brains. They showed that the synaptic transmission was the main pathway affected in AD and that RBFOX proteins encoding synaptic transmission proteins were destabilized in the brain of people with AD.

http://www.nature.com/articles/s41467-017-00867-z

17 October: M3 Biotechnology initiates Phase 1 trial of NDX-1017 for AD

On 17 October, M3 Biotechnology, an innovative therapeutics company with a novel platform of disease-modifying regenerative therapies particularly relevant to neurodegenerative diseases, announced the launch of a regenerative therapy for Alzheimer’s disease (AD). The Phase 1 trial is testing NDX-1017, a drug expected to slow or stop the disease progression and restoring lost connections in the brain. The Phase 1 study is a randomized, placebo-controlled and double-blinded trial evaluating the safety and tolerability of NDX-1017. It aims also to establish the optimal dosing range of NDX-1017 in both healthy adults and participants with mild Alzheimer's disease.

http://m3bio.com/m3-biotechnology-launches-clinical-trials-for-alzheimers-disease-drug-focused-on-restoring-lost-connections-in-the-brain/

24 October: Research suggests that oral anticoagulation drugs could protect against dementia

On 24 October, Leif Friberg and Mårten Rosenqvist from the Karolinska Institute in Stockholm (Sweden) published an article in the European Heart Journal suggesting that oral anticoagulation in people with atrial fibrillation (AF) is associated with reduced risk for dementia.

The authors analysed data from Swedish health registries and included 444106 participants with AF between 2006 and 2014. During the period, 26210 of them were diagnosed with dementia. They found that people taking oral anticoagulation for AF had a 29% lower risk to develop dementia compared to those who had not received the drugs. They also reported that people with AF who continued to take oral anticoagulation over a period of time had 48% lower risk of dementia.


DEMENTIA IN SOCIETY

8 October: “Panorama - Living with Dementia: Chris’s Story”, nominated for BAFTA

The BBC documentary, which aired on 2 June 2107, was nominated for a BAFTA (British Academy of Film and Television Arts) award. It follows former businessman Chris Roberts, a fifty-five-year-old from Rhuddlan, Denbighshire, North Wales and his wife Jayne and daughter Kate during an 18 month period.

The Roberts family recorded itself using video diaries and CCTV, to show how it has come to terms with Mr Roberts’ Alzheimer’s diagnosis. Mr Roberts, who has been living with dementia for five years, since the age of 50, chronicles his changing life, from choosing his own care home to writing a living will.

Although the programme did not win the BAFTA award, it is a key documentary raising awareness of dementia and dispelling the stigma surrounding the disease.

LIVING WITH DEMENTIA

Petri Lampinen, member of the EWGPWD, writes about rehabilitation and dementia in Finland

My name is Petri and I was diagnosed with Frontotemporal Dementia (FTD) in 2015. This is a rare disorder - there are less than a thousand of us in Finland. Last year, I went to the rehabilitation programme for people with disabilities organised by Kela (Finnish Social Insurance Institution). It wasn’t easy to get in. First, the information that I received was not correct, as I was told people with dementia could not access this type of service and I could only benefit from adaptation training. I couldn’t believe this, so I decided to contact the Kela’s office myself. As it turned out, dementia is a valid cause to access rehabilitation services although I had been told otherwise in the hospital. All I needed was a rehabilitation plan from my own doctor and then I could apply for it. I’m lucky to have a nice doctor who does things properly. He did the necessary paperwork. However, without my own initiative I couldn’t have participated in the rehabilitation and once again, it was clear that nobody comes and just offers you services like this. Finding everything out by myself was stressful, but on the other hand, it was good for my brain. I try to fix things myself as long as it’s still possible so that my wife can take care of other matters.

I went to the rehabilitation open minded and got more than I expected. This year, many things have changed for the better. We focused on my ability to function and on developing helpful devices and strategies. I came up with an idea of checking lists and notes on a white board. In physiotherapy, I learnt how to play badminton and table tennis and got hooked. Last summer, I bought a ping pong table and played ping pong all summer. In the autumn, I booked a term in a sports hall of the City of Hämeenlinna and played badminton over the winter. Through playing, I keep up my movement/mobility skills and it has become a great activity for the whole family. I feel like I have a life now and I’m happy to share my ideas and thoughts with others!

Idalina, member of the EWGPWD, describes her activities in Portugal and Spain

My daughter, Nelida, and I have been very busy and have been travelling a lot lately. My daughter has a flexible job, I am so grateful that she accompanies and supports me in all these activities and travelling. My involvement would not be possible without her. This month we participated in a “memory tour” in Lisbon, a conference on active ageing in Funchal and the World Alzheimer’s Summit at the Champalimaud Foundation. On World Alzheimer’s Day (21 September), we had the privilege to visit the first day care centre for people with dementia in Portugal. The President of the Republic of Portugal attended this event and spoke about dementia, which was very important. At the end of the day, there was a concert in solidarity of people with dementia, and we spoke in front of a full audience who joined the 14 singers for such a noble cause. Then during the last week of September, I was invited, as member of the EWGPWD, to attend a meeting of the INDUCT project in Salamanca, Spain. INDUCT stands for Interdisciplinary Network for Dementia Using Current Technology and brings together researchers from several European countries. Members of the EWGPWD are supporting 15 PhD students who are part of this project. Our experience, perspectives and above all our curiosity about what is currently being done in the field of research is a bonus. We were delighted with the professionalism, the will to win and above all with the precious information that we were given. The institution that hosted the INDUCT meeting in Salamanca was called CREA which stands for State Reference Centre for People with Alzheimer’s and other dementias. It was a huge surprise to find a centre specialised in dementia so close to Portugal. We had the opportunity to visit the centre and to hear more about the work they do. In the centre, there are highly specialised rooms for sessions for Snoezelen (sensory rooms), music therapy, dance, art therapy and therapy with dogs. They also have an exercise room and a swimming pool amongst other things, including the famous “PARO”, a robotic seal that interacts in different ways with people with dementia. It was an unforgettable and greatly enriching experience for us. We are on the right track. It is possible to live with dementia!

Chris Roberts, Vice Chair of the EWGPWD, reports about the INDUCT summer school in Salamanca (25-29 September 2017)

INDUCT is a project facilitated by INTERDEM. Its aim is to develop a multi-disciplinary, educational research framework for Europe, which hopes to improve technology and care for people with dementia, something I’m personally very interested in, and to provide evidence which will show how technology will improve the lives of people affected by dementia. We, three members of the European Working Group for People with Dementia (EWGPWD) and supporters, got together in Salamanca, Spain, to present updates on the research progress of the 15 Early Stage Researchers (ESRs) and to exchange knowledge and skills including our own knowledge as experts by experience in our dementia. During
lectures, workshops and interactive group meetings, various topics concerning current technology for people affected by dementia were discussed.

The topics ranged from recruitment to research to publishing tips to patenting. The involvement of us members of the EWGPWD after listening to the conversations and feedback was a real asset to the Summer School, all the ESRs were greatly inspired by our input and by our supporters’ knowledge. All said it was an invaluable source of first-hand information and experience which helps bring their textual knowledge to a practical level of understanding, proving yet again the value of collaboration and involvement of experts by experience in all things usually done “for us” instead of “with us”. It was invaluable for us too. We learn so much which helps us to live better lives and was an excellent experience finding out about all the work and research being conducted on our behalf which is so appreciated. Being involved also allows our needs and wants to be heard now, and what we may want or need in the future when we might not be listened to in the same way as now.

Research work and collaboration like this gives us hope where before there might have been little or none. People living with, and affected by, dementia become experts by experience in their own right. They bring their own unique contribution which can only add to the expert knowledge of all. It is refreshing to see that INDUCT, with the help and assistance of Alzheimer Europe and INTERDEM, has acknowledged this, and fully involves people living with, and affected by, dementia. Thank you INDUCT and especially the ESRs and facilitators that made this event happen. Myself (Chris Roberts, Vice Chair), Idalina Aguiar and Nina Balackova, with our supporters, Jayne Goodrick, Nelida Aguiar and Iva Coelho, attended the event.

NEW PUBLICATIONS & RESOURCES

2 October: World Health Organization (WHO) launches new publication: Civil Society and Health

WHO have launched a new publication looking at how governments can work better with civil society for health and health systems. This study is intended to outline some of the challenges and assist policy-makers in furthering their understanding of the part civil society organisations (CSOs) can play in tandem and alongside government.

It analyses existing evidence and draws on a set of seven thematic chapters and six mini case studies. They examine experiences from Austria, Bosnia-Herzegovina, Belgium, Cyprus, Finland, Germany, Malta, the Netherlands, Poland, the Russian Federation, Slovenia, Turkey and the European Union and make use of a single assessment framework to understand the diverse contexts in which CSOs operate.

This book is intended to guide policy-makers working with CSOs. The editors outline a practical framework for such collaboration which suggests identifying key CSOs in a given area; clarifying why there should be engagement with civil society; being realistic as to what CSOs can or will achieve; and an understanding of how CSOs can be helped to deliver.

The full publication can be downloaded here: http://www.euro.who.int/en/publications/abstracts/civil-society-and-health-contributions-and-potential-2017

9 October: EFPIA publishes a document to underline collaborative efforts between Patient Organisations and pharmaceutical industry

On 9 October, the European Federation Pharmaceutical Industry and Associations (EFPIA) issued a document entitled “Working together with patient groups” to provide guidance for collaboration between Patient Organisations and pharmaceutical industry to ensure that the patient voice is heard.

The document was developed by the EFPIA Patient Think Tank, a working group who provides a forum for an open exchange of ideas, information and perspectives between Patient Organisations and industry on topical issues impacting patients. Alzheimer Europe is a member of the EFPIA Think Tank and contributed to the document through the Think Tank meetings.

The full document can be read here: https://www.efpia.eu/media/288355/working-together-with-patient-groups-09102017.pdf
13 October: FGDP publishes a book on Dementia-Friendly Dentistry

The UK Faculty of General Dental Practice (FGDP) in conjunction with the Alzheimer’s Society, launched a book entitled “Dementia-Friendly Dentistry: Good Practice Guidelines” to offer guidance on how to care the people living with dementia. This document enables dental professionals to understand dementia and its implications for dental practice, and adapt their patient management and clinical decisions accordingly.

For more information or to download this book, visit: https://www.fgdp.org.uk/publication/dementia-friendly-dentistry

AE CALENDAR

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<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tr>
<td>1-4 November</td>
<td>Clinical Trials in Alzheimer’s Disease (CTAD) Conference (Boston, USA)</td>
<td>Jean</td>
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<tr>
<td>6 November</td>
<td>ISPOR 9th Patient Representatives Roundtable (Glasgow, Scotland)</td>
<td>Chris</td>
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<tr>
<td>7 November</td>
<td>Informal Carers Interest Group - ‘Looking back and looking ahead: celebrating its 10th anniversary’ (Brussels, Belgium)</td>
<td>Vanessa</td>
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<td>8 November</td>
<td>EPAD Meeting (Antwerp, Belgium)</td>
<td>Cindy</td>
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<tr>
<td>11-16 November</td>
<td>56th ICCA Congress, Prague, Czech Republic</td>
<td>Gwladys</td>
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<tr>
<td>16 November</td>
<td>Memory Conference (Helsinki, Finland)</td>
<td>Jean</td>
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<tr>
<td>20-21 November</td>
<td>Joint Action on Dementia WP4 meeting in (Paris, France)</td>
<td>Ana</td>
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<tr>
<td>21 November</td>
<td>Patients and Consumers training session of European Medicines Agency (London, United Kingdom)</td>
<td>Cindy</td>
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<tr>
<td>21 November</td>
<td>EPF Policy Advisory Group meeting (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>22 November</td>
<td>Patients and Consumers Working Party of European Medicines Agency (London, United Kingdom)</td>
<td>Jean</td>
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<tr>
<td>28 November</td>
<td>GSK Health Advisory Board (London, United Kingdom)</td>
<td>Jean</td>
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<td>28 November</td>
<td>ENNHRI Older Persons and Long-term Care Stakeholder Conference (Brussels, Belgium)</td>
<td>Vanessa</td>
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<tr>
<td>30 Nov-1 Dec</td>
<td>AETIONOMY meeting (Basel, Switzerland)</td>
<td>Jean and Dianne</td>
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CONFERENCES

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<tr>
<th>Date</th>
<th>Meeting</th>
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<tr>
<td>1-4 November</td>
<td>Clinical Trials in Alzheimer’s Disease (CTAD) Conference <a href="http://www.ctad-alzheimer.com/">https://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.alzi.or.id">www.alzi.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/6nWv1a">https://goo.gl/6nWv1a</a></td>
<td>Washington, DC, USA</td>
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<tr>
<td>1-3 March 2018</td>
<td>Nutrition and maintaining functions with aging (IANA 2018)</td>
<td>Miami, Florida, USA</td>
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<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>2-4 May 2018</td>
<td>24th Nordic Congress of Gerontology (24NKG), <a href="http://www.24nkg.no">www.24nkg.no</a></td>
<td>Oslo, Norway</td>
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<td>7-8 June 2018</td>
<td>HammondCare International Dementia Conference - Mission Impossible? Truth and Lies in the Age of Choice, <a href="http://www.dementiaconference.com">www.dementiaconference.com</a></td>
<td>Sydney, Australia</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:
Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org, www.alzheimer-europe.org

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28th Alzheimer Europe Conference
Making dementia a European priority
Barcelona, Spain
29–31 October 2018
www.alzheimer-europe.org/conferences #28AEC

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