Welcome

As this newsletter is going out, Alzheimer Europe is busy preparing our December meetings with a regular meeting of the AE Board, a lunch debate in the European Parliament, a meeting with our corporate sponsors and the third edition of our Alzheimer’s Association Academy. We will make sure to update you on those in our next newsletter.

November has been a busy month and important progress has been made in a number of EU projects which we are involved in. Our EPAD project reached two important milestones in November as it screened its 400th research participant and also extended its network to 10 trial delivery centres able to recruit research participants. I was happy to co-chair a meeting of the EPAD dissemination work package to discuss how we can support the outreach of the project even more effectively. In this newsletter, you can also find updates from our AMYPAD, EMIF, INDUCT, MOPEAD and ROADMAP projects.

On the research front, I was able to attend this year’s Clinical Trial’s in Alzheimer’s disease (CTAD) Conference in Boston and we have dedicated a section of this newsletter to the research news presented at the conference. Both Axovant and Merck presented disappointing phase III trial results of their verubecestat and intepirdine programmes, but it was encouraging to see that companies disclose these results more promptly and in a more transparent fashion way than in the past. Also, the field is able to learn from past mistakes and failures and a number of companies, including Amgen, Biogen, Novartis and Roche updated the participants about the progress or plans for phase III trials.

On the policy front, we heard that the Spanish Alzheimer’s Plan will be launched shortly, saw the official signature of the European Pillar of Social Rights in Gothenburg and learned that the European Medicines Agency will be relocated to Amsterdam. At a meeting with patients’ and consumers’ organisations, Guido Rasi, the Agency Director stressed that the agency will continue to prioritise patient safety. The future role of the United Kingdom within (or without) the European regulatory system for the approval and monitoring of medicines is however still uncertain.

As always, you will learn about some of the great initiatives and projects of our national members and I wanted to single out and welcome the creation of the Swiss Working Group of People with Dementia here. Great to see that our example of effectively involving people with dementia is being followed across Europe.

Finally, you will find out who won the best poster awards at our Annual Conference in Berlin.

Happy reading

Jean Georges
Executive Director
ALZHEIMER EUROPE

6 November: ISPOR meets with patient representatives to discuss patient involvement in health technology assessment

On 6 November, representatives from Patient organisations, Payers and Health Technology Assessors (HTAs), Researchers, Regulatory and Government agencies and from the pharmaceutical Industry from Europe and the USA met with ISPOR (International Society for Pharmacoeconomics and Outcomes Research) staff for the Ninth Patient Representatives Roundtable at the Scottish Event Campus in Glasgow (Scotland).

The event at which Alzheimer Europe was represented, took place during the ISPOR 20th Annual European Congress. Here, the representatives discussed the evolution of patient involvement in HTA as well as the strength and the benefit of real-world and patient-level data. The roundtable was chaired by Nadia Naaman (Senior Director, Scientific & Health Policy Initiatives). Discussions and updates entailed, ISPOR patient Initiatives, ISPOR collaboration with the European Patients’ Forum (EUPATI), as well as case study examples: The real-world impact and outcomes from the use of patient level data was also discussed.

10 November 2017: Alzheimer Europe Foundation announces winners of best posters at AE Conference in Berlin

Based on the votes of over 150 conference participants, the Alzheimer Europe Foundation was able to select the best posters presented during the Alzheimer Europe Conference in Berlin. On the first conference day, the winner was Siren Eriksen (Sweden): Living a meaningful life in relational changes: A systematic meta-synthesis of qualitative studies on persons with dementia followed by Wilhelmina Hoffmann (Sweden): My handbook – when I have received a dementia diagnosis. The winner on the second day was Andrea Fabbo (Italy): The Rosemary diary: a tool for daily life with Francesca Neviani (Italy): “Tea for two”: a psychosocial intervention for PwD and their caregivers as the runner up.

The Alzheimer Europe will award EUR 750 to each of the winners and EUR 250 to each of the runners up. Amongst the voting delegates, the Foundation also drew Isabelle Donnio (France) as the winner of a free registration for the Alzheimer Europe Conference in Barcelona.

11-15 November: Alzheimer Europe shares its conference experiences at 56th ICCA Congress

During the recent 56th ICCA Congress in Prague, Gwladys Guillory, the Conference and Events Coordinator of Alzheimer Europe, participated in a session on the GDS-Index (Global Destination Sustainability) and moderated a workshop on the social sustainability aspects and “Creating Accessible Destinations” using the Alzheimer Europe model. She presented the logistics of Alzheimer Europe when preparing for a conference in a new country, the collaborations needed to make the event accessible to all delegates and the importance of leaving a legacy after the event. The workshop was attended by convention bureaus, city officials, venue representatives and other association representatives.
19 October: First ROADMAP face to face Advisory Group meeting

On 18 October, Barcelona (Spain), WP6 – which focuses on regulatory and Health Technology Assessment (HTA) engagement – organised the first Regulatory, HTA, and payer Expert Advisory Group (EXAG) meeting for the ROADMAP project.

The aim of the EXAG meeting was for the project to present and discuss their results with the EXAG members. The meeting was chaired by WP6 leads, Robin Thompson as well as Jacoline Bouvy and mainly focused on discussions on ongoing work on the development of a model that illustrates how people move through all the stages of Alzheimer’s disease / dementia, from very early (to before the start of any symptoms) to the later stages of the disease. WP5 (Health Economics) discussed questions regarding their economic model with the panel, such as economic, legal and ethical aspects of including (formal and informal) caregiver time in the model. ROADMAP was very pleased about the attendance and contribution of Alzheimer Europe’s European Working Group of People With Dementia (EWGPWD) Chair Helen Rocheford-Brennan and her supporter Carmel Geoghegan during the meeting. The very open and lively discussion was inspiring for both WP5 and EXAG members as well as the other ROADMAP attendees.

For more information on the EXAG, check out: advisory group on the ROADMAP website.

19 October: Several Innovative Medicines Initiative (IMI) projects join forces during cross-Disease Modelling Workshop in Edinburgh

On 16-18 October, the European Prevention of Alzheimer’s dementia (EPAD) project organised its first IMI-AD Platform Disease Modelling Workshop in Edinburgh, UK. The aim of the meeting was to bring together the modelling community within IMI funded projects to facilitate and encourage interactions between the overlapping communities.

On the first day, the chair of the workshop Graciela Muniz-Terrera (University of Edinburgh) welcomed the attendees. The event gathered 20 participants from several IMI projects (AMYPAD, EPAD, ROADMAP and AETIONOMY). The workshop consisted of three sessions divided by area: clinical perspective, drug discovery and systems/molecular biology.

The workshop gave the opportunity to the majority of the attendees to present their research topics throughout the three sessions. Attendees working on the different knowledge areas briefly introduced their models and the challenges they encounter when working on them, which inspired discussions amongst methodologists who had used different quantitative approaches in the area. One of the most discussed and challenging topic was data storage, data access and data sharing.

The last day concluded the workshop with a wrap up and definition of plans for the future, among which it is worth mentioning the creation of a cross-IMI Alzheimer’s Disease modelling working group with the aim of creating synergies between this group of experts and their IMI-founded projects.

6 November: MOPEAD communication team publishes infographic on value of early diagnosis

On 6 November, the communication team of the MOPEAD project released an infographic on the value of early diagnosis.

The infographic is designed to support the understanding of the need for such approaches, emphasises benefits of a timely diagnosis for patients and families as well as healthcare providers and advantages on a societal level.

You can find the infographic here:
https://docs.wixstatic.com/ugd/e8882a_4613cabaf4f4486faacdf78f6a35a8ad0.pdf

9 November: European Medical Information Framework (EMIF) launches two new videos providing an overview of a service approach

On 9 November, the European Medical Information Framework (EMIF) launched two new videos on their website http://www.emif.eu/.

The mission of the EMIF project is to improve identification, access and assessment as well as re-use of health data within the European Union.
The Alzheimer’s disease topic, known as EMIF-AD, aims to discover and validate biomarkers of AD onset in the preclinical and prodromal phases and also during disease progression. This will help to identify high-risk individuals and will facilitate drug development and clinical trial design.

The videos provide an overview of a service approach from the Innovative Medicines Initiative (IMI) project with Electronic Health Record (EHR)-derived, population data as well as cohort-derived data. Alzheimer Europe is a partner in the work packages “Sustainability and Outreach” and “Programme Management and Dissemination”.

15 November: BD4BO meets with sister projects ROADMAP, HARMONY and BigData@Heart to discuss communications and outreach activities in London

On 15 November, the Innovative Medicines Initiative (IMI) projects; ROADMAP (focussing on Alzheimer’s disease – AD), Harmony (Hematology) and BigData@Heart (Cardiovascular) met with BD4BO (Big Data for Better Outcomes) in London (UK) to discuss collaborative communication and outreach activities. BD4BO is an umbrella programme aiming to improve health outcomes and healthcare systems in Europe by maximising the potential of Big Data.

The meeting, chaired by Shahid Hanif (Association of the British Pharmaceutical Industry - ABPI), aimed to provide a platform for the projects to update one another on recent and future activities. Further, it enabled discussions on synergistic efforts to engage with common stakeholders.

The representatives for communication activities also discussed the recently launched website, social media plans, best practice of webinars and a potential video amongst others. If you are interested in finding out more about the project(s), visit: www.bd4bo.eu.

16 November: INDUCT consults with people living with dementia in UK

On 30 October (Cumbria, UK), the Interdisciplinary Network for Dementia Using Current Technology (INDUCT) project consulted on their research with the Cumbria Alzheimer’s Society Service User Review Panel (SURP).

Cumbria is a rural part of the Northwest UK with pockets of high deprivation and is characterised by an ageing population. For the people living there, travel times are long with little public transport, and the sparse population as well as geographical terrain present challenges to accessing services.

This is important to consider in developing sustainable opportunities for people to participate in activities. Connecting with existing local groups and networks to add value and offer complementary opportunities for research consultation has been vital.

Kizzy Pyne is the dementia support worker for the Alzheimer’s Society in West Cumbria and the catalyst for the newly formed SURP. Kizzy said:

“This sounded like a genuine opportunity for the group to put forward their views with no hidden motives. This is a new group and it’s essential that we get we start out as we mean to go on and make sure that the time people spend discussing topics leads to real action and change. Perhaps we will build more connections with people who share that focus.”

Sarah Wallcook (Karolinska Institute) met this fledgling group, together with Kizzy and volunteer, Julie Barncroft at their second meeting. “Hearing the SURP members’ insights and perspectives on the agenda items was compelling. I am pleased to have this connection with the group and I look forward to discussing new and important ideas about why the research matters to their communities. If we collaborate on those ideas, we can make more impact with the study.”

20 November: Members of the EPAD communication team meet to update the project’s communication strategy

On 20 November, members of the EPAD WP6 communication team held a one-day meeting in Amsterdam to update the communication plan for the final two years of the project. The team discussed the updated communication strategy, focus plan and activities for 2018-2019. The participants started to review the communication activities undertaken from 2015-2017. The team also took this opportunity to analyse the project through a SWOT analysis evaluating its strengths, weaknesses, opportunities and threats. Then, the participants discussed external communication goals and expectations. Alzheimer Europe Executive Director Jean Georges and Project Officer Cindy Birck attended the meeting.
23 November: EPAD project opens six new study sites

The European Prevention of Alzheimer’s Dementia Consortium (EPAD) is recruiting research participants at six new sites, bringing the total to ten centres in six European countries.

People in France, the Netherlands, Spain, Sweden, Switzerland and UK can now take part in the study, which aims to develop tests to identify early signs of Alzheimer’s disease that may indicate when a person is at risk of dementia before symptoms appear.

Researchers are developing a Europe-wide cohort of study participants, drawing on information from existing cohort studies, patient registers and other European studies that have identified potential participants.

The Europe-wide study aims to recruit thousands of people, of which many may be selected to participate in trials to test new treatments for the prevention of Alzheimer’s dementia. Volunteers will provide samples for genetic analysis and will undergo tests to assess their thinking skills. Detailed images of their brains will be captured using magnetic resonance imaging.

The EPAD Longitudinal Cohort Study began recruitment in May 2016, with the first centre opening in Edinburgh (UK). Three sites opened later in 2016 in Amsterdam (Netherlands), Barcelona (Spain) and Toulouse (France).

An additional six centres are now recruiting volunteers in Geneva (Switzerland), Lille (France), Montpellier (France), Nantes (France), San Sebastian (Spain) and Stockholm (Sweden).

Its ultimate goal is to develop new medicines and interventions that prevent or delay the onset of Alzheimer’s dementia.

For more information on the EPAD initiative and to keep up to date with its progress, follow @IMI_EPAD on Twitter and visit: http://ep-ad.org/

27 November: AMYPAD reports its project progress

On 27 November, the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project released its third external newsletter and reported what has been achieved during the first year of the project as well as its excitement for the next year.

In this first year, WP1 (Overall project governance and management) has been very active in setting up the structure in which AMYPAD can thrive. As a result, all WPs now have regular meetings to discuss their activities, and the first General Assembly of AMYPAD was a great success. In addition, WP1 has been vital in the development and submission of a number of project deliverables, as well as the management of the legal and financial aspects of setting up this large Consortium.

One of the big challenges of AMYPAD is linked to its size – setting up a project aiming to perform 6000 PET scans is no easy task. This year, WP2 (Tracer delivery, PET scanning and image analysis) has mapped out the optimal logistics of radiotracer supply to each centre so that resources can be used efficiently. It has also developed the imaging protocols that will provide high quality images and allow for the desired participant throughput. After a year of hard work, WP2 is currently busy with certifying all scanning sites, so that the group is ready to start including once our clinical studies receive green lights from the ethical committees.

The first of the clinical studies in line for patient recruitment is the Diagnostic and Patient Management Study (WP3). This European study on the clinical utility of PET has been very challenging due to the diversity within its participating centers. It was important that the study design would be fully integrated into the daily clinical routine of each center, and this challenge translated into a year of various meetings and scientific discussion for the team. It has also been very rewarding, since the end result was a study protocol that will address several key aspects of the utilization of PET in clinical routine, while capturing the important differences across European healthcare systems. As the challenging year comes to an end, the WP3 team waits anxiously for the good news from the Geneva ethical committee – the green light all hope for so that the scanning can start.

In parallel, WP4 (Risk stratification: natural history and enrichment strategies) has had a difficult task at hand. The Prognostic and Natural History Study is not only a large scale PET study, but it also has the additional challenge of being integrated into the EPAD Longitudinal Cohort Study (LCS). As a consequence, the past year for WP4 was filled with important meetings that aimed at ensuring the smooth integration of both studies and the delivery of scientific output that will help close the current knowledge gap in the natural history of Alzheimer’s disease. During this year, WP4 has successfully developed its study protocol and its operational structure, bringing AMYPAD closer to actively bring amyloid PET to the EPAD LCS.

While both WP3 and WP4 have been working intensively in setting up their respective studies, the team behind WP5 (Monitoring treatment: quantifying patient-specific efficacy) was preparing for the future data collection of AMYPAD. WP5 will be studying how quantitative measures of amyloid PET can help better understanding the disease course, as well as the potential of the technique in monitoring treatment efficacies.

Since these efforts require large amounts of data, WP5 used its first year to set up collaborations with external groups to initiate its analyses on existing datasets. With exciting analyses plans and rich available datasets, WP5 enters its second year...
eager to deliver important scientific output both internally and to the research community.

A big support for the dissemination of results coming from each of the previous WPs comes from the WP6 team (Ethics, communication and dissemination). Throughout the year, WP6 has kept track of every potential opportunity for disseminating the project and developed valuable tools to better connect the researchers and the community. These include the website, the newsletter, as well as project flyers which can be distributed at different events. In parallel, the ethics team within WP6 was very active in supporting both WP3 and WP4 when designing their studies. Their involvement in developing both protocols and patient information leaflets were crucial to the team and resulted in important improvements to both studies.

Alzheimer Europe Networking

From 1-4 November (Boston, USA) Jean attended the CTAD (Clinical Trials on Alzheimer’s disease) conference.

On 6 November (Glasgow, Scotland) Chris attended the 9th Patient Representatives Roundtable during the 20th ISPOR Annual European Congress.

On 8 November (Temse, Belgium) Cindy attended an EPAD WP6 meeting.

On 9 November (Luxembourg, Luxembourg) Gwladys attended the HRG Event and meet with Airlines representatives.

On 11-15 November (Prague, Czech Republic) Gwladys attended the 56th ICCA Congress.

On 15 November (London, UK) Chris attended the BD4BO Communication and Outreach Coordination F2F meeting.

On 16 November (Helsinki, Finland) Jean gave a presentation of the European Dementia Monitor at the Memory Conference of the Finnish Alzheimer’s Society.

On 20 November (Amsterdam, Netherlands) Jean and Cindy attended a meeting of WP6 - Dissemination of the EPAD (European Prevention of Alzheimer’s Dementia) project.

EU DEVELOPMENTS

27 October: EFPIA hosts Patient Think Tank Meeting

On 27 October, the European Federation of Pharmaceutical Industries and Associations (EFPIA) held a Patient Think Tank Meeting in Brussels. Stefan Oschmann, the new EFPIA president, was invited to attend the meeting. He talked about the presidency priorities especially related to patient relations. The audience discussed with him on the plan for the coming two years. During the meeting, the group discussed the plans for a potential EU-level patient engagement platform on patient data and how the Patient Think Tank can play a role in shaping and developing this online resource. On the agenda was a discussion on the clinical trials. Some clinical trial recruitment platforms were presented and an update about developments on clinical trial transparency was reported. EFPIA gave a feedback on the “Working Together with Patients Groups” workshop held in Bucharest to report how the document “Working Together with Patients” was received. This paper was drafted by the members of the EFPIA Patient Think Tank and the Ethics & Compliance Committee. Finally, EFPIA gave a policy update on Brexit. Alzheimer Europe Project Officer Cindy Birck attended the meeting.
On 15 November in Gothenburg, Sweden at the Social Summit for Fair Jobs and Growth, the European Pillar of Social Rights was signed by Jean-Claude Juncker, President of the European Commission, Antonio Tajani, President of the European Parliament and Jüri Ratas, Presidency of the Council of the European Union.

About the European Pillar of Social Rights
The Pillar of Social Rights is about delivering new and more effective rights for citizens. It builds upon 20 key principles, structured around three categories:

- **Equal opportunities and access to the labour market**
- **Fair working conditions**
- **Social protection and inclusion**

Many of the 20 rights/principles in the proposal are very relevant and important to older people and people with dementia and their carers in particular:

The **right to work-life balance** is already a legislative proposal with five days per year of paid leave to care for dependent relatives. The proposal gives carers the right to request flexible working arrangements, like reduced or flexible working hours or flexibility at work The proposal is currently being debated by the EU Council and the European Parliament as part of the legislative process.

The **right to long-term care** states that everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.


20 November: Help make medicines safer by reporting suspected side effects: Medicines Healthcare products Regulatory Agency (MHRA) launches social media campaign

From 20-24 November, MHRA is running a social media campaign to promote recognition and reporting of suspected side effects from over-the-counter medicines, as part of an EU-wide awareness week. The Medicines and Healthcare products Regulatory Agency is responsible for protecting and improving the health of millions of people every day through the effective regulation of medicines and medical devices, underpinned by science and research. The agency consists of three centres: CPRD, NIBSC and MHRA.

While medicines are safe and effective, side effects can happen, even with over-the-counter medicines. It is important the risks associated with all medicines are understood and communicated to health professionals and patients.

Potential side effects may range from a headache or sore stomach, to flu-like symptoms or just “feeling a bit off” and
reporting these can help regulators monitor medicines on the market and take action as appropriate. Regulators such as MHRA rely on the reporting of suspected side effects to make sure medicines on the market are acceptably safe. Unfortunately, all reporting systems suffer from under reporting – this is why our campaign is important to both raise awareness and help strengthen the system. The campaign is part of the Strengthening Collaboration for Operating Pharmacovigilance in Europe (SCOPE) Joint Action project. One of its main aims is to raise awareness of national reporting systems for suspected side effects in medicines. To report a suspected side effect from an unlicensed medicine visit:

https://yellowcard.mhra.gov.uk/counterfeit-products

20 November: 22 November: Patients and consumers' organisations learn about impact of relocation of European Medicines Agency

22 November: 22 November: Patients and consumers' organisations learn about impact of relocation of European Medicines Agency

The meeting of the Patients’ and Consumers’ Working Party of the European Medicines Agency took place on 22 November. The Agency’s Director Guido Rasi updated the participants about the recent decision of the Council to move the Agency to Amsterdam. Prior to the decision, the Agency had stayed neutral, but highlighted the potential impact of the new location on staff retention and business continuity. Staff surveys had indicated that the Agency could lose significant numbers of EMA and even a move to Amsterdam could result in staff losses of up to 19%.

Guida Rasi also highlighted that there was no indication as to the role which the United Kingdom would play in the future European regulatory system and whether the UK would stay involved in EMA activities.

During the meeting, EMA staff also updated the representatives of patient organisations on the Agency's communication and social media strategy, as well as some of its key activities such as a recent public hearing on valproate, the work on real world evidence and big data, as well as the plans to improve product information for patients.

The different working parties of the Agency were also present and gave updates on their recent activities. Finally, the agency staff informed the participants about the work programme for 2018 and 2019 of the Patients’ and Consumers’ Working Party. Jean Georges represented Alzheimer Europe at the meeting.

23 November: European Commission publishes the State of Health in the EU 2017

On 23 November the European Commission published the State of Health in the EU in 2017 with 28 country health profiles and overview report. The reports were prepared in cooperation with the OECD and the European Observatory on Health Systems and Policies. The findings show that Europe needs to focus on being more effective, accessible and resilient.

Key findings:

- Health promotion and disease prevention pave the way for a more effective and efficient health system. Aside from the unbalanced investments in prevention, social inequalities need to be tackled, as illustrated by the differences in cancer screening or physical activity between people with higher and lower income and education.

- Strong primary care efficiently guides patients through the health system and helps avoid wasteful spending. 27% visit an emergency department because of inadequate primary care. Only 14 EU countries require primary care referral for consulting a specialist; 9 other countries have financial incentives for referrals.

20 November: Amsterdam selected as new location for European Medicines Agency (EMA)

On 20 November the EU 27 ministers selected Amsterdam, the Netherlands, as the new seat for the European Medicines Agency (EMA). The selection took place in the margins of the General Affairs Council in accordance with the procedure endorsed by the EU 27 Heads of State and Government on 22 June 2017.

The European Medicines Agency (EMA) currently based in the UK, needed to be relocated in the context of the UK’s withdrawal from the EU.

The European Medicines Agency (EMA) is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. The EMA is essential for the functioning of the single market for medicines in the EU. The European Medicines Agency (EMA) is responsible for the scientific evaluation, supervision and safety monitoring of medicines in the EU. The EMA is essential for the functioning of the single market for medicines in the EU.


21 November: EMA organises a PCO Training session

On 21 November, the European Medicines Agency (EMA) organised a training session for patients and consumers organisations (PCO) interested in EMA activities in London, UK. The meeting was chaired by Juan Garcia Burgos, the head of EMA’s Public Engagement Department who welcomed 71 participants including PCO, healthcare professionals, academics and young people.

The agenda provided a complete overview of how the EMA evaluates medicines for use in EU countries. During the day, information on Scientific Advice procedures, Scientific Advisory Group meetings and the role of PCO involvement within the EMA was also part of the agenda. Alzheimer Europe Project Officer Cindy Birck attended the meeting.

www.ema.europa.eu/ema
• Integrated care ensures that a patient receives joined-up care. It avoids the situation we currently see in nearly all EU countries, where care is fragmented and patients have to search their way through a maze of care facilities.
• Proactive health workforce planning and forecasting make health systems resilient to future evolutions. The EU has 18 million healthcare professionals, and another 1.8 million jobs will be created by 2025. Health authorities need to prepare their workforce for upcoming changes: an ageing population and multimorbidity, the need for sound recruitment policies, new skills, and technical innovation.
• Patients should be at the centre of the next generation of better health data for policy and practice. The digital transformation of health and care helps capture real-world outcomes and experiences that matter to patients, with great potential for strengthening the effectiveness of health systems.

Vytenis Andriukaitis, Commissioner for Health and Food Safety, said: “Spending only 3% of our health budgets on prevention, compared with 80% on the treatment of diseases, is simply not enough. We need better access to primary care so that the emergency room isn’t people’s first port of call. And we need to enshrine health promotion and disease prevention into all policy sectors to improve people’s health and reduce pressure on health systems. These are just a few of the diagnoses coming out from our 2017 State of Health in the EU report. By offering comprehensive data and insights, we aim to support national health authorities in tackling the challenges and in making the right policy and investment choices. I hope they will make good use of it.”

Following the presentation to Health Ministries of all EU countries, national authorities can further discuss these reports with the experts of the OECD and the European Observatory on Health Systems and Policies. The voluntary exchanges will be able to take place from the beginning of 2018 and help ministries to better understand the main challenges and develop the appropriate policy responses.

https://ec.europa.eu/health/state

POLICY WATCH

19 October: Global Alzheimer’s and Dementia Action Alliance (GADAA) hosted a webinar highlighting the disproportionate impact that dementia has on women

On 19 October, the Global Alzheimer’s & Dementia Action Alliance (GADAA) hosted a global webinar to share more about one of the 21st century’s biggest global health priorities and its effect on women worldwide. Participants including human rights, gender and development NGOs, dementia specialists, academics and government representatives discussed dementia’s disproportionate impact on women around the world.

9-11 November: CEAFA conference learns of imminent approval of Spanish National Alzheimer’s Plan

The 7th National Congress of Alzheimer organised by CEAFA took place in November in Malaga, Spain. In the last plenary session, dedicated to governmental policies for Alzheimer’s disease, the chairperson of CEAFA, Cheles Cantabrana, referred to the close collaboration of CEAFA in the development of the National Alzheimer’s Plan.

Fernando Vicente, Advisor of the General Directorate of Imserso (Spanish Institute for older people and social services) and Coordinator of the National Alzheimer’s Plan referred to dementia as a public health priority and a major social health challenge. He acknowledged the good collaboration with CEAFA in developing the plan and highlighted that he expected the Plan to be formally approved before the end of the year.


22 November: UK Alzheimer’s Society responds to lack of social care funding in budget

On 22 November the UK Government presented their budget in Parliament. Jeremy Hughes, Chief Executive at Alzheimer’s Society, responding to a lack of funding for social care in the budget, said: “The extra money for the NHS is hugely needed, but by neglecting social care the Government is just filling up a bucket with holes in it. They have ducked an opportunity today - to put into action their commitment to tackle dementia care head on. People with dementia will rightfully feel betrayed and abandoned. The absence of state support for vulnerable people with dementia is a travesty, and an embarrassment for our society.”

https://www.alzheimers.org.uk
MEMBERS’ NEWS

21 October: First joint Alzheimer, Parkinson and Multiple Sclerosis conference held in Portugal

Almost 500 people attended this conference held on 21 October in Torres Novas, a beautiful city in Ribatejo, a county in the middle of Portugal.

It was a joint initiative from Alzheimer Portugal, “Associação Portuguesa de Doentes Parkinson” (Parkinson Association) and “Associação Movimento Esclerose Múltipla do Médio Tejo” (Multiple Sclerosis Association).

For the first time in Portugal, people with Dementia, Multiple Sclerosis or Parkinson, carers, volunteers, associations representatives, medical doctors and other health care professionals, researchers, joined to discuss the common issues of neurodegenerative diseases and the biggest challenges that people living with such diseases and their carers are facing.

Member of the European Parliament, Marisa Matias was present throughout the conference. Local authorities and of the National Coordinator for the Reform of the Continuous Care Network, Professor Manuel Lopes, also participated. He announced that a National Dementia Plan for Portugal is being prepared as well as an Active Ageing programme.

Idalina Aguiar, a member of the European Working Group of People with Dementia (Alzheimer Europe) together with João Pedro Belo (Parkinson) and Manuel Subtil (Multiple Sclerosis) were some of the speakers.

All of them highlighted the need of having positive attitudes and to struggle against stigma and misperceptions of the diseases. Their voices really touched the participants and certainly strengthen their willingness to improve the quality of life of people living with neurodegenerative diseases.

31 October: First Meeting of the Swiss Working Group of People with Dementia

On 31st October, the very first meeting of the Swiss Working Group of People with Dementia took place in Bern. Out of the five persons with dementia registered for this day, three could participate. One participant was accompanied by her husband. Additionally, three colleagues from the national office of Alzheimer Switzerland were present.

After a welcome and the personal introduction, different topics (i.e. the importance of GPs, financial aspects of care, etc.) and possibilities of cooperation were discussed. The group decided to name itself “Working Group” in order to differentiate their purpose from a self-help group and to clearly indicate its objective.

The group will start its work in 2018 with four meetings and a concrete topic, which will be decided in the first meeting in the next year. The different examples of already existing working groups in other countries show that there is no ‘ideal’ form of collaboration for a group like this. The organisation of the collaboration of the Swiss group will develop organically during its future activities.

8 November: From Seldom Heard to Seen and Heard: England’s Dementia Action Alliance’s newest campaign

This autumn, members of Dementia Action Alliance (DAA) came together to campaign for improved outcomes for people living with dementia and their carers who come from seldom heard groups.

Their 2017 campaign, From Seldom Heard to Seen and Heard, focuses on improving care and support for people affected by dementia who come from seldom heard groups. People from seldom heard groups face barriers to accessing good health and social care, which at time fails to meet their needs. Challenges can include a lack of awareness and cultural understanding across health and social care settings. This problem has become more acute as public service budgets have been cut. Through their diverse membership the DAA is well placed to improve this situation by harnessing the resources and ideas of its members and of other organisations operating across health and social care.

The campaign has three primary objectives:

1. Raise awareness of the challenges faced by people with dementia from seldom heard groups
2. Influence system-wide change
3. Bring about organisational change.

As part of the campaign they held a series of roundtables, each focusing on a specific seldom heard group. Through the roundtables they explored areas where progress is needed and where the DAA, through the influence of its members, can affect wider change.

They ran roundtables focused on dementia in the following groups and produced recommendations:

- Prisons
- Lesbian Gay Bisexual & Transgender
- Learning Disabilities.

At their launch event in September, they additionally discussed the following communities:

- Black, Asian, Minority Ethnic (BAME)
- Young onset dementia
- Social deprivation
- Irish
- Gypsies and Travellers.

You can find further information on From Seldom Heard to Seen and Heard on the DAA’s website.

You can follow them on Twitter at @Dementia_Action and use the hashtag #dementiaseenandheard to track their campaign.

**9 November: Germany welcomes 20,000th Demenz Partner**

The German Alzheimer Association runs a nationwide information campaign called “Demenz Partner”. This initiative is part of the worldwide Dementia Friends movement.

470 organisations now offer Demenz Partner information sessions in Germany. On 9 November fourteen policemen and women in Weyhe, a small county near Bremen, attended an information session about dementia. Police officers have noticed that there are more and more people with dementia, but are often uncertain how to speak to someone who is searching his or her home. With this course they wanted to gain more confidence when dealing with people with dementia. With those 14 policemen and women it brings the number of Demenz Partner in Germany to 20,000 and we are sure there will be many more in the next years.

For more information: www.demenz-partner.de

**15 November: Czech Alzheimer Society remains vigilant in raising dementia awareness**

From 6 to 8 November, the Czech Alzheimer Society held a campaign to raise dementia awareness following on the success of their previous campaign during the “Memory Week”, that took place in September.

Further, representatives of the Czech Alzheimer Society spoke at the local television as well as Czech Radio about signs of dementia, prevention and memory screening methods, which they provided for free at the radio station. The society stresses the benefit for society of such events referring to the supplemental calls they received on their helpline by people asking to receive more information on memory screening.

A day after on the 9 November, the society organised a charity concert for the support of people with dementia and their supporters.

Finally yet importantly, on 14 November the Czech Alzheimer’s Society set up a conference program entitled “Life with Alzheimer's Disease"’, which took place in the realm of a project supporting the active life of seniors in the Olomouc region and mainly focused on family carers.

**14 November: Slovenian Alzheimer’s Society continues its “Dementia Friendly Spot” campaign**

In July, Spominčica-Alzheimer Slovenia opened a first Dementia Friendly Spot at Human Right Ombudsman Office. After this successful event another three Dementia Friendly Spots were opened in nursing homes Tisje Litija and Danice Vogrinec Maribor.

14 November: Slovenian Alzheimer’s Society continues its “Dementia Friendly Spot” campaign

In November, the organisation had a meeting where more than 25 associations from different Slovenian towns showed interest to become Dementia Friendly Spots. With Dementia Friendly Spots, the organisation contributes to better public awareness about dementia, especially among public workers (policemen, pharmacists, fireworkers, in libraries, at hospitals) and hopes to turn Slovenia into an even more dementia friendly country.

**17 November: Annual Memory Conference in Finland attracts international participants**

The annual Memory Conference of Finland took place in Helsinki from 15 to 16 November. During the conference, accentuations with regard to human rights but also stigma were emphasised by the different attendees. The voice of people with memory diseases and the many faces of memory diseases were highlighted.
during the conference as well. The event brought together people with memory diseases, their close relatives, local associations of the Alzheimer Society of Finland and professionals of the field.

Jouni Rasi, who is chair of the Memory Activists of Finland, reminded that the human rights must be secured for people with memory related diseases. Chair of the Alzheimer Society of Finland and member of Parliament Merja Mäkisalo-Ropponen pointed out that words do matter when talking about memory diseases. In Finland, we do not speak about dementia or people with dementia but memory related diseases, and even so, false terms still exist in the Finnish media, Mäkisalo-Ropponen continued.

Rehabilitation is a crucial part in the care of the memory diseases, emphasized Memory Activist Petri Lampinen, who is also a member of the European Working Group of People with Dementia. The memory disease does not only take, but also gives new content to my life, he continued. It gives you a unique feeling when you can give the audience something that awakens them, Petri Lampinen described.

Further, the conference hosted a session entitled; “From big picture to multicultural connections” which was the first international session in the history of Memory Conferences in Finland. During the session chaired by Sirpa Pietikäinen, Executive Director of Alzheimer Europe, Jean Georges, presented European dementia strategies and policies. Sirpa is a Member of the European Parliament and Vice President of the Union Council of the Alzheimer Society of Finland.

**23 November: Alzheimer Society Finland publishes update on advance directives and translates it into English**

An advance directive is a written or spoken expression of will that specifies the wishes for good care and rehabilitation, commonly emphasising the wishes for end-of-life care. With the advance directive, a person can appoint someone to make certain decisions for themselves in case they no longer can.

The Alzheimer Society of Finland has published an advance directive form already over ten years ago. So far, the form was updated and at the same time translated into English. The form can be found on their website, where it can be printed or filled out electronically.

An advance directive card has also been translated into English, it can be kept in a wallet in order to prove that you have a written advance directive, with whom you have it as well as where it is kept.

The Alzheimer Society of Finland encourages every person in the early stages of a memory-related disease to make an advance directive. An advance directive strengthens the implementation of the right to self-determination: according to the Finnish Act on the Status and Rights of Patients all health-care professionals are obliged to comply with the advance directives of their patients.

The Alzheimer Society of Finland thanks Alzheimer Europe for the functional model on which it modified and updated the form in order to adapt it to the Finnish circumstances. A number of medical, social and health-care legal experts were consulted during the editorial process.


**24 October: The Alzheimer’s Association and ADDF collaborate to fund a Phase 2 trial for AD**

The Alzheimer’s Association and Alzheimer’s Drug Discovery Foundation (ADDF) will fund a new clinical Phase 2 trial for Alzheimer’s disease (AD).

The biotechnology company Amylyx Pharmaceuticals will receive $1.85 million to conduct a trial of AMX0035, a combination of sodium phenylbutyrate and tauroursodeoxycholic-acid. The study is expected to begin in the first half of 2018 with approximately 50 participants with mild cognitive impairment or mild-to-moderate AD.


**30 October: LipiDiDiet study fails to meet primary outcome**

On 30 October, researchers announced the results of the LipiDiDiet project, a 24-month randomised, controlled, double-blind, parallel-group, multicentre trial (11 sites in Finland, Germany, the Netherlands, and Sweden) which had failed to meet its primary outcome (change in a neuropsychological test battery).

An interdisciplinary team of scientists recently published long-term results from the LipiDiDiet study in the journal The Lancet Neurology. The study assessed the effects of a once-daily medical drink in people with the pre-dementia stage of Alzheimer’s disease (AD). Extension studies are currently ongoing and will be reported in future.

The study encompassed 382 participants, of which 311 were screened and randomly assigned to either receive the medical drink (n=153) or a control product (n=158). Participants with dementia were excluded according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV).

Despite the inefficacy with regard to the neuropsychological tests, cognitive decline in the group that received the medical drink was lower than expected and group differences on secondary endpoints of disease progression measuring cognition and function as well as the hippocampal atrophy were observed.

The biotechnology company Amylyx Pharmaceuticals will receive $1.85 million to conduct a trial of AMX0035, a combination of sodium phenylbutyrate and tauroursodeoxycholic-acid. The study is expected to begin in the first half of 2018 with approximately 50 participants with mild cognitive impairment or mild-to-moderate AD.

In order to rule out random results that are based on chance, the research team concluded that further studies of nutritional approaches with larger sample sizes, longer duration, or a primary endpoint more sensitive in this pre-dementia population, are needed to further clarify potential benefits.

http://www.thelancet.com/pdfs/journals/laneur/PIIS1474-4422(17)30332-0.pdf

1 November: Study suggests a link between brain glucose levels and AD

A recent study published in Alzheimer’s & Dementia: the Journal of the Alzheimer’s Association revealed a brain glucose dysregulation in Alzheimer’s disease (AD). The National Institute on Aging (NIA), part of the National Institutes of Health, supported the study. Researchers measured glucose levels in various brain regions from participants in the Baltimore Longitudinal Study of Aging (BLSA) including healthy controls and participants with AD pathology.

In the published study, scientists showed a decline of glucose transporter proteins as well as enzymes controlling the process by which the brain breaks down glucose, in brains of people with AD compared to normal brains. In addition, these levels were associated with the severity of the disease and the accumulation of amyloid proteins.

http://www.alzheimersanddementia.com/article/S1552-5260(17)33765-2/fulltext

10 November: Cerebrospinal fluid exits mainly through the lymphatic system

On 10 November, scientists from the Swiss Federal Institute of Technology in Zurich (ETH Zürich) published research on the way cerebrospinal fluid exists in the cranial cavity in the Nature Communications journal.

The human brain swims in a liquid called cerebrospinal fluid (CSF). For decades, scientists have assumed this fluid, which is constantly produced and replaced, mostly leaves the skull via blood vessels.

The team of scientists were now able to test this assumption by injecting tiny fluorescent molecules into the brain of mice and tracing them using an imaging-technique. During the analysis, it became known, that the injected molecules appeared in the lymphatic vessels and lymph nodes outside the brain after a few minutes while the researchers were unable to find any in the blood vessels this fast after injection.

A recent hypothesis in the development of neurodegenerative disorders proposes that toxic proteins such as amyloid beta and tau (which are strongly related to Alzheimer’s disease - AD) may accumulate in the brain due to reduced clearance.

Therefore, the team also assessed whether there is diminished fluid flow out of the brains of older mice. Due to their findings showing much less CSF flows out of the brain of older mice, the next step in their research focus will be to assess the effect of stimulating the flow of CSF in order to see if they can slow down the progression of AD in a mouse model.

15 November: Risk of death associated with new benzodiazepine use among persons with Alzheimer disease

On 15 November, scientists from the University of Eastern Finland have published an article on the risk of death associated with new benzodiazepine and related drug (BZDR) use in people with Alzheimer’s disease (AD) in the International Journal of Geriatric Psychiatry.

Benzodiazepines are a class of psychoactive drugs, known as minor tranquilizers, often prescribed for the treatment of anxiety. The research team used data from the register-based MEDALZ cohort, which includes all community-dwelling Finns diagnosed with AD between 2005 and 2011, bringing together information of more than 70,000 people.

For the assessment of new users, the researchers excluded all persons who had any BZDR use preceding the year of their AD diagnosis. Altogether, the data set included 10,380 new users, the team then matched for each of them two nonusers (20,760) on age and sex as well as the time of diagnosis. They then looked at the 180-day mortality for the analysis after adjusting for multiple factors such as psychiatric disorders, substance abuse, stroke and other psychotropic drug use.

The follow-up showed, that Benzodiazepine and related drug use was associated with an increased risk of death in persons with AD. They concluded that their results support treatment guidelines stating that non-pharmacological approaches should be the first-line option for symptomatic treatment of AD.

15 November: Bill Gates announces USD 50 million investment in Dementia Discovery Fund

On 13 November, American business magnate Bill Gates announced a USD 50 million investment in UK-based Dementia Discovery Fund (DDF), which is a private fund working to diversify the clinical pipeline and identify new targets for treatment. He will follow up the initial investment with an additional USD 50 million to be distributed to start-ups working on Alzheimer’s research.

On his personal blog, Gates explains the challenge a lack of treatment for Alzheimer’s disease (AD) poses to our society
and how his interest in AD developed through both its monetary and emotional costs.

Bringing together the feedback from researchers, academics, funders and industry experts, he underlines five key areas that need progress in order to substantially alter the course of AD:

- We need to better understand how Alzheimer’s unfolds.
- We need to detect and diagnose Alzheimer’s earlier.
- We need more approaches to stopping the disease.
- We need to make it easier to get people enrolled in clinical trials. We need to use data better.

To learn more visit: https://www.gatesnotes.com/Health/Digging-Deep-Into-Alzheimer's

21 November: Progress in the research on how dementia with Lewy bodies affects synapses

On 21 November, a research team led by scientists from the University of Edinburgh and the Universitat Autònoma de Barcelona (UAB) has published their findings on the small changes that occur during the disease progression of people with Lewy body dementia (LBD) in the journal Brain. The team examined the influence of LBD on the synapses (a structure that permits brain cells to communicate). Research until now had provided some evidence that the damage caused on the brain in LBD could be caused by clumps of a protein called alpha-synuclein.

With the help of a powerful technology named array tomography, the team examined five post-mortem brains of people with LBD and five healthy controls. They found that, the alpha-synuclein could form around the synapses by analysing 1.318.700 so-called pre- or post-synaptic terminals (the two sides of the synapses).

The researchers found small aggregates of alpha-synuclein on both sides of the synapses in the brain tissue of the people with LBD. According to the researchers, this offers new insights into how brain damage occurs in LBD, as it suggests that the toxic protein might jump between neurons via synapses.

CTAD NEWS

The 10th edition of the Clinical Trials on Alzheimer’s Disease (CTAD) Conference took place from 1 to 4 November 2017 in Boston. In this section, you will learn more about the key research development which were presented during the conference.

1 November: Professor Bruno Dubois is awarded CTAD Lifetime Achievement Award

During the welcome ceremony of the CTAD Conference, Professor Bruno Dubois was presented with the Lifetime Achievement Award by his colleagues Bruno Vellas and Jacques Touchon. With this award, CTAD recognised the outstanding work of Professor Dubois who is the Director of the “Institute for Memory and Alzheimer Disease2 and of the Research INSERM Unit on “Cognition and Neuroimaging in Brain Diseases at the ICM at the Salpêtrière Hospital in Paris, France. He was co-chairing the task force on the criteria and guidelines for the diagnosis of Parkinson’s disease dementia and leads an international working group of experts on the new criteria for Alzheimer disease.

Professor Bruno Dubois is also a member of Alzheimer Europe’s Expert Advisory Panel.

1 November: Roche announces launch of GRADUATE phase III programme

During the CTAD Conference, Roche presented data from its Marguerite and Scarlet RoAD open label extension studies. Which showed that approximately one third of subjects were below the amyloid positivity threshold after 6-9 months of active treatment with a higher dose of gantenerumab. Amyloid reduction was significantly higher with the higher dose compared to lower doses and the results showed consistent amyloid removal across subgroups and subjects. The PK/PD modelling and open label extension data also showed that optimised titration to the target dose reduced the risk of ARIA-E,

On the basis of these findings, the company announced the launch in 2018 of GRADUATE 1 & 2, two phase III trials investigating the efficacy of higher dose gantenerumab.

1 November: Lundbeck and Otsuka will develop a new Phase III trial of brexpiprazole in participants with dementia of the Alzheimer's type

In May 2017, it was announced that brexpiprazole may reduce agitation in people with Alzheimer’s dementia. Two Phase 3 trials were investigated to evaluate the safety and efficacy of brexpiprazole in the treatment of people who have agitation due to Alzheimer’s dementia.

On 1 November, global pharmaceutical companies Otsuka and Lundbeck announced that they will start a third Phase IIIa trial for brexpiprazole in the treatment of agitation in participants with dementia of the Alzheimer’s type. The trial is expected to recruit participants during the first half of 2018.

2 November: Biogen announces new Phase 1b results for its experimental AD drug aducanumab

On 2 November, Biogen presented new data of its investigational drug, aducanumab, developed for the treatment of Alzheimer’s disease (AD) at the CTAD conference in Boston. The company presented results from the long-term extension of its ongoing Phase 1b study, which is a randomized, double-blind, placebo-controlled, multiple-dose study evaluating the safety, tolerability and clinical effects of aducanumab.

Data presented included results from participants with prodromal or mild AD receiving gradually increased doses of the drug during 24 months and those who received fixed doses of 3, 6 or 10 mk/kg during 36 months. Results presented were in accordance with previous findings. A reduction of amyloid plaque levels was observed in participants who received the drug during 24 months and those who received fixed doses of 3, 6 or 10 mk/kg during 36 months. Results presented were in accordance with previous findings. A reduction of amyloid plaque levels was observed in participants who received the drug during 24 months and those who received fixed doses of 3, 6 or 10 mk/kg during 36 months.

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The presentation of the findings is available on the Anavex website.


2 November: Novartis and Amgen launch a new Phase 2/3 trial for AD

On 2 November, both biopharmaceutical companies Novartis and Amgen announced expanded collaboration with Banner Alzheimer’s Institute to launch a new clinical trial “Generation Study 2” using the BACE inhibitor CNP520. This trial follows the launch of the Generation S1 study last year evaluating whether two investigational drugs called CAD106 and CNP520 can slow down the onset and progression of clinical symptoms associated with Alzheimer’s disease (AD) in participants at the risk to develop clinical symptoms based on their age and who carried two copies of the apolipoprotein E (APOE) 4 gene.

Generation S2 is a randomised, double-blind, placebo-controlled trial designed to evaluate the efficacy and safety of CNP520 in participants at risk for the onset of clinical symptoms of AD, who only have one copy of the APOE4 gene. The trial started enrolling participants in August 2017 in US. The five-year study will recruit approximately 2000 cognitively healthy participants in the world, aged 60 to 75, who will receive the placebo or the drug CNP520 (15 or 50 mg).


4 November: Biogen announces new clinical data of Anavex2-73 for AD

On 4 November, Biogen presented new clinical results from three trials, a Phase 1 study, a Phase 2a study and a Phase 2a long-term extension study investigating Anavex2-73, a drug targeting cellular homeostasis.

- The company reported that the Phase 2a long-term extension study appeared safe. In addition, the drug showed improved cognitive and functional measures in participants with mild to moderate AD who received the highest doses.
- Both Phase 1 and Phase 2a studies showed a strong dose-response relationship. Participants with milder AD stage responded better to Anavex 2-73 than those with more advanced stage.

The presentation of the findings is available on the Anavex website.


4 November: Acadia reports Phase 2 study of Pimavanserin for AD

On 4 November, the company Acadia Pharmaceuticals, which develops innovative therapies in the nervous system area, presented findings from the Phase 2 study of Pimavanserin in Alzheimer’s disease (AD) psychosis at the 10th Clinical Trials on Alzheimer’s Disease (CTAD) meeting in Boston.

The trial was a double-blind, placebo-controlled trial designed to evaluate the efficacy and safety of Pimavanserin in participants with AD psychosis. Top line results were announced in December 2016. The presentation at CTAD reported that the Phase 2 trial met its primary endpoints. Pimavanserin could significantly reduce psychosis in participants with AD compared to placebo. Indeed, at 6 weeks, 55.2% of pimavanserin-treated participants had improved their psychosis score by at least 30%, compared to 37.4% for the placebo. However, the study failed to meet its secondary goals including global impression changes and a reduction in agitation.

A Phase 3 study, Harmony, is now evaluating the efficacy and safety of Pimavanserin for the treatment of hallucinations and delusions associated with dementia-related psychosis.


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4 November: Small trial on blood plasma infusions for people with Alzheimer’s disease suggests safety of method

On 4 November, principal investigator Sharon Sha, professor at Stanford Research, presented the results from the recently finished PLASMA trial (Plasma for Alzheimer’s Symptom Amelioration) at the 10th annual Clinical Trial on Alzheimer’s Disease conference in Boston.

The trial investigated safety, tolerability and feasibility of administering blood plasma infusions from young donors (18-30 years) in a small group of 18 people with mild to moderate Alzheimer’s disease (AD).

The design of the study was led by previous research, which has shown that factors in the blood of young mice might have the ability to rejuvenate the brain tissue and improve cognitive performance in old mice.

The trial, sponsored by a biotechnology company, had been carried out in two stages. During the first stage, nine participants with mild to moderate AD received either plasma or placebo infusions once weekly during four weeks. After a six-week “washout period”, the participants that had received plasma infusions were then given the placebo and vice versa during the second stage.

During the trial, the investigators decided to modify the trial design for their next group of nine participants, so all newcomers would receive young-donor plasma infusions.

All participants underwent a battery of tests and questionnaires to assess mood, cognition as well as functional ability before and after the first four weeks and, again before and after the second four-week period.

Results indicate that the plasma infusions were generally well tolerated with a single instance of excessive itching. Further, they demonstrated improvement in two of three different assessments of functional ability based on caregiver reports, although the trial wasn’t powered to show efficacy.

The principal investigator commented on the study saying, that the enthusiasm concerning the findings needs to be tempered by the fact that this was a small trial, but that these results warrant further study.

8 November: EPAD presented its first data analysis at the CTAD conference

Craig Ritchie from The University of Edinburgh (EPAD Co-coordinator and AMYPAD WP4 co-lead) presented the first data analysis from EPAD Longitudinal Cohort Study (LCS) in a plenary lecture entitled “The European Prevention of Alzheimer’s Dementia (EPAD) and Amyloid Imaging for Prevention of Alzheimer’s Dementia (AMYPAD) Projects: Cohort Readiness for the Adaptive Clinical Trial Platform”.

The first analysis of EPAD LCS Data can be read on the EPAD website.

DEMENTIA IN SOCIETY

8 November: Study underlines positive impact of neighbourliness on wellbeing in people living with dementia

On 8 November, preliminary findings from the Neighbourhoods and Dementia study have been made public. The study is part of a suite of studies that form part of England’s Prime Minister’s 2012
Challenge on Dementia and results underline the positive impact of neighbourliness on wellbeing in people living with dementia.

The research is part of a five-year study funded by the Economic and Social Research Council and the National Institute for Health Research.

The team interviewed altogether 56 participants, 29 of which had dementia and 27 of which were carers in order to investigate how people living with dementia and their partners experience their local neighbourhoods.

According to Research Associate Sarah Campbell, from The University of Manchester neighbourliness has several positive aspects, underlining that familiarity with people in local shops, cafes and even on the street, was crucial to the participants of the study. Further, she said, that acts of kindness by neighbours like taking the bins out each week, had a huge effect on their wellbeing.

The researchers also highlighted that some people with dementia still had a valuable role in their neighbourhoods by “keeping an eye” out, collecting newspapers and caring for grandchildren.

Commenting on the study, S. Campbell said, that their “findings together indicate how the neighbourhood operates through a series of links between people and place from the dementia café, to the local newsagents, and the neighbour two doors down. Many people with dementia will be living independently in neighbourhoods and communities, with the support of family, friends, neighbours and formal and informal service providers”.

19 November: Legendary AC/DC guitarist Malcolm Young dies after battle with dementia.

Tributes have been paid to legendary Australian guitarist and AC/DC co-founder Malcolm Young, who has died aged 64 after a long battle with dementia. Malcolm had been living with Dementia for several years and passed away peacefully with his family by his bedside.

Malcolm, along with his brother Angus, was the founder and creator of AC/DC. With enormous dedication and commitment he was the driving force behind the band. As a guitarist, songwriter and visionary he was a perfectionist and a unique man.

In an earlier interview about his brother Angus touched on Malcolm's condition: “Malcolm was always very organised [so] it was kind of strange. For the first time I'd seen him disorganised, being confused about a lot of things. That's when it kind of, you know, hit me. Something was not right with him.”

Malcolm is survived by his wife O’Linda, children Cara and Ross, son-in-law Josh, three grandchildren, sister and brother.

22 November: Singer and actor David Cassidy dies aged 67

David Cassidy, who was diagnosed with dementia in his 60s has passed away.

In a previous interview, he told People magazine that he was in denial for a time about his dementia. “But a part of me always knew this was coming,” he said.

Cassidy entered a Florida hospital over the weekend and deceased due to organ failure in the hospital’s intensive care unit. His publicist Geffen released a statement from his family that said Cassidy died surrounded by loved ones “with joy in his heart and free from the pain that had gripped him for so long”.

Cassidy, who lived in Florida late in life, is survived by his son, Beau, and his daughter, Katie.

22 November: Oscar winning actress Carey Mulligan addresses the UN on women and dementia

25 November marks the International Day for the Elimination of Violence against Women. This year, to commemorate the day, UN Women and the UN Secretary General’s campaign to End Violence Against Women (UNiTE) brought civil society, government and UN representatives together at an Official Commemoration event on 22 November. The theme for this year’s event was ‘Leave No one Behind: End Violence Against Women & Girls’ focusing on the far-reaching consequences of violence against women within some of the world’s most marginalised groups.

Within her role as Alzheimer’s Society and UK Global Dementia Friends Ambassador, Oscar-nominated and BAFTA-winning actress, Carey Mulligan joined a panel to speak out on the stigma that surrounds dementia globally and discuss how extreme forms of discrimination can lead to abuse and even violence against women. Carey offered her personal experiences of women affected by dementia and spoke of other real-life stories where women in South Africa and Nigeria have been ostracised and discriminated against due to their condition or association to someone living with dementia.

Championing the work of the Global Alzheimer’s and Dementia Action Alliance (GADAA), Carey acknowledged the need to address dementia as a global health issue. She also spoke of her involvement in GADAA’s recent film “And Then I looked Up Dementia… Women Speak Out” which documents
how women are disproportionately affected by dementia. Globally more women than men live with the condition, they provide the majority of care support and also face the greatest stigma. Carey also highlighted the work of the Global Dementia Friends movement as an awareness-raising solution to tackle the isolation, abuse and violence women affected by dementia can face.

Carey concluded her statement by calling on governments and civil society partners to “get behind this global challenge and unite for a world where no woman faces violence because of her dementia ... Dementia is a global women’s health and human rights issue that can no longer be ignored.”

You can watch or read Carey’s statement on GADAA’s website.

LIVING WITH DEMENTIA

Carol Hargreaves speaks about coping with good and bad times

As a person with dementia many people think we can’t cope with real life, so I feel I must put this into words. I lost a close relative recently. I was devastated but still, I was able to be there for his mum and my family. We are still numb from this heartbreak. I was able to help and be there so that’s why I feel I have to write this. Having this illness doesn’t stop me from living in happy times and in sad times. We learn to cope.

Karin Gustavsson reports about a meeting with a pharmaceutical company in Sweden

A pharmaceutical company called AstraZeneca is testing a new drug for Alzheimer’s disease which is currently in Phase 3. The company wants to give more information about dementia and what it is like to live with the condition to their staff so they contacted Alzheimer Sweden and asked for a volunteer. My husband and I have volunteered to do this. We have already attended a preparatory meeting with two members of the company on 6 November at their head office in Göteborg/Mölndal. I will talk to the employees in mid-December about my experience of living with Alzheimer’s. Around 250-300 staff members will attend the meeting.

Helen Rochford-Brennan talks about her participation in the AlzTalks in Cork

The Alzheimer Society of Ireland (ASI) hosted a celebratory AlzTalks event which featured people living with dementia, carers and musicians at the Cork Arts Theatre, Carroll’s Quay, Cork, Ireland to mark World Alzheimer’s Month 2017 on Wednesday, September 27th. This brilliant event was aimed at shattering the stigma and misconceptions that surround dementia. People with dementia and carers are given the opportunity to present to a live audience and speak about their personal experience of the condition alongside musical acts.

As well as me, other dementia advocates including people with dementia Sean Toomey and Michael Higgins shared their stories. Also, former carer Sean Donal O’Shea and Catherine Kennedy offered their personal insights on caring for a loved one with dementia. My presentation was primarily dedicated to discussing my own dementia journey so far, breaking down the stigma that often surrounds dementia and also looking at a rights-based approach to dementia. This platform allows awareness building and perception changing of the condition, given that lack of understanding and stigma is still widespread in Irish society. Having people speak about their own lives and experiences creates a better understanding of the unique experiences of people living with this challenging condition.

The videos from all of the presentation will be available on the ASI’s AlzTalks YouTube channel in the coming weeks.

NEW PUBLICATIONS & RESOURCES

10 November: Organisation for Economic Co-operation and Development (OECD) releases new Health at a Glance 2017 report

This new edition of Health at a Glance presents the most recent comparable data on the health status of populations and health system performance in OECD countries. This edition contains a range of new indicators, particularly on risk factors for health. It also places greater emphasis on time trend analysis. Alongside indicator-by-indicator analysis, this edition offers snapshots and dashboard indicators that summarise the comparative performance of countries, and a special chapter on the main factors driving life expectancy gains.

Healthier lifestyles, higher incomes and better education have all contributed to boost life expectancy in recent decades. Better health care has also helped, according to a new OECD report.

Health at a Glance 2017 says that all OECD countries have seen life expectancy at birth increase by over 10 years since
1970 to reach an average of 80.6 years.


**14 November: European Patients Forum (EPF) launches new report looking at the added value of patient organisations**

On 14 November EPF launched a new report entitled - The Added Value of Patient Organisations. Patient organisations represent and voice the situation of a specific population that would otherwise not be represented. Yet, the scope and the role of these organisations are still very often misunderstood. With this in mind, EPF commissioned a report to highlight the value of patient organisations as legitimate stakeholders in civil dialogue in health-related policies.

Alzheimer Europe contributed to the report which is available on the EPF website.

http://www.eu-patient.eu/

**23 November: RHAPSODY Carer's Guide for Young Onset Dementia - new online tool now available**

Most People develop dementia later in life but for some the disease comes earlier, in their 50s or early 60s. In these cases, dementia is often especially disruptive to the life of the person affected and their family. Their and their partner’s life planning is profoundly affected by the diagnosis. They may have to give up their job and stop contributing to the family income. Their children who are not quite adults themselves have to experience the slow loss of a parent they still depend upon in many ways. For people in this situation there is still not enough information, counselling and support.

The German Alzheimer’s association has collaborated with seven partners from six European countries to develop a Carer’s Guide for this specific situation. Within the RHAPSODY research project from April 2014 to December 2017 the partners went through and evaluated the policy and information environment that provides the framework for the treatment and care of people with young onset dementia and their carers within the six countries. And they assessed the specific and individual needs of this particular group. Their findings informed the development of a multimedia online tool providing information about young onset dementia. The Carer’s Guide is available in four different languages (English, French, Portuguese, and German). It is supposed to help relatives and carer’s of people with young onset dementia to better manage life with the disease. It provides information on medical aspects, on options for support, on legal aspects, communication, and self-care.

If other associations are interested in translating or hosting the Carer’s Guide, please contact Susanna Saxl via E-Mail at: info@rhapsody-project.eu.

The German version of the RHAPSODY Carer’s Guide for Young Onset Dementia is available for free at www.ratgeber-junge-demenz.de.

### AE CALENDAR

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>AE representative</th>
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<tbody>
<tr>
<td>5-6 December</td>
<td>European Parliament lunch debate “Improving the diagnosis of Alzheimer’s disease”, Company round table, Alzheimer’s Association Academy (Brussels, Belgium)</td>
<td>AE Board, members and staff</td>
</tr>
<tr>
<td>5-7 December</td>
<td>European Working Group of People with Dementia meeting (Brussels, Belgium)</td>
<td>Ana and Dianne</td>
</tr>
<tr>
<td>11-12 December</td>
<td>Human Brain Project seminar on data governance and informed consent (Paris, France)</td>
<td>Cindy</td>
</tr>
<tr>
<td>11-12 December</td>
<td>Launch of WHO Global Dementia Observatory (Geneva, Switzerland)</td>
<td>Jean</td>
</tr>
<tr>
<td>13-14 December</td>
<td>CEOi Workshop: “The road to 2025 - Building the Ecosystem for Alzheimer’s innovation” (Lausanne, Switzerland)</td>
<td>Jean</td>
</tr>
<tr>
<td>18 December</td>
<td>Joint Action on Dementia Programme Board (telcon)</td>
<td>Jean</td>
</tr>
</tbody>
</table>

### CONFERENCES

<table>
<thead>
<tr>
<th>Date</th>
<th>Meeting</th>
<th>Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-16 Feb 2018</td>
<td>8th International Conference on Pharmacoeconomics of Alzheimer’s Disease (IPECAD), <a href="http://www.ipecad.org/">www.ipecad.org/</a></td>
<td>Paris, France</td>
</tr>
<tr>
<td>1-3 March 2018</td>
<td>Nutrition and maintaining functions with aging (IANA 2018)</td>
<td>Miami, Florida, USA</td>
</tr>
<tr>
<td>15-18 March 2018</td>
<td>AAT-AD/PDTM Focus Meeting on Advances in Alzheimer’s and Parkinson’s Therapies</td>
<td>Torino, Italy</td>
</tr>
<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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