

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



I am delighted to announce three new Alzheimer Europe publications this month: Our 2019 Yearbook on the prevalence of dementia in Europe, which has been attracting quite a bit of media attention; our 2019 discussion paper looking at ethical challenges affecting the involvement of people with dementia in research; and our latest Dementia in Europe magazine, which covers a number of our own activities, as well as recent policy news relevant to people with dementia, both at European and national level. There is also a special section looking back at our 2019 conference in The Hague. All three of these publications are available via our website and you can find more information about each in the Alzheimer Europe section of this newsletter. The publications were officially launched at our European Parliament lunch debate, on the topic of "The Innovative Medicines Initiative (IMI): Advancing Alzheimer's research through private-public partnerships". The event was held in Brussels on 18 February and was hosted by Christophe Hansen, MEP. I would like to express Alzheimer Europe's gratitude to Mr Hansen, for hosting this event and for his interest in our work. He joined the European Alzheimer's Alliance of MEPs last year and is Vice-Chairperson of the group. On the topic of the Alliance, following the UK's departure from the EU at the end of January, a number of new MEPs have been re-allocated parliamentary seats. As a result

of this, three signatories from our #DementiaPledge2019 campaign have now taken their seats and have also joined the European Alzheimer's Alliance. It is a pleasure to welcome back previous member Deirdre Clune MEP (Ireland), and two new members; Barry Andrews MEP (Ireland) and Alviina Alametsä MEP (Finland).

We held a number of other meetings in Brussels, including a Board meeting, Company round-table, a meeting of the European Working Group of People with Dementia (EWGPWD), and a public affairs meeting with our members. These were all highly productive and positive meetings. It was a pleasure to attend them and to get vital input on our work, from policymakers and colleagues from across the European region, from our sponsors, our national member associations, and from members of the EWGPWD.

We received great news from Spain at the end of the month, where the Government has now officially launched its "Plan Integral de Alzheimer y otras Demencias". The plan has 20 objectives, under which more specific action points are outlined, to ensure the plan is rolled out.

In closing, I am pleased to announce that we have opened the call for abstracts and registrations for the 30th Alzheimer Europe Conference #30AEC. Make sure you submit your abstracts before the deadline of 15 May 2019. Please also take advantage of the Early Bird registration fees, which are available until 15 July!

Jean Georges
Executive Director

ALZHEIMER EUROPE

17 February: 32nd edition of Dementia in Europe magazine published

DEMENTIA IN EUROPE



Issue 32
February 2020



The 32nd edition of Dementia in Europe magazine, published on 17 February 2020, highlights some of our efforts to make dementia a European priority, including: our December 2019 lunch debate; Alzheimer Europe's 2019 Yearbook on dementia prevalence statistics for Europe, and our 2019 ethics report on promoting inclusive dementia research; and two significant research initiatives in which Alzheimer Europe is involved - the INTERDEM

network and the PARADIGM project.

The Policy Watch section opens with welcome news from the Czech Republic, which has finalised its new national dementia strategy. At the international level, we cover the recent meeting of the Government Expert Group on Dementia, which met for the 3rd time in December 2019, and the Scottish Government discusses the conclusion of the 2nd EU Joint Action on dementia. We also look at how dementia is being prioritised by the World Health Organization (WHO) and the World Dementia Council.

"Dementia in Society" includes interviews with Jeremy Hughes and Michel Goedert, both important figures in the dementia field, though working in very different roles. In a third interview, author Nicci Gerrard (aka French) provides a touching glimpse into the subject matter and her motivations for writing her book, "What Dementia Teaches Us About Love". We also take a closer look, together with three external experts, at results from Biogen's Phase III clinical trials of Aducanumab. Two members of the European Working Group of People with Dementia (EWGPWD) share their experiences in this section: Chairperson Helen Rochford-Brennan shares her thoughts on a human rights symposium and Stefan Eriksson and his family discuss how life has changed since his diagnosis of young-onset dementia. Finally, we look at how deaf people living with dementia can be better supported.

The final magazine section shines a spotlight on our 29th Alzheimer Europe Conference "Making valuable connections" (#29AEC) in The Hague, in October 2019.

You can buy the magazine via our E-shop: <http://alzheimer-europe.org/Publications/E-Shop>

Our magazines can also be downloaded here: <http://alzheimer-europe.org/Publications/Dementia-in-Europe-magazines>

17-18 February: Alzheimer Europe Board meets in Brussels

The Alzheimer Europe Board met in Brussels on 17-18 February 2020. The meeting agenda included various financial and operational matters, including preparations for the 30th Alzheimer Europe Conference, which will be held in Bucharest from 20 to 22 October 2020. The Board approved the 2019 Annual and Financial Report and also discussed the progress of the organisation's 2020 Work Plan. The next Board meeting will take place on 8-9 June in Brussels.

18 February: Alzheimer Europe holds lunch debate examining European research collaborations



Alzheimer Europe has co-hosted, with Neuronet, a lunch debate on 18 February 2020, focusing on research collaborations at a European level. The lunch debate, entitled "The Innovative Medicines Initiative (IMI): Advancing Alzheimer's research through private-public partnerships", was attended by 70 people including national member organisations, government experts on dementia, academics, industry representatives and policy makers.

Christophe Hansen MEP (EPP, Luxembourg), Vice-Chairperson of the European Alzheimer's Alliance (EAA), opened the session by noting that the lack of a disease modifying treatment meant dementia must be prioritised as a research topic, with significant investment coming from public-private partnerships over the past decade.

Carlos Diaz, Project Coordinator for the Neuronet project, outlined the work of the project in supporting the neurodegeneration portfolio of the IMI, as well as the opportunities to identify gaps and potential synergies between the different projects. He also explained how Neuronet would ensure that projects in the IMI portfolio did not work in isolation and the outputs from their work would be more visible.

Bart Vannieuwenhuyse, Co-Lead of the European Medical Information Framework (EMIF) project (2013 – 2017), provided a background to the project which established a foundational information framework supporting dementia research. The project operated as part of the first IMI and responded to a recognition that data was often held in silos, which was often detrimental to research into dementia.

Pierre Meulien, Executive Director of IMI, provided an overview of the public-private partnerships in relation to neurodegeneration research, as well as looking to future collaborations. It was explained that the IMI portfolio covered created conditions to allow for multi-sector and multi-disciplinary engagement at the forefront of research, providing the necessary scale for funding, expertise, knowledge, skills and resources.

Jean Georges, Executive Director of Alzheimer Europe, formally launched two new Alzheimer Europe publications. The first, the Dementia in Europe Yearbook 2019 focuses on the prevalence rates of dementia across Europe, whilst the second is an ethics discussion paper, focusing on the involvement of people with dementia in research.

Alzheimer Europe Vice-Chairperson, Charles Scerri, closed the session by thanking speakers and attendees for coming to the

debate. Christophe Hansen also thanked attendees from across sectors and disciplines for attending the meeting, highlighting the importance of collaboration between partners when conducting dementia research, with the political support for programmes such as Horizon Europe being crucial to continue this work.

Sponsor of the month

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2020 activities.

Read more about sponsorship opportunities here:

<http://bit.ly/sponsorAE>



Impressions from the lunch debate



Our lunch debate host, MEP Christophe Hansen, addresses delegates



Our first speaker, Carlos Diaz, presents the Neuronet project



Our second speaker, Bart Vannieuwenhuyse, discusses EMIF,



Our third speaker, Pierre Meulien discusses current and future priorities of the IMI



Jean Georges, Executive Director, Alzheimer Europe presents our 2019 publications



Charles Scerri, Vice-Chairperson, Alzheimer Europe makes some closing remarks



Nélida Aguiar and Stefan Erikssson pose with our new Dementia in Europe magazine



Lenny Shallcross, of the World Dementia Council, asks a question



Chris Roberts, Vice-chairperson of the EWGPWD, asks a question

18 February: Despite a marked reduction in the prevalence of dementia, the number of people with dementia is set to double by 2050 according to new Alzheimer Europe report



On 18 February, at a European Parliament lunch debate hosted by Christophe Hansen MEP (Luxembourg), Alzheimer Europe launched a new report presenting the findings of its collaborative analysis of recent prevalence studies and setting out updated prevalence rates for dementia in Europe.

The key findings of Alzheimer Europe’s report include:

- Across men and women and across most age groups, there has been a reduction in the prevalence of dementia over the past ten years when compared to 2008 estimates.
- The number of people living with dementia in the European Union (EU27) is estimated to be 7,853,705 and in European countries represented by AE members, 9,780,678. Compared to its earlier estimates, this constitutes a significant reduction from 8,785,645 for the EU27 and from 10,935,444 for the broader European region.
- Women continue to be disproportionately affected by dementia with 6,650,228 women and 3,130,449 men living with dementia in Europe.
- The numbers of people with dementia in Europe will almost double by 2050 increasing to 14,298,671 in the European Union and 18,846,286 in the wider European region.

Commenting on the findings, Alzheimer Europe Executive Director, Jean Georges, said “It is promising to see that healthier lifestyles, better education and improved control of cardiovascular risk factors seem to have contributed to a reduction of the prevalence of dementia. However, our report also demonstrates that the number of people living with the condition is set to increase substantially in the years ahead, which will only place greater pressure on care and support services unless better ways of treating and preventing dementia are identified. If people with dementia, their families and carers are to receive the high-quality and person-centred

care they need, governments must ensure their health and care systems are ready to meet this demand and greater investments in research into the treatment and prevention of dementia are needed.”

The 2019 Yearbook “Estimating the prevalence of dementia in Europe” received funding under an operating grant from the European Union’s Health Programme (2014-2020). The policy report was authored by Project Officer Christophe Bintener and Policy Officer Owen Miller.

It can be purchased via the Alzheimer Europe website: <https://www.alzheimer-europe.org/Publications/>

It can be downloaded, here: <http://bit.ly/AEYearbook2019>

18 February: Alzheimer Europe discussion paper highlights need for ethically sound involvement of a more diverse set of people with dementia in all aspects of research

On 18 February, Alzheimer Europe launched its new publication: “Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research.”

The ethics working group set out in 2019 to explore different ethical challenges affecting the involvement of people with dementia in research. Ethically sound involvement in research is about how people with dementia are treated but also about who sets the research agenda, who is involved, at what stage and in what capacity. People with dementia should be involved in research not only as participants but also in the context of Public Involvement. A comprehensive review of the literature and rigorous debate led to the publication of a discussion paper and recommendations which are targeted at researchers, members of ethics research committees and funders of research. Valuable input was also provided by the European Working Group of People with Dementia and several independent experts.

People with dementia form a diverse heterogeneous group made up of people with multiple/intersecting identities and characteristics. There are, for example, people with dementia from different ethnic groups, of different ages and gender identities, and with different disabilities, levels of education and socio-economic backgrounds. People from minority and marginalised groups continue to be underrepresented in research, resulting in their experience, perspectives and needs being ignored.

Multiple characteristics and factors need to be considered when trying to attract a diverse set of people to research. However, it is important to avoid locating ‘the problem’ in the individual, as this detracts attention from the way that structures, organisations, procedures and systems create problems and lead to discrimination and marginalisation. The tendency for researchers to consider some people with dementia as ‘hard to reach’ may result in them overlooking their own responsibilities with regard to the promotion of diversity and inclusive research. At the same time, the

requirements and methods needed for inclusive research must correspond to those required for good quality and hence ethical research. Failure to find the right balance would result in unsound research which needlessly exposes people to risk, inconvenience and burden.

It is hoped that this discussion paper will promote useful and constructive debate and encourage the ethically sound involvement of a more diverse set of people with dementia in all aspects of research.

Alzheimer Europe would like to thank the members of the ethics working group, namely Dianne Gove (Chair), Jean Georges, Mohammed Akhlak Rauf, Ann Claeys, Corinna Porteri, Ingrid Hellström, Jennifer van den Broeke, Karen Watchman, Karin Jongsmma, Krista Tromp and Saloua Berdai Chaouni.

The 2019 discussion paper received funding under an operating grant from the European Union’s Health Programme (2014-2020).

It can be purchased via the Alzheimer Europe website: <https://www.alzheimer-europe.org/Publications/>

It can be downloaded, here: <http://bit.ly/AE-EthicsReport2019>

18 February: Alzheimer Europe hosts Company Round Table meeting in Brussels



On 18 February, Alzheimer Europe hosted a Company Round Table meeting in Brussels. It was attended by representatives from Biogen, Lundbeck, Nutricia, Otsuka and Roche. Also in attendance, were: 4 members of the AE staff, including Executive Director Jean Georges; 20 representatives of AE member organisations; and 1 representative of the World Dementia Council (WDC).

Jean Georges updated sponsors and other delegates on a new Alzheimer Europe report on the prevalence of dementia in Europe, sharing some of the main findings (see article on the report for these). Project Officer Cindy Birck then gave an overview of recent developments in Alzheimer Europe’s Clinical Trials Watch. Policy Officer Owen Miller shared some recent policy development at WHO and EU level. He particularly focused on changes at the Parliament and Commission, and on the future research and health programmes of the EU. Finally, Jean Georges looked back at

some of Alzheimer Europe’s activities in 2019 and gave some insight into the organisation’s 2020 activities.

The meeting was chaired by Charles Scerri, Vice-Chairperson of Alzheimer Europe, who ensured there was time for questions and discussions after each presentation.

We would like to thank our sponsors for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting in Brussels, on 9 June.

18-20 February: Members of the EWGPWG meet in Brussels



The first meeting of the EWGPWD in 2020 was held in Brussels from 18-20 February. Members of the EWGPWD welcomed Nina Baláčková, who has been re-nominated by the Czech Alzheimer’s Society to join the group for the rest of its term of office (2018-2020). During the meeting, members provided feedback to AE’s ethics work for 2020, received an update on clinical trials in dementia in Europe (by AE Project Officer Cindy Birck) and started planning their contributions to the next AE conference in Romania and their annual work on dementia-inclusive meetings, transport and venues.

During the morning of the second and third day, members of the EWGPWD had the opportunity to discuss and provide feedback to the various tools and templates which the IMI PARADIGM project is currently developing. Giorgio Barbareschi, Programme Manager at the patient organisation European AIDS Treatment Group (EATG) - who is also part of PARADIGM - participated in the session dedicated to Community Advisory Boards.

Part of the meeting was also dedicated to the Patient Advisory Board of the IMI RADAR-AD project, for this session members welcomed two persons with Mild Cognitive Impairment who live in the Netherlands and their carers. As members of the PAB, they provided feedback to the Participants’ Manual for the RADAR-AD trials and were engaged in discussions on relevant ethical issues. Many of them, participated in one-to-one interviews about ethical issues in the project conducted by Federica Lucivero and Sebastien Libert (University of Oxford). Dianne Gove and Ana Diaz participated in the meeting.

19 February: Alzheimer Europe hosts Public Affairs meeting in Brussels



On 19 February, Alzheimer Europe hosted its first Public Affairs meeting of 2020, in Brussels. 20 representatives from member associations and 5 Alzheimer Europe staff members were in attendance and the meeting was led by Vice-Chairperson Charles Scerri (Malta).

The agenda focused on:

- The 2020 Dementia in Europe Yearbook: National training and education programmes for healthcare professionals in the field of dementia (presented by Policy Officer Owen Miller)
- Assessing the views of AE members on AE activities and preparing the next Alzheimer Europe strategy (2021-2025) (presented by Executive Director Jean Georges)
- Improving the lobbying and campaigning activities of Alzheimer Europe and its national member organisations (Owen Miller)
- Dementia as a European public health priority (Jean Georges)
- Representatives from each member organisation attending the meeting also had the opportunity to present their national campaigning activities and national education and training programmes for healthcare professionals on dementia.

The next Public Affairs meeting will take place in Brussels on 10 June 2020.



25 February: Call for abstracts and registrations open for 30th Alzheimer Europe Conference



Alzheimer Europe and Societatea Română Alzheimer are pleased to announce that registrations and the call for abstracts are both open for the 30th Alzheimer Europe Conference (#30AEC). The conference will take place in Bucharest, Romania from 20 to 22 October 2020.

Abstracts for oral and poster presentations in English are welcome in the following categories:

People: Carers of people with dementia; Minority ethnic groups; Dementia and sexuality; Involving people with dementia.

Care approaches: Post-diagnostic support; Psychosocial interventions; Assistive technologies; Palliative care.

Care services: Memory clinics and centres; Acute and hospital care; Day and respite care; Training of care professionals.

Medical and public health aspects: Diagnosis; Risk factors and prevention; Young onset dementia; Genetics.

Policy: Awareness campaigns; National dementia strategies; Supporting family carers; Legal and ethical issues.

Please read the abstract submission guidelines carefully before submitting an abstract. The submissions deadline is 15 May 2020: <https://www.alzheimer-europe.org/Conferences/Bucharest-2020/Call-for-Abstracts>

Registration is also open. Take advantage of the early bird registration fee (EUR 340 instead of EUR 475) until 15 July 2020. Conference registrations: <https://www.alzheimer-europe.org/Conferences/Bucharest-2020/Online-registration-form>

Alzheimer Europe networking

On 4 February (Barcelona, Spain), Jean attended the Change Management Team meeting for the EPAD project.

On 10 February (Brussels, Belgium), Dianne and Ana attended a WP4 PARADIGM meeting.

On 12 February (Luxembourg, Luxembourg), Jean attended the Ethics Committee of the Luxembourg Alzheimer’s Association.

On 17 and 18 February (Brussels, Belgium), the Alzheimer Europe Board met.

On 18 February (Brussels, Belgium), Chris attended a Neuronet consortium meeting.

On 18 February (Brussels, Belgium), Alzheimer Europe organised its European Parliament lunch debate “The Innovative Medicines Initiative: Advancing Alzheimer’s research through private-public partnerships”.

On 18 February (Brussels, Belgium), Alzheimer Europe organised a company round table meeting with its members and sponsors.

On 18 February (Brussels, Belgium), Biogen organised an information meeting with Alzheimer Europe members.

From 18-20 February (Brussels, Belgium), Dianne and Ana attended the meeting of the EWGPWD.

On 19 February (Brussels, Belgium), Alzheimer Europe organised a public affairs meeting with its members.

On 20 February (Amsterdam, Netherlands), Jean attended the investigators meeting of the EPAD project.

On 26 February (Diegem, Belgium), Angela attended a meeting of the Neuronet Working Group on data sharing.



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EU PROJECTS

20 January-3 February: Celebrating the Mind collaboration and its achievements

Living the Life



The MinD project (March 2016-February 2020) has been dedicated to research, innovation and staff development with the aim to develop innovative design solutions to support people with early to mid-stage dementia with social engagement and quality of life. This two-week research visit was the last of about 40 such collaborative

project visits for the MinD project “Designing for people with Dementia” over the last four years.

This last secondment, hosted by the psychiatric and geriatric clinic of the Alexianer Hospital Berlin, focussed on two important aspects of the project: Colleagues from Manchester Metropolitan University and University of Twente worked on finishing key documents for publication; and colleagues discussed opportunities for future collaboration in Berlin and at a short visit at the Technische Universität Dresden.

All in all, Mind developed four design solutions with and for people with dementia, to support a positive focus and quality of life after the diagnosis and to enable people living with dementia to maintain agency and to continue to be socially active and engaged. Key publications include MinD’s “Policy Recommendations”, the “Design Guidelines Report”, a “Mindful Co-design Toolkit” and a number of academic papers, which are or will all be available on the project website: www.designingfordementia.eu

The Policy Recommendations highlight the contribution that design can make to quality of life and the need to recognise and support this contribution. The Design Guidelines Report offers an overview of the context, frameworks and co-design values and methods that have guided the MinD team. The design toolkit offers hands-on advice for designers and others wishing to engage in the co-design process. The full project outcomes will be communicated through a number of

academic journal papers, which offer an overview of the research process, findings and design development and evaluations.

MinD has been a celebration of international, intercultural and interdisciplinary diversity, including 18 partners and 57 visiting researchers in the project consortium, who have joined together to work with and support people with dementia through mindfulness and design. While this is the end of the project, many strands of the MinD project will continue in diverse ways, such as through a two-year European Marie Curie Fellowship, which one of the MinD researchers will spend at Manchester Metropolitan University, to continue the work on designing with and for people with dementia for a better quality of life.

14 February: RADAR-AD’s two UK sites accepted to National Institute for Health Research portfolio

The RADAR-AD project is pleased to announce that both of its UK sites, King’s College London and the University of Oxford, have had their application to be added to the National Institute for Health Research (NIHR) portfolio accepted. This means that the NIHR’s Clinical Research Network will be lending their resources to RADAR-AD to help ensure the project’s success over the next two years.



Clinical Research Network

Read the full news story here: <http://bit.ly/2PDWV9J>

18 February: Neuronet holds Consortium meeting in Brussels

On 18 February, the Efficiently Networking European Neurodegeneration Research



(Neuronet) Coordination and Support Action held its third Consortium meeting in Brussels (Belgium).

The afternoon kicked off with an overview of action items from the previous [Scientific Coordination Board](#) meeting that was held at the end of January.

Amongst others, consortium members discussed the prototype of an asset map that has been developed based on interviews with project leaders. The asset map aims to provide an adaptive high-level overview of the main assets that have been produced by the projects so far. It was discussed that the aim will be to make it as visible as possible, adding it both to

the website as well as on a closed online platform (the Neuronet Knowledge Base).

In this context, the communication team will prepare an outreach plan. It is envisaged that the asset map will be shared through Neuronet communication channels and by communication departments of Neuronet partners.

Following on, the Neuronet consortium discussed its, soon to be launched, online Forum. The Forum aims to promote dialogue and participation across projects on different topics and project collaborators from the whole portfolio will be invited within the coming weeks.

Nina Coll from Synapse then presented an overview of potential further synergies that could be supported between the individual projects as well as [public materials](#) some of the projects developed. It was suggested to make some of these available on the Neuronet website.

The consortium members then discussed the upcoming review by the Innovative Medicines Initiative.

After that, the Project Leader Lennert Steukers (Janssen) and Project Coordinator Carlos Diaz (Synapse) wrapped up the meeting with a recapitulation of the main conclusions as well as the next steps.

24 February: RADAR-AD members hold ethics interviews with patients and carers from Patient Advisory Board



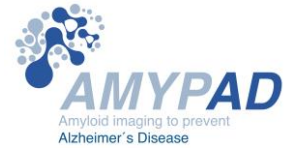
“It is crucial for us to analyse at an early stage what emerging ethical and social concerns raise from RADAR-AD research and address them throughout the project”, says Dr Federica Lucivero, on behalf of the RADAR-AD project consortium.

Federica Lucivero and Sébastien Libert from University of Oxford have been conducting interviews on ethical and social perspectives towards the research done in RADAR-AD. So far they have interviewed 11 people from the Patient Advisory Board (PAB) for RADAR-AD that includes patients and their carers. Through their interviews, Federica Lucivero and Sébastien Libert seek to explore the ethical and social issues emerging from the use and research of Remote Measuring Technologies (RMTs) for Alzheimer’s disease.

The interviews took place on 18-20 February in Brussels, in the context of the parallel meetings of RADAR-AD’s PAB and the European Working Group of People with Dementia (EWGPWD). Patients and carers were asked about their motivations, hopes and concerns in relation to the research done in RADAR-AD. They shared their opinions on privacy issues when it comes to obtaining data through tracking devices. They expressed ideas on how to best accommodate their needs and resolve their problems with tracking, thereby addressing critical issues within the RADAR-AD study.

Read the full news story here: <http://bit.ly/392q2ul>

24 February: AMYPAD Prognostic and Natural History Study reaches milestone of 500 research participants



The members of the Amyloid Imaging to Prevent Alzheimer’s Disease (AMYPAD) initiative reached a significant milestone this month with the enrolment of the 500th research participant in its Prognostic and Natural History Study (PNHS).

In this clinical study, the aim of the researchers is to understand the role of amyloid imaging in the earliest stages of Alzheimer’s disease, in order to increase the chances of successful secondary prevention trials. The study recruits individuals suspected of possible Alzheimer’s disease from various ongoing European parent cohorts.

According to Dr José Luis Molinuevo, the Director of the Alzheimer’s Prevention Program of the BarcelonaBeta Brain Research Center (BBRC), “Having reached 500 research participants in the AMYPAD Prognostic Natural History Study is without doubt a major milestone. This represents one of the biggest European cohorts to study the role of amyloid PET imaging in the earliest stages of Alzheimer’s disease”.

Recruitment started in late 2018 and is expected to continue until late 2021. 503 participants have been enrolled so far in 7 European countries (Belgium, France, Netherlands, Spain, Sweden, Switzerland and UK), of which 372 have been scanned. The PNHS will recruit up to 2,000 participants and follow half of them longitudinally within the next 2 years. This study was designed to evaluate the additional value of quantitative amyloid imaging in determining Alzheimer’s disease dementia risk based on quantitative PET amyloid imaging measures, with or without other biomarkers.

24 February: AMYPAD reports on recent progress and activities



In its February newsletter, the Amyloid imaging to prevent Alzheimer’s disease (AMYPAD) project reported the important advances that have been made during the past year.

In 2019, the Diagnostic and Patient Management Study (DPMS) reached its initial target by activating all eight sites. In addition to UNIGE (Geneva), VUmc (Amsterdam) and CHUT (Toulouse), there were another five sites coming on board last year. These new sites include BBRC (Barcelona), UCL (London), UKK (Cologne), KI (Stockholm) and CHUV (Lausanne). The 50% enrolment milestone was reached in August 2019 and the last quarter showed a dramatic increase in the recruitment rate, reflecting the impact of the addition of the remaining sites. With 636 patients recruited at the end of 2019 and 429 scans performed, DPMS is on track to finish enrolments by June 2020. In parallel to the recruitment process, the data

management task (data cleaning and queries) is being led by a team at UNIGE, and the first analysis will be performed by the dedicated team.

In 2019, the Prognostic and Natural History Study (PNHS) went from having one active site (VUmc, Amsterdam) to having ten active sites. These sites are: UEDIN (Edinburgh), BBRC (Barcelona), CHUT (Toulouse), UNIGE (Geneva), CHU Montpellier, NHS Tayside, Hôpital Pitié-Salpêtrière (Paris), UZ Leuven and Hôpital Lariboisière (Paris). By the end of 2019, 369 participants had been recruited, from which 295 have been scanned. Additional sites were also approached last year to come on board to strengthen the study.

In early 2020, KI (Stockholm), CHU Nantes, CITA (San Sebastian), Fundacio ACE (Barcelona), CHU Lille, UGOT

(Gothenburg) and UC Louvain had their Site Initiation Visit becoming fully active in AMYPAD PNHS, completing the number of sites, as of today, to a total of 17. The AMYPAD PNHS is now active in seven European countries.

The last year has been really exciting for the AMYPAD project with the activation of new sites and the increased recruitment rate. The two next years will bring new challenges but the team is confident that its recruitment target will be reached within targeted timelines.

http://bit.ly/AMYPAD_newsletter_Feb2020



EU project acknowledgement



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter are:

AMYPAD- grant agreement 115568

RADAR-AD - grant agreement 806999

Neuronet - grant agreement 821513

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **94**, representing **26** 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 (EAA):

Austria: Monika Vana (Greens/EFA). **Belgium:** Petra de Sutter (Greens/EFA); Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D). **Czech Republic:** Tomáš Zdechovský (EPP). **Denmark:** Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (Renew Europe); **Finland:** Alviina Alamestä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany:** Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece:** Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE-NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciàran Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); Isabel Wiseler-Lima (EPP). **Malta:** Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland:** Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal:** Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Clàudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estaräs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).

EUROPEAN ALZHEIMER'S ALLIANCE

1 February: European Alzheimer Alliance welcomes new members



Following the UK's departure from the EU, a number of new MEPs have taken their seats, following the re-allocation of 27 of the UK's seats. Alzheimer Europe is delighted to announce that three of these members signed up the Dementia Pledge during the campaign in the run up to the European election in May 2019.

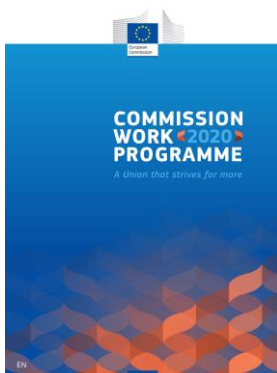
Alzheimer Europe is pleased to welcome back Deirdre Clune (EPP, Ireland) to the European Alzheimer's Alliance (EAA), who had previously been an active member prior to the 2019 election. Ms Clune is also joined by Barry Andrews (Renew Europe, Ireland) and Alviina Alametsä (Greens-EFA, Finland) who also have joined the EAA.

Alzheimer Europe looks forward to working with them to help ensure that dementia remains a European priority!



EU DEVELOPMENTS

1 February: European Commission sets out Work Programme for 2020



The European Commission has published its Work Programme for 2020, setting out the key policy developments for the year ahead. The programme contains:

- 43 new policy objectives
- 126 ongoing files
- 44 initiatives for regulatory simplification.

The policy programme is centred around the [priorities previously outlined](#) by Commission President Ursula von der Leyen and addresses topics including green energy, digital, research and the Multi-annual Financial Framework (MFF). Of relevance for dementia policy:

- A report on the Impact of Demographic Change
- A Green Paper on Ageing
- Communications on European Research Area and Horizon Europe
- Report on the application of the General Data Protection Regulation (GDPR)
- Alignment of relevant Union law enforcement rules with regard to data protection.

The full Work Programme 2020 of the Commission can be found at:

https://ec.europa.eu/commission/presscorner/detail/en/ip_20_124

1 February: State of play following UK exit from the EU

Following the departure of the United Kingdom from the European Union as of 1 February 2020, Alzheimer Europe has set out below a brief overview of the impact of this change on a number of policy areas at a European level and what it means for the European dementia movement.

What has changed

- The UK no longer has representation in any EU institutions or agencies. This includes, European Commission, the European Council, the European Parliament, the European Medicine's Agency, the European Economic and Social Committee (amongst others).
- The number of MEPs has been reduced to 705 (from 751) – 27 of the UK's 73 seats were reallocated to other Member States.
- As a result of there being no UK MEPS, the UK is no longer represented in the European Alzheimer's Alliance (EAA) – though the EAA gained some new members through the redistributed seats.

What has stayed the same

- The membership of Alzheimer Europe and the European Working Group of People with Dementia (EWGPWD) is unaffected by any of these changes – we will continue to work with our UK colleagues as before.
- As the "transition period" has come into effect (concluding at the end of 2020), current EU legislation will continue to apply to the EU (meaning no changes to travel etc.).
- Any UK involvement in current EU-funded research and/or projects will continue until the conclusion of the projects.
- The UK will, during the transition period, accept authorisation decisions of the EMA with regards to medicines.

What is not yet clear

- The UK's future involvement with EU programmes such as the EU Health Programme (which funded the Joint Actions on Dementia) or the Horizon Europe research programme has not been decided.

- Cooperation in areas related to data sharing are unclear and will be subject to an adequacy decision of the EU.

18 February: “Brain health as a global priority – time for the EU to act now” event hosted by EFNA, EBC and EAN at European Parliament



The European Academy of Neurology (EAN), with the coordination of the European Federation of Neurological Associations (EFNA) and the European Brain Council (EBC), participated in an event in the European Parliament which aimed to raise awareness about brain and neurological diseases. EAN was represented by its President, Professor Claudio Bassetti, and past-President Professor Guenther Deuschl who both presented the extensive work EAN is doing, tackling the burden of disease as well as the education and training of workforce in the field of neurology. Joke Jaarsma, President of EFNA represented the European patient associations in neurology and Fred Destrebecq, CEO of EBC, chaired the meeting.

The event was hosted by Jaroslaw Duda MEP (Poland, EPP), while several other MEPs were present and supported the cause, including Ewa Kopacz MEP (Vice-President of the European Parliament, EPP), Miriam Dalli MEP (Vice-Chair of the S&D political group in the European Parliament), Katerina Konecna MEP (GUE/NGL) and Tilly Metz MEP (Greens). Speakers and participants included the WHO, the European Commission, representatives of Member States and other relevant stakeholders representing patient and professional organisations.

Some of the focal points of the event were:

- The WHO’s work on its Neurology Atlas, Global Dementia Action Plan and reducing the epilepsy treatment gap were highlighted. The main challenge identified was the transposition of this progress into policy actions at Member State and EU levels.
- Professor Bassetti of EAN, called for joint forces on all levels and for an EU initiative for brain health awareness.
- Speakers also called for more EU coordination on science and research on brain diseases and access to health services. The European “Beating cancer plan”

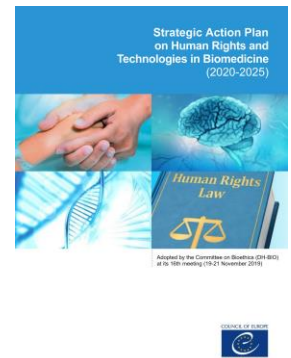
outlined by the European Commission was put forward as an example and blueprint for future action on neurological diseases.

- The significant gap in brain health investment and a mismatch of funding for different categories of diseases.
- The European Commission, DG Sante, reiterated its commitment to the UN’s sustainable development goals and its close work with the European Member States.
- DG Research reminded delegates that Horizon 2020 is still running, and that an ambitious plan for brain research could potentially be developed by 2023-24.
- Overall, it was agreed that neurological diseases should be an EU priority as well as at national level; there is need for more visibility and general understanding, as well as more patient involvement, which is crucial to identify unmet needs and fight stigma.

24 February: Council of Europe adopts five year action plan on biomedicine

The Committee of Ministers of the Council of Europe has adopted a new five-year strategic action plan, presented by the Committee on Bioethics, on human rights and technologies in biomedicine.

The action plan, “Protecting human rights in biomedicine: A new Human Rights and Technologies Action Plan (2020-2025)”, is designed to protect human dignity, human rights and individual freedoms with regard to the application of biology and medicine.



It is divided into three main strands:

- Governance of technology - to embed human rights in the development of technologies which have an application in biomedicine.
- Equity in health care - to promote equitable access to innovative treatments and appropriate technologies, including a guide to health literacy for older persons.
- Specific measures in relation to physical and mental integrity.

On the third strand, there is a proposal for a legal instrument to protect the human rights and dignity of persons with mental disorders with regard to involuntary placement and/or involuntary treatment, alongside a compendium of good practice.

You can read the new strategic plan here:

<https://rm.coe.int/strategic-action-plan-final-e/16809c3af1>

25 February: Commission publishes AI White Paper and Data Strategy



The European Commission has published two new documents looking at the future of Artificial Intelligence and data in the European Union.

The White Paper on Artificial Intelligence (AI) aims to support its development and uptake in the EU, as well as ensuring that European values are respected. It identifies key opportunities and challenges, analyses regulatory options and puts forward proposals and policy actions related to ethics, transparency, safety and liability etc. Key proposals within the paper include:

- Development of rules for high-risk AI systems for healthcare, transport etc., requiring systems to be “transparent, traceable and guarantee human oversight.”
- A requirement for unbiased data to be used to train high-risk systems so that they “perform properly, and to ensure respect of fundamental rights, in particular non-discrimination.”
- Establishment of consumer protection rules so authorities can “test and certify” data used by algorithms (as exists for other products).
- Proposals for the creation of an EU governance structure to ensure compliance with the rules and avoid fragmentation across Europe.

The purpose of the Data Strategy is to explore how to make the most of non-personal data as an expanding and re-usable asset in the digital economy, building on the non-personal data regulation. Key topics within the strategy include:

- A regulatory framework incentivising data sharing, including issues of governance, access and data (between businesses, between businesses and government, and within administrations)
- Working towards making public sector data more widely available by opening up “high-value datasets” to enable their reuse to foster innovation
- Support for cloud infrastructure platforms and systems to support data reuse goals – with the Commission looking to contribute to projects on European data spaces
- Sector-specific actions to build European data spaces that focus on specific areas e.g. healthcare, transport, etc.

You can read the White Paper on AI here:

https://ec.europa.eu/info/sites/info/files/commission-white-paper-artificial-intelligence-feb2020_en.pdf

You can read the Data Strategy here:

https://ec.europa.eu/info/sites/info/files/communication-european-strategy-data-19feb2020_en.pdf



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MEMBERS' NEWS

1 February: Alzheimer's Society launches Dementia Friends collaboration with UK Girlguiding movement

Alzheimer's Society has teamed up with Girlguiding in the latest initiative to help create a dementia-friendly generation.

Leaders from Girlguiding groups, which include Rainbows, Brownies, Guides and Rangers now have access to bespoke activity packs that

raise awareness about dementia, create Dementia Friends and inspire girls and young women to take action within their communities.

Becoming a Dementia Friend involves finding out more about how dementia affects a person and then, armed with this understanding, taking action to support someone affected by the condition. For example, being patient in a shop queue or spending time with someone you know who's living with dementia.

In the UK, it is estimated that nearly one third of young people know someone who is affected by dementia. “As the number of people living with dementia increases, more and more young people are likely to be affected, therefore it is vital that we continue to raise awareness among younger generations. Our packs are designed to be fun, informative and inspiring so young people are empowered to take action” said Sophie Woods, Senior Youth Engagement Officer at the Society.

Alzheimer's Society's partnership with the Scouts contributed 23,000 Dementia Friends to the total of over 300,000 young Dementia Friends (aged 5 – 25) already in the UK. The Society is looking forward to seeing where this new exciting collaboration with Girlguiding will take them, and the actions that Girlguiding groups will carry out to help fight the fight against dementia!

To find out more about Alzheimer's Society resources for Girlguiding groups visit:

www.alzheimers.org.uk/get-involved/dementia-friendly-communities/dementia-teaching-resources/youth-groups

12 February: Alzheimer's Society calls for maximising the impact of UK dementia research at the first Dementia Research Care Summit

The current UK Government has pledged to double dementia research funding to over GBP 160 million (EUR 187.7 million) a year by 2030, through the delivery of a “Dementia Moonshot”. This month, Alzheimer's Society has set out to drive



forward the vision of what this funding could achieve for people affected by dementia.

Dementia is one of the greatest health challenges facing society, both in the UK and around the world. By 2040, it is estimated dementia will cost the UK economy GBP 94.1 billion (EUR 110.4 billion).

Since 2013, the UK Government has increased research investment, including the establishment of a national Dementia Research Institute in partnership with Alzheimer’s Society and Alzheimer’s Research UK. The last decade of investment in dementia research has built a foundation that is primed for accelerating progress in understanding dementia.

A Dementia Moonshot must prioritise research to establish how to support people with dementia and those who care for them to live better with the condition. It must also take steps towards developing new treatments and ultimately a cure.

Alzheimer’s Society is calling for a broad focus which must explore the causes of the disease; clinical and drug discovery research providing hope of a cure for the future; and social care, technological innovation and public health research to address the care needs of today.

Alzheimer’s Society is working collaboratively across the sector to ensure these plans are expert led, and, on 12 February, the Society supported the first Dementia Care Research Summit bringing together almost 100 top researchers, clinicians and experts in dementia care to set forward the blueprint for dementia care research.

Alzheimer’s Society has established five priorities where the Government’s Dementia Moonshot investment can make the biggest difference for people affected by dementia, now and in the future:

1. A national network of excellence in dementia care research
2. Transforming care through technology for people with dementia, including a potential “Dementia Technology Challenge Prize”
3. Public health and prevention research
4. Finding a cure (including additional funding for the UK Dementia Research Institute)
5. Training the dementia researchers of the future.

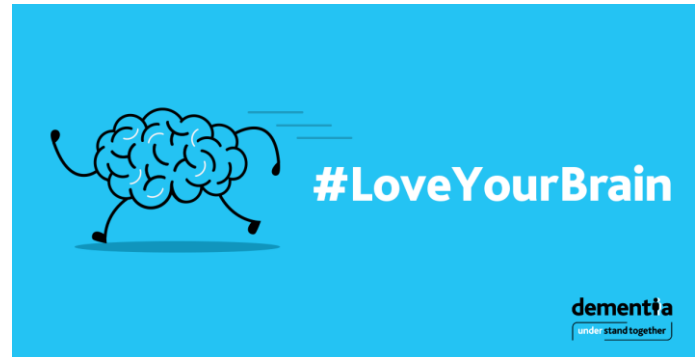
These ambitious plans address the prevention, diagnosis, treatment and care of dementia and have the potential to impact the disease at all stages.

Fiona Carragher, Chief Policy and Research Officer at Alzheimer’s Society, said: “It is crucial that the government not only works on developing effective treatments and finding a cure, but, also, ensuring the funding is there to continue to explore ways we can help individuals with dementia live well.”

For more information, visit:

www.alzheimers.org.uk/news/2020-02-12/5-priorities-government-dementia-moonshot

18 February: The Alzheimer Society of Ireland and partners launch National Brain Awareness Week in Ireland



Brain Awareness Week is the global campaign to foster public enthusiasm and support for brain science. Every March, partners host imaginative activities in their communities that share information and the everyday impact of brain science. This year, it takes place from 16-22 March.

In Ireland, National Brain Awareness Week, co-ordinated by the Neurological Alliance of Ireland, sees a range of information events taking place countrywide. Ahead of the Week the Health Service Executive, National Dementia Office, The Alzheimer Society of Ireland (ASI) and other partners will highlight the growing evidence from the World Health Organization (WHO) that leading a healthy, active lifestyle may help maintain brain health and reduce the risk of developing dementia. It can also help those with dementia to live better with the condition.

It is clear that some risk factors for dementia, such as age or genetics, cannot be controlled. However, scientific research has shown that there are ways to help reduce the risk of developing dementia, one of which is to stay physically active.

ASI encourages every adult to include a minimum recommended level of physical activity, such as brisk walking, in their week.

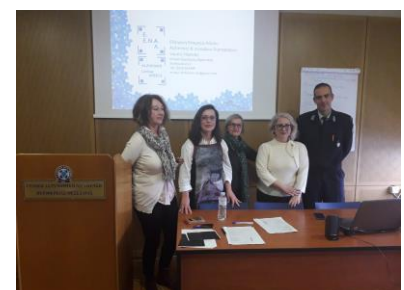
Get involved and share this message using the hashtag #LoveYourBrain2020

For more information on the things we can all do to keep our brains healthy: <https://www.understandtogether.ie/about-dementia/what-is-dementia/am-i-at-risk/>

19 February: Alzheimer Larissa recently organised dementia training in Police Headquarters

19 February: Alzheimer Larissa recently organised dementia training in Police Headquarters

Alzheimer Larissa Greece (EENAA) continues its work to raise awareness



on dementia issues while also encouraging community

development, where people with dementia live well and feel secure. As part of this work, the association has now included the police force in dementia sensitivity training.

The General Regional Police Authority of Thessaly agreed on a series of educational seminars. Three separate groups, 96 officers in total, participated in the introductory 4-hour training in Larissa Police Headquarters during November and December 2019. The training programme was carried out by a number of instructors: Georgia Xiromerisiou, Assistant Professor of Neurology from the University of Thessaly; Artemissia-Phoebe Nifli, Neuroscientist and Scientific Advisor of EENAA; Kyriaki Giota, Psychologist and volunteer; Ioannis Pagitsas, Neurologist and Vice President of EENAA; and Eleni Kamboura-Nifli, President of EENAA.

Each instructor presented different aspects of dementia, and applied a unique approach. In order to actively engage those attending, seminars began with an interactive module. The clear message was that dementia does not only affect memory, but also a variety of cognitive functions. Specific topics were discussed, such as behavioural and psychological symptoms, knowledge on dementia, social stigma, and the rights of people with dementia. By examining real cases of the people “wandering”, it was concluded that officials and relatives should perform a thorough work when creating a personal profile or when completing a missing person form, and these efforts would ensure a rapid and safe recovery. It was acknowledged that dementia is not simply part of normal ageing. It was also explained that focusing on one’s history, abilities and preferences, rather than keeping the focus on memory loss, is essential for people with dementia in order to achieve a good quality of life.

Police officers found the seminar very beneficial in increasing their understanding of how to interact with people with dementia and to better support them as members of the community. The General Regional Police Authority of Thessaly now wants to extend the training, together with EENAA, to the three other prefectures (Karditsa, Trikala and Magnesia).

19 February: The Alzheimer Society of Ireland asks the new Irish Government to deliver on dementia



Ireland recently held a General Election where the country voted to elect its next government. The Alzheimer Society of Ireland (ASI) election campaign “Deliver on Dementia – Time to End the Crisis” aimed to ensure that dementia is included in the new Programme for Government, so people with

dementia and their families can get the support that they need.

Over 500 candidates were asked to pledge to “Deliver on Dementia” in the next Programme for Government, to ensure: The National Dementia Strategy is fully implemented

Home care for everybody

Dementia is in the Chronic Disease Management Programme.

ASI used its extensive grassroots network to distribute 3,000 voter prompt cards to staff, clients, families, volunteers and advocates across the organisation. Voters were asked to use these prompt cards when they met an election candidate, to help explain the challenges of dementia. The campaign aimed to get as many people as possible to highlight the crisis in dementia care.

ASI also issued 27 press releases, incorporating national and local statistics and details of candidates in every constituency, to every press and media outlet in the country.

Through social media, ASI highlighted real-life case studies of families in crisis and used its network of volunteer advocates to develop video soundbites. In total, over 5,000 e-mails were sent to candidates. With the engagement of ASI’s grassroots network, over 190 candidates pledged their support, and of those, 91 were elected. This means that almost 60% of the new TDs (government ministers) in the Dáil have pledged to “Deliver on Dementia”. Dementia was specifically highlighted in six of the seven political parties’ Manifestos. The full impact of the ASI campaign will probably only become clear once the new government is formed and operational, but ASI is proud of the results of the campaign and is determined to ensure the crisis in dementia care is addressed

19 February: Panhellenic Federation of Alzheimer’s Disease and Related Disorders takes intergenerational approach with “Bridge” project

Continuing on from the launch last summer of the Erasmus+KA2 “BRIDGE” project, the development of prototype games for young people and people with dementia, aims to bridge the generation gap.



People with dementia are often excluded from intergenerational social activities due to stigma. The generation gap is constantly widening and young people seem to be losing interest in participating in volunteer work with older people. This three-year pan-European initiative aims to develop a set of prototype Serious Games (SGs) which act on cognitive and behavioural symptoms of dementia, involving both younger and older people.

A number of workshops have already been run in Greece, Italy and Romania. 8 prototype games were created by the participants and have now been further developed by the consortium. Four games are digital and four games are physical. A second round of workshops will be organised in each country in order to examine these results and test the effectiveness of the games.

The end result will be a Bridge web-platform, containing MOOCs (Massive Open Online Courses) on the methodology of the game-creation workshops and the final eight selected prototype games: <https://projectbridge.eu/>

24 February: Digital Art Therapies being developed to benefit those with dementia, reports Turkish Alzheimer’s Association



Art therapy has already been shown to be an effective tool for the benefit of those with Alzheimer’s disease dementia. More than just a way of keeping people busy, art therapy stimulates the brain, stirring up old memories and giving those who struggle to speak, a way of communicating. Art therapy partially gives back that which the disease itself has taken away. It stimulates the senses, triggers some dormant memories and encourages conversation.

Art can be used as a form of expression, whether looking at art or creating it, especially for those who cannot communicate verbally. People with dementia may not necessarily recover lost words through art therapy, but they can explore a whole new vocabulary. Some caregivers turn to the arts, such as painting, music or dance, to build a new form of communication. Rather than relying on language as the method of communication, using art as the medium activates a different part of the brain. This change of interaction lessens frustration and offers those with dementia another chance to connect socially, thereby also lowering the sense of isolation that is often experienced.

The Turkish Alzheimer Association has joined other partners in a two--year Erasmus+ project designed to develop a training programme to improve quality of life for those with Alzheimer’s disease and other dementias, through innovative, creative art therapies supported by digital tools.

Although the creative use of art is widely used for therapeutic purposes, digital creative art therapies (CATs) are relatively new. Also, despite the accessibility of CATs and supporting digital tools, practical implementation levels are low and as

such their high potential for improving the quality of life for those with dementia is underexploited.

AD-ARTS is launched with the main objective of increasing the competences (attitudes, knowledge, skills) of people with dementia (mild and moderate), relatives and professionals on the implementation of CATs supported by digital tools for improving quality of life. Partners include Asociacion Familiares Enfermos Alzheimer Valencia, Spominčica Alzheimer Slovenija, Aristotelio Panepistimio Thessaloniki, Univesitat Politecnica de Valencia, Il Cerchio Società Cooperative Sociale Consort Italy.



POLICY WATCH

5 February: Alzheimer Slovenia is working with MEPs and national policymakers to ensure dementia is a priority

In the latter part of 2019 in Ljubljana, Slovenia, the National Institute of Public Health (NIJZ), the Research Centre of the Slovenian Academy of Sciences and Arts (ZRC SAZU) and non-governmental organisation



Spominčica-Alzheimer Slovenia co-organised an event entitled “Status and challenges of Alzheimer’s disease in Slovenia”. The main objectives of this meeting were: destigmatising dementia; raising awareness; improving timely diagnosis and treatment of the disease; and, additionally, encouraging networking among various departments, stakeholders, experts and non-governmental organisations in Slovenia. Some of the high-profile participants at the event were representatives of the Ministry for Social Affairs and of the Ministry for Health, as well as noted Slovenian professionals in the dementia field. The meeting also included discussion with Slovenian MEPs Romana Tomc, Milan Brglez and Klemen Grošelj, all of whom are members of the European Alzheimer’s Alliance. They each presented their views and lent their support to activities aiming to reduce stigma and to provide better care for people with dementia and their families.

Challenges regarding epidemiological monitoring of dementia were also presented at the 2019 event, emphasising the importance of early recognition of the disease and early treatment of dementia, which can potentially slow down its progression. There was also an interactive discourse about the availability of medical and social care in Slovenia.

Spominčica-Alzheimer Slovenia is pleased to continue to have close links with Slovenia's European and national policymakers, who are instrumental in ensuring positive change for people with dementia, in Slovenia and beyond. The organisation is also pleased to report that, in the future, the National Institute of Public Health (NIJZ) intends to focus more on dementia, since it is being recognised more and more as a priority area of public health.

7 February: Bulgarian Ombudsman joins ranks of Dementia Friends and calls for a national dementia strategy



On 7 February, Bulgarian Ombudsman Diana Kovacheva became Alzheimer Bulgaria's 441st Dementia Friend. She also made a call to the country's Ministry of Health and Ministry of Labour and Social Policy, to prepare a national dementia plan, to help support prevention, early diagnosis and care of people with dementia. The call was made official in the Obudsman's Annual Report 2020, on 11 February.

10 February: Gibraltar Alzheimer's & Dementia Society calls for long-term dementia plan

The Chair of the Gibraltar Alzheimer's & Dementia Society (GADS), Daphne Alcantara has spoken to local newspaper, the Gibraltar Chronicle, about the need for a long-term dementia plan. The resulting article was published in the print newspaper on 10 February 2020, as well as online.

A national dementia strategy was launched by the Gibraltar Health Authority five years ago. It was updated in September 2019 and extended to the end of 2020. In her interview with the Gibraltar Chronicle, however, Ms Alcantara stressed that, while the strategy exists, it is not fully implemented. She particularly highlighted the lack of a promised National Dementia Committee for Gibraltar. She also highlighted the needs for a longer-term strategy and for the current strategy to be made available online.

<https://www.chronicle.gi/gads-call-for-long-term-dementia-plan-as-number-of-cases-rise-worldwide/>

26 February: WHO calls for submissions for GDO knowledge exchange platform



The World Health Organization (WHO) is requesting submissions for the Knowledge Exchange Platform of the Global Dementia Observatory (GDO), an online database which includes country-level information on policy, service delivery, population needs and research related to dementia.

Alzheimer Europe and its member associations play an important role in creating the GDO as a vibrant platform for up-to-date information relevant to all countries.

The GDO Knowledge Exchange Platform contains key resources to support the implementation of the WHO's Global Dementia Action Plan, as well as enhancing country-level responses to dementia. By providing a space for all relevant stakeholders to share resources, whether through good policy, clinical guidelines, or examples of effective interventions, the platform aims to facilitate mutual learning and the exchanging of good practices in the area of dementia.

The WHO is calling for submissions of resources for the GDO. Resources can be from a broad spectrum, ranging from national plans and laws, to local initiatives that work well in communities. All resources will undergo a peer-review process and will be mapped to the strategic action areas of the Global Dementia Action Plan. The WHO is looking for a wide range of geographical, linguistic, cultural, and contextual diversity, and strongly encourages all who are interested to submit resources!

The new GDO Knowledge Exchange Platform will go live in 2020. To submit resources please follow this link:

<https://extranet.who.int/dataform/895286?lang=en>

Learn more about the Global Dementia Observatory here:

https://www.who.int/mental_health/neurology/dementia/Global_Observatory/en/

Pictured: A design mock-up of the platform

27 February: Spanish Government publishes Alzheimer's action plan

The Spanish Government has published its "Plan Integral de Alzheimer y otras Demencias" (Comprehensive Alzheimer's and other dementia Plan), setting out how



it plans to improve the lives of people living with dementia in the country.

The plan has four axes along which the actions of the plan are based:

Sensitisation, awareness and transformation of the environment

The person at the centre of social and health care: prevention, diagnosis and treatment

Rights, ethics and dignity of the person

Research, innovation and knowledge.

There are 20 “objectives” spread across the four axes, under which more specific action points are outlined, detailing how the objective is to be achieved.

The full strategy (in Spanish) can be accessed here:

https://www.mscbs.gob.es/profesionales/saludPublica/docs/Plan_Integral_Alzheimer_Octubre_2019.pdf



SCIENCE WATCH

27 January: Corium announces FDA filing acceptance for Adlarity for the treatment of AD

On 27 January, Corium, a biopharmaceutical company focused on the development, manufacture and commercialisation of specialty transdermal products, announced that the Food and Drug Administration (FDA) has accepted for filing the new drug application for its investigational donepezil transdermal system Adlarity for the treatment of Alzheimer’s disease (AD).

Adlarity has been designed as a donepezil transdermal patch that would be applied to the skin once weekly. Donepezil is the most commonly prescribed medication to treat the symptoms caused by AD. Currently, donepezil is only available in tablets administered once daily and the most common side effects are gastrointestinal. By delivering donepezil through the skin, the company reported that Adlarity has the potential to reduce gastrointestinal side effects. The FDA’s decision is expected by 30 July.

<http://bit.ly/39jm3ud>

28 January: Alector announces the recruitment of the first participants with mild to moderate AD in Phase Ib trial of AL003



On 28 January, Alector, a biotechnology company developing immunoneurology therapies for the treatment of neurodegenerative diseases, announced the dosing of the first participants with Alzheimer’s disease (AD) in its Phase Ib trial of AL003.

“We have developed AL003 to block the

inhibitory function of SIGLEC 3, an immune receptor linked to Alzheimer’s disease. AL003 is intended to allow the brain’s immune system to simultaneously address multiple parallel pathologies involved in the progression of Alzheimer’s disease,” said Arnon Rosenthal, Chief Executive Officer of Alector.

The Phase Ib trial named INTERCEPT is a multi-centre, randomised, double-blind and placebo-controlled study evaluating the safety and tolerability of AL003. Approximately 12 research participants with mild to moderate AD will be enrolled to receive multiple-doses of AL003 by intravenous infusion. The company reported that tolerable doses were found in healthy research participants.

<http://bit.ly/2PxEinP>

29 January: Researchers investigate the possible relationship between flavonols and risk of Alzheimer’s dementia

On 29 January, scientists from the United States published an article on the possible relationship between the regular intake of dietary flavonols and the potential subsequent lowered risk of developing Alzheimer’s dementia in the Journal Neurology.

In order to help shed light into the unclear relationship between dietary flavonols intake and later development of Alzheimer’s dementia, the scientists enrolled participants in a large-scale trial.

The scientists recruited over 900 participants through an ongoing community-based cohort to conduct their study. These completed annual neurologic evaluations and participated in dietary assessments using a questionnaire about what they ate.

The team then contrasted participants who reported a high intake of foods that contain flavonols versus those who reported low intake regarding their neurological evaluations but also factors such as education.

After adjusting for other influencing factors (such as age, sex, education, APOE ε4, and others), the authors reported that dietary intakes of flavonols were inversely associated with incident Alzheimer dementia.

<https://www.ncbi.nlm.nih.gov/pubmed/31996451>

3 February: Clinical study shows possession of two APOE2 alleles confers substantial protection against Alzheimer’s dementia

On 3 February, Dr Eric Reiman and colleagues published a paper in Nature Communications, showing that people with two copies of the APOE2 allele have a substantially lower risk of developing Alzheimer’s



dementia (AD) compared to people with two copies of APOE4.

We each possess two copies (or “alleles”) of the APOE gene, of which there are three different variants: APOE2, APOE3 and APOE4. The combination of APOE alleles we possess determines our APOE “genotype” - for example, E2/E2, E2/E4 or E4/E4. In 1993, a landmark study showed that individuals with two copies of APOE4 (named APOE4 “homozygotes”) were at much higher risk of developing AD at a younger age. Conversely, the APOE2 variant appeared to be neuroprotective, reducing the risk of developing AD. Of the three APOE variants, APOE4 has attracted the most attention. Much less is known about APOE2, in part due to the fact that it is the least common of the three variants: 78% of people have at least one APOE3 allele, compared to only 8% for APOE2. Based on these numbers, only 0.64% of the population are likely to carry two APOE2 alleles. This means that to fully understand the risk benefit of APOE2, studies must incorporate thousands of participants in order to have a sufficiently large number of APOE2 homozygotes to study. Moreover, many studies do not include neuropathological (i.e. autopsy) assessment of AD, arguably the most definitive and reliable way to diagnose AD. As a result, the impact of APOE genotype on AD may have been underestimated.

To address this methodological issue, and to dissect the risk contribution of the different APOE variants, Dr Reiman and colleagues decided to study the Alzheimer’s Disease Genetics Consortium (ADGC) cohort. The ADGC cohort includes brain autopsy samples and clinical data from 4018 participants with neuropathologically-confirmed AD alongside 989 unaffected controls. The wider ADGC cohort includes clinical data from 10,430 probable AD cases and 13,426 unaffected controls.

Confirming the results of previous studies, the researchers found that each additional copy of APOE4 confers a substantially higher risk of AD; participants with two APOE2 alleles had 99.6% lower risk of developing AD compared to those with two APOE4 alleles. Interestingly, the odds ratios (measuring the likelihood of an association between APOE genotype and AD) for the neuropathologically confirmed group were slightly different to the odds ratios for the group of participants without neuropathological confirmation. In the neuropathologically-confirmed group, people with two APOE4 alleles had an odds ratio of 31.2 (i.e. they were 31 times more likely to have AD compared to APOE3 homozygotes), versus to an odds ratio of 10.7 in the group without neuropathological confirmation. At the other end of the scale, people with two copies of APOE2 had an odds ratio of 0.13 (i.e. they are ~90% less likely to develop AD compared to APOE3 homozygotes), compared to an odds ratio of 0.52 for APOE2 homozygotes without neuropathological confirmation. The protective effect of APOE2 extended to Tau pathology in the brain, with APOE2 homozygotes having far fewer neurofibrillary tau tangles compared to all other genotypes.

Together, these results show that the possession of two APOE2 alleles confers an even larger protective effect against the development of AD than previously estimated, confirming that the opposite is true for APOE4. Further studies with

neuropathological confirmation are now required to clarify the impact of the different APOE genotypes on AD, incorporating larger numbers of APOE2 homozygotes from different ethnic groups and socioeconomic backgrounds. Link to article:

<https://www.nature.com/articles/s41467-019-14279-8>

3 February: Merck has FDA approval to expand indication for suvorexant for insomnia in people with mild to moderate AD dementia

On 3 February, Merck, a leading global biopharmaceutical company known as MSD outside of the US and Canada, announced that the US Food and Drug Administration (FDA) has approved an expanded



indication for suvorexant for the treatment of insomnia in people with mild to moderate Alzheimer’s disease (AD) dementia. Suvorexant was previously approved in the US for the treatment of insomnia characterised by difficulties with sleep onset and sleep maintenance.

This update includes findings of a randomised, double-blind and placebo-controlled Phase III trial evaluating suvorexant for insomnia in people with mild to moderate AD dementia. 285 participants (average age 70) from 8 countries (Canada, Finland, Italy, New Zealand, Peru, South Korea, UK, US) were included in the Phase III trial from May 2016 to September 2018 and received either 10 mg of suvorexant or placebo. Among the 142 patients who received suvorexant, 77% were increased to 20 mg.

Data have recently been published in the journal Alzheimer’s & Dementia. Findings showed that suvorexant was safe and increased total sleep time (28 minutes) in people with mild to moderate AD. An improvement in wake after persistent sleep onset (WASO) was also observed in the suvorexant group compared with placebo (16 minutes improvement for the drug). Furthermore, the investigators reported that somnolence was the most common adverse event but was of mild-to-moderate severity and did not result in discontinuation of the trial. Detailed results can be found in the publication:

<https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12035>

4 February: Researchers investigate the outcomes of a passive monitoring device in people with dementia and their carers

On 4 February, scientists from the United Kingdom published an article on the outcomes of a new tool to monitor and report on the daily use of electronic devices such as the television or kettle.

According to the developers, the aim of the tracking and reporting device is to provide reassurance to the caretaker that the person with dementia is up and using the connected device. The monitoring and reporting device sends a message to up to 10 contacts, but also transmits an alert if there is no activity recorded.

As part of their pilot study, the researchers recruited 30 paired participants (person with dementia and family carer) who were surveyed for frailty, wellbeing, and perceived carer impact burden before and after using the device for four months.

The researchers reported that participants found the technology acceptable and useful to predict patterns of behaviour and deviations. In addition, the team noted that there was a reported reduction in burden workload for the family carer group. The scientists stressed that this finding was particularly significant as they had also measured an increase in frailty and decline in wellbeing among the participants who had dementia.

Concluding, the researchers therefore noted that these findings might support the hypothesis that such remote monitoring could have the potential to reduce the concerns of family carers.

<https://content.iospress.com/download/journal-of-alzheimers-disease/jad190844?id=journal-of-alzheimers-disease%2Fjad190844>

10 February: Investigational AD drugs solanezumab and gantenerumab fail to meet its primary endpoint in DIAN-TU Phase II/III study

On 10 February, the Washington University School of Medicine announced top line results for its Dominantly Inherited Alzheimer Network Trials Unit (DIAN-TU) Phase II/III study.

The adaptive platform trial is a randomised, double-blind and placebo-controlled clinical trial assessing the safety, tolerability and efficacy of two drugs, solanezumab (made by Eli Lilly) and gantenerumab (made by Roche), in people at risk for and with a type of early-onset form of Alzheimer's disease (AD) caused by a genetic mutation, called autosomal dominant AD. The trial testing two investigational drugs to slow or prevent the progression of AD in autosomal dominant AD families recruited participants in Australia, China, Europe and US.

An initial analysis of the data from 194 participants showed that both investigational drugs missed the primary endpoint in the DIAN-TU Phase II/III study, which was a slowing cognitive decline as measured by multiple tests of thinking and memory. Additional analyses of secondary endpoints and biomarkers are ongoing. The company plans to present results at the Advances in Alzheimer's and Parkinson's Therapies (AAT-AD/PD™) Focus Meeting in Vienna in April.

Whilst disappointing, the results will not change Roche's plans for the continuation of its GRADUATE 1 and GRADUATE 2 Phase III trials evaluating gantenerumab in people with early

AD. Solanezumab also continues to be studied in the A4 Phase III study.

<https://medicine.wustl.edu/news/alzheimers-diantu-trial-initial-results/>

11 February: Alzheimer's Research UK announces launch of global digital diagnostics initiative, EDoN



Alzheimer's Research UK (ARUK), a British dementia research charity, has launched a global initiative aimed at developing new digital diagnostics for the early detection of Alzheimer's disease and other dementia-causing conditions. The EDoN (Early Detection of Neurodegenerative diseases) initiative was launched at the World Economic Forum held in Davos earlier this year.

EDoN is co-funded by ARUK, the Bill and Melinda Gates Foundation and the Iceland Foods Charitable Foundation, bringing together experts in data science, digital technologies and neurodegeneration to share ideas, technologies and data. EDoN aims to create a digital toolkit that could be used to detect early behavioural and functional signs of neurodegeneration associated with the development of Alzheimer's disease and related conditions. By measuring these digital fingerprints using wearable devices, EDoN aims to provide a valuable behavioural counterpoint to complement minimally-invasive clinical measures such as blood tests. Together, it is hoped that these composite measures will more accurately detect the very earliest signs of dementia-causing conditions.

13 February: Annovis Bio is set to continue its Phase II DISCOVER trial of ANVS401 in AD

On 13 February, Annovis Bio, a clinical-stage drug platform company developing novel treatments for neurodegenerative diseases such as Alzheimer's disease (AD), announced an update for its Phase II clinical trial investigating its lead compound ANVS401 in AD. The study is being conducted in collaboration with the Alzheimer Disease Cooperative Study (ADCS) group.

The trial is a randomised, double-blind and placebo-controlled Phase II study evaluating the efficacy and safety of ANVS401 in

people with early AD. ANVS401 is a small orally administrated brain penetrant inhibitor of neurotoxic proteins. Previous Phase I studies reported that ANVS401 was well tolerated.

The Data Safety Monitoring Board overseeing the Phase II study has reviewed the data (safety, enrolment, participant status, demographic and vital signs of patients) and recommended the continuation of the trial without modification. The analysis of the data did not show any adverse effects in the enrolled research participants. The trial is designed to recruit 24 research participants at 6 US sites and has already enrolled 11 research participants. Interim data from the study are expected in Q4 2020.

ANVS401 is also being developed to treat Parkinson’s disease, Lewy Body dementia and other Lewy Body diseases.

<http://bit.ly/389rnP4>

25 February: Biogen has a dedicated website about its Alzheimer’s drug candidate

The biotechnology company Biogen has launched a website specifically looking at its Alzheimer’s drug candidate aducanumab. You can visit <https://biogenalzheimers.com/> for updates on aducanumab and on Biogen’s plans for regulatory filing. If approved, aducanumab would become the first therapy to reduce the clinical decline of early Alzheimer’s disease.

LIVING WITH DEMENTIA

8 February: Angela Pototschnigg, member of the EWGPWD, introduces Alzheimer Austria’s pioneer project “Turn the Corner”



On 8 February, the Diplomatic Academy in Vienna dedicated its annual charity ball, under the motto “the glorious moment”, to Alzheimer Austria’s pioneer project, “Turn the Corner”.

This project aims to provide post diagnostic support for the “empowerment and social-inclusion of people with MCI or early stage dementia”. Group meetings are organised regularly, facilitated by both peers and professionals, to exchange personal experiences and share coping strategies. Input from experts is provided for the benefit of those with dementia, advising on a wide variety of subjects from physiotherapy and cognitive training, to technical supports and communication skills.

This is something I was looking for when I first began experiencing symptoms of dementia. I was overwhelmed by the scope of the problems I faced. I was depressed and felt very much alone. I am deeply grateful to the students and all donors of the Diplomatic Academy that this support structure for those with dementia can be now offered in Vienna.

The charity ball started in a very relaxed and joyful atmosphere. During the opening ceremony speeches, Ambassador Dr Emil Brix and members of the ball committee underlined the importance of supporting people with dementia. I had the opportunity to thank everyone on behalf of Alzheimer Austria. It was with great pleasure that I spoke for the first time in public, with the support of my daughter, who translated my speech from German into English.

I was amazed by the interest of the students, who talked to me at every possible moment and asked about my life with the condition. When the mood became a little more exuberant due to younger guests, I was able to observe the ball in a quieter area. Knowing that these young people are interested in learning more about us and caring for us, meant that the ball was not only a very nice evening for me, but also a “glorious moment”.

13 February: Carol Hargreaves, member of the EWGPWD, shares some of the daily challenges of living with dementia

I must say that working with the European Working Group of People with Dementia (EWGPWD) has been a privilege. My life started to change. I have been in hospital a few times which I absolutely hate. Although I accepted my illness many years ago, lately it has been quite scary. Working with the EWGPWD keeps me motivated and feeling well. The knowledge that I have gained has allowed me to help people outside our group which still amazes and encourages me.

On two occasions in the past, I just started talking with people who were working in an airport. I explained why I was travelling and just got into a conversation. These ladies later phoned me to thank me for sharing my experiences of living with dementia. I had given



them both my card and I was able to explain what had happened to me and what support I had found. Thankfully they were both able to get the support they needed, in turn.

I want to mention my dear friend George, who has been fantastic, not only in supporting me and attending EWGPWD meetings with me, but who is also appreciated by the entire group, because he is just so helpful and uplifting.

Sadly, my uncle has just passed away with Alzheimer’s disease. My family is grieving and I am sad to have now lost 8 out of my 9 aunts and uncles on my mother’s side.

Thankfully, my mother’s mind is as sharp as a needle, although unfortunately she has some other health issues. I am still able to be there for her. It can be hard but as I only have one sister, we need to work together to support our mother. Getting involved with the Scottish Dementia Working Group and then the EWGPWD, has given me the strength and courage to continue to be there for my mother and for others.

I want to sincerely thank everyone I have got to know so well in the past 11 years. When I was first diagnosed, I honestly thought my life was over. I feel like I got my life back through working with these groups, and that I have a more fulfilling and better life as a result.

16 February: Idalina Aguiar is proud to be included in the photos chosen by the President of Portugal, of his favourite moments of 2019



I live at home with my sister, Clarita, who takes care of me. I was a caregiver myself but since my diagnosis of dementia, I have also become in need of regular care myself. Although life is often hard, I am so grateful that I have my sister and my daughter, Nélide and that I can remain at home with my family around me. Not everyone can enjoy this privilege.

Nélide and I are both members of the National Association of Informal Caregivers and we seek better conditions and recognition for those who stay at home to care for their families. On 20 February 2019, to show his support for our cause, the President of the Portuguese Republic attended an event organised by the National Association of Informal Caregivers and I was proud to be next to him in the official photograph taken of this event.

Almost exactly a year later, in February 2020, a weekly magazine in Portugal called SÁBADO (Saturday), published the same photograph. The President, Marcelo Rebelo de Sousa, had accepted the SÁBADO challenge and chose 12 special photos taken by his official photographers, one for each month of 2019. In some of these photos, the President recalled meetings with Pope Francisco, President of the European Central Bank Christine Lagarde, Chinese President Xi Jinping, French President Emmanuel Macron and German Chancellor Angela Merkel.

It was with huge pride that I recognised that his photograph for February 2019 was the one taken at the event of the National Association of Informal Caregivers, where I stand beside him and am hugged. This gives me great hope for the future.

Idalina is a member of the European Working Group of People with Dementia (EWGPWD) and is supported by her daughter Nélide, to whom we are grateful for her help in translating Idalina’s words to English.

<https://www.sabado.pt/portugal/detalhe/o-ano-visto-por-marcelo-rebelo-de-sousa>

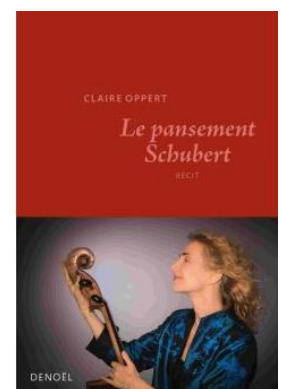
NEW PUBLICATIONS AND RESOURCES

6 February: In “Le pansement Schubert” Claire Oppert shares stories of patients benefitting from music therapy in a hospital setting

On 6 February 2020, French author and musician Claire Oppert published her new book “Le pansement Schubert”. The book shares the author’s experience at Sainte-Périne Hospital in Paris, where she carried out an experimental music therapy she calls “Le pansement Schubert” (the “Schubert Bandage”),

aiming to relieve pain, anxiety and to brighten the daily lives of patients.

The idea came to her in March 2012, when she was in the palliative care unit of Sainte-Périne Hospital. A female patient was screaming and struggling while two nurses tried to dress her. Ms Oppert, a cellist, began to play the slow movement of Schubert’s Trio n° 2. The music had an immediate impact: everyone involved calmed down, visibly and the mood lightened considerably.



Claire Oppert subsequently formed a plan and with the support of Dr Jean-Marie Gomas, was able to implement a trial run in the hospital. The results of the trial were positive: 50% of the patients showed a reduction in pain, 90% of them displayed lower levels of anxiety, and 100% of caregivers reported enjoying the benefits.

“Le pansement Schubert”, published by Éditions Denoël, shares the stories of the patients, the healthcare providers, and the carers involved.

7 February: BDA Scotland publishes BSL video about “sundowning” in dementia



Sometimes a person with dementia will behave differently, often in the late afternoon or early evening, which is known as “sundowning”, writes BDA Scotland (the British Deaf Association in Scotland). BDA

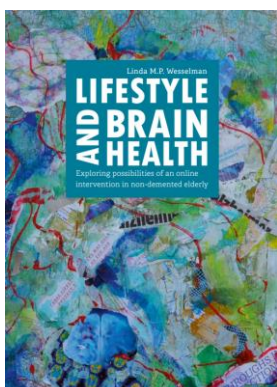
Scotland has published a video about “sundowning”, in British Sign Language (BSL), to help Deaf people to better understand what “sundowning” is.

This is one of a number of informative videos by BDA Scotland, all of which are available on the association’s Facebook page (follow the below link). The aim is to help Deaf people with dementia and Deaf carers, as well as Deaf members of the general public, to better understand different aspects of dementia. View it here:

<https://www.facebook.com/BritishDeafAssociation/videos/1371712323038530/>

For other helpful BSL information and resources about dementia, visit www.bda.org.uk/dementia

14 February: Amsterdam UMC PhD student publishes thesis addressing the relationship between lifestyle and brain health



Linda Wesselman, a PhD student working at Amsterdam UMC, has published her thesis, addressing the relationship between lifestyle and brain health. She specifically investigated the association between nutrition and cognition in cognitively normal individuals with subjective cognitive decline. In addition, she collaborated with individuals with subjective cognitive decline (SCD) to develop the online lifestyle programme “HelloBrain”. Linda Wesselman investigated the needs and preferences of the target population, and evaluated user-experiences.

<https://books.ipskamprinting.nl/thesis/539878-Wesselman/>



JOB OPPORTUNITIES

13 February: MIRIADE project is hiring an Early Stage Researcher in Stockholm

The division of Affinity Proteomics at the Department of Protein Science at KTH Royal Institute of Technology and SciLifeLab in Stockholm is recruiting a PhD-student in a project entitled “Immunoassay development and clinical validation in CSF and blood for dementias”.



The project is a part of the “Multi-omics Interdisciplinary Research Integration to Address DEmentia diagnosis (MIRIADE)” H2020-MSCA-ITN-2019 Innovative Training Network. The four-year MIRIADE project (2019-2023), under the Marie Skłodowska-Curie Actions Programme, aims to train a new generation of scientists that become experts in effective development of novel biomarkers for dementia. Alzheimer Europe is an associated partner in this project.

The closing date for applications is 13 March 2020.

To find out more and to apply: <https://euraxess.ec.europa.eu/jobs/492544>

To read out more about the MIRIADE project: <https://miriade.eu/>

25 February: Two fully-funded dementia PhD positions are available in Liverpool

Two fully-funded dementia PhD positions are currently open for applications at the National Institute for Health Research Applied Research



Collaboration North West Coast (NIHR ARC NWC) at the University of Liverpool, in the UK. These focus on different topics of inequalities in dementia, and are open to UK and European students. The deadline for applications is 22 March 2020.

For more information:

Position 1: <http://bit.ly/2HWbIYN>

Position 2: <http://bit.ly/3c7NYPq>

EDUCATION

31 January: Registrations now open for KU Leuven 2020 Summer Course on Ethics in Dementia Care

KU LEUVEN

The Centre for Biomedical Ethics and Law of the KU Leuven is organizing the 6th edition of its “Summer Course on Ethics in Dementia Care”, taking place in Leuven, Belgium, from 7-10 July 2020. The objective of the course is to foster exchanges on foundational, clinical-ethical and organizational-ethical approaches to dementia care practices.

During the Summer Course, national and international experts will give presentations on various ethical topics in the domain of dementia care. There will be time for intensive discussions. The language of instruction will be English.

The Summer Course is aimed at participants from diverse professional backgrounds, such as medicine, nursing, psychology, social work, gerontology, health care administration, philosophy and theology, and to PhD students undertaking courses of study in these areas. Detailed

information on the programme, funding opportunities, registration and payment can be found here:

https://gbiomed.kuleuven.be/english/research/50000687/50000697/education-1/Summer_Course

6 February: Royal College of Physicians of Ireland offers healthcare professionals a “Clinical Update on Dementia”



ROYAL COLLEGE OF PHYSICIANS OF IRELAND

The Royal College of Physicians in Ireland will be running a one-day course to provide healthcare workers in a range of clinical settings - including acute hospitals, community settings and GP practices - with up-to-date guidelines in preventing, diagnosing, and managing dementia and associated symptoms.

The course, which will take place on 25 March 2020, includes problem-solving considerations and panel discussions centred on the workshop themes, with questions and observations from the audience encouraged. It is open to all healthcare professionals. More information can be found here:

<https://courses.rcpi.ie/product?catalog=Dementia-A-Clinical-Update>

Contact Alzheimer Europe:

Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org; www.alzheimer-europe.org

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AE CALENDAR

Date	Meeting	AE representative
3-4 March	Patients and Consumers' Working Party of the European Medicines Agency (Amsterdam, Netherlands)	Jean
3-4 March	RADAR AD Annual meeting and General Assembly (Basel, Switzerland)	Ana and Dianne
9 March	DISTINCT meeting (Prague, Czech Republic)	Dianne
11 March	Kick off meeting of EUROFINGERS project (Stockholm, Sweden)	Ana and Jean
16 March	AD Detect and Prevent meeting (Oxford, United Kingdom)	Dianne
17-19 March	IEEPO - International Experience Exchange with Patient Organisations IEEPO (Berlin, Germany)	Jean
21 March	"Dementia through the lens of European social and health care policies" symposium (Sofia, Bulgaria)	Jean
23-24 March	ICCA Benelux Chapter Summit (Hasselt, Belgium)	Gwladys
24 March	EU Carers Intergroup meeting (Brussels, Belgium)	Jean
24 March	Judging Panel for AAL Smart Ageing prize (Brussels, Belgium)	Angela
27 March	Alzheimer Europe working group on minority ethnic groups (Amsterdam, Netherlands)	Dianne and Jean
31 March	PREFER - PARADIGM workshop (Brussels, Belgium)	Cindy

CONFERENCES

Date	Meeting	Place
26-29 March	14 th World Congress on Controversies in Neurology (CONy), http://cony.comtecmed.com/	London, UK
2-5 April	International Conference on Alzheimer's and Parkinson's Diseases and related neurological disorders (AD/PD), https://aat-adpd.kenes.com/general-information/	Vienna, Austria
12 May	281 ^{ème} colloque Alzheimer: Nos droits et nos réalités - Ligue Alzheimer ASBL, https://alzheimer.be/colloque-2/	Libramont, Belgium
13-14 May	AAIC satellite symposium – Discover new pathways in Alzheimer's and dementia research, https://www.alz.org/greece/overview.asp	Athens, Greece
18-19 May	Alzheimer's Society Annual Conference 2020, https://www.alzheimers.org.uk/dementia-professionals/alzheimers-society-annual-conference/about-conference	London, UK
23-26 May	Congress of the European Academy of Neurology (EAN), https://www.ean.org/paris2020/6th-Congress-of-the-European-Academy-of-Neurology-Paris-2020.3833.0.html	Paris, France
11-12 June	Care in the Age of Outrage, dementiaconference.com	Sydney, Australia
12-13 June	"Dementia Care and Policies of extended Danube Region", www.alzheimerbih.org	Sarajevo; Bosnia and Herzegovina
26-30 July	Alzheimer's Association International Conference (AAIC), https://www.alz.org/	Amsterdam, Netherlands
10-12 December	34 th International Conference of ADI "Hope in the age of dementia", https://adi2020.org/	Singapore
20-22 October	30 th Alzheimer Europe Conference "Building bridges"	Bucharest, Romania
26-29 June 2021	Brain & Brain PET 2021, http://brain2021.scot/	Glasgow, UK
11-13 October 2021	31 st Alzheimer Europe Conference	Helsinki, Finland

30th Alzheimer Europe Conference

Building bridges

Bucharest, Romania

20–22 October 2020

www.alzheimer-europe.org/conferences

 #30AEC

