

HIGHLIGHTS

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WELCOME

After the European Parliament elections at the start of June, our Dementia Pledge campaign has drawn to a close. With 304 candidates signed up during our 2024 campaign, we are delighted to have broken our previous record of 230 pledgees in the 2019 elections.

I would like to thank all our national member associations who supported

the campaign, contacted candidates and played an integral part in making the campaign such a success! I also want to thank the European Working Group of People with Dementia and the European Dementia Carers Working Group (EDCWG) for their contributions to the campaign, helping us send strong messages to candidates that dementia needs to be a priority during the next parliamentary term. Lastly, I of course want to extend a big thank you to all the signatories.

We will be hard at work during the summer to re-establish the European Alzheimer's Alliance and will announce the new group. We currently expect, following this part of our EU campaign and the election results, to have upwards of 70 members.

Moving on to our Annual Conference, organised together with Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève, I am delighted to announce that the detailed programme is now on our website and would like to remind you to register before our Early Bird rates come to an end on 15 July!

I am also pleased to announce some important new publications, with the 45th edition of our Dementia in Europe magazine being launched this month, at a series of meetings in Luxembourg. The meetings including a meeting of the Alzheimer Europe Board, a Corporate Affairs meeting with our sponsors and members, our Annual General Meeting (AGM), a meeting of the current EDCWG and a Public Affairs meeting with our members.

Following our 2024 AGM, at which 32 full members out of 36 were present or represented, ensuring the meeting had quorum, we are pleased to congratulate the members of our new Board of directors. You can see the Board's Executive and members listed in the bottom lefthand corner of this page. The AGM also reviewed and unanimously adopted our 2023 Annual Report, which has now been published online. Printed copies will be available at our Geneva conference. The Board elections and the publication of our 2023 Annual Report are just two of the important outcomes from the AGM in Luxembourg. You can find more details in our meeting report on page 7 of this newsletter.

Jean Georges, Executive Director

Alzheimer Europe Board

Chairperson: Maria do Rosário Zincke Dos Reis (Portugal); Vice-Chairperson: Mario Possenti (Italy); Honorary Secretary: Lorène Gilly (France); Honorary Treasurer: Marco Blom (Netherlands); Members: Stefanie Becker (Switzerland), René Friederici (Luxembourg), Andy Heffernan (Ireland), Martina Mátllová (Czech Republic), Mary-Frances Morris (United Kingdom), Chris Roberts, Chairperson of the European Working Group of People with Dementia (United Kingdom), Katarina Suomu (Finland), Jochen René Thyrian (Germany).

Alzheimer Europe Staff

Executive Director: Jean Georges; Conference Coordinator: Gwladys Guillory; Executive Assistant: Tara Klassen; Events Coordinator: Cristina Pencea; Finance Officer: Stefanie Peulen; Director for Communication and Policy: Kate Boor Ellis; Policy Officer: Owen Miller; Communications Assistant: Grazia Tomasini; Director for Research: Angela Bradshaw; Project Communications Officer: Christophe Birtener; Project Officer: Cindy Birck; Project Officer: Lukas Duffner; Director for Public Involvement and Ethics: Dianne Gove; Public Involvement Lead: Ana Diaz; Public Involvement Officers: Sarah Campill, Daphné Lamirel and Soraya Moradi-Bachiller.

SPOTLIGHT ON EUROPEAN ELECTIONS

5 JUNE

Entire EU elections candidate list of French political party Les Républicains signs Dementia Pledge 2024, promising to make dementia a policy priority at EU level!

We are delighted to announce that, thanks to the hard work of our member France Alzheimer, the entire list of the French political party Les Républicains (which is a member of the European People's Party, EPP) has signed our Dementia Pledge 2024, which forms part of our EU elections campaign. François-Xavier "FX" Bellamy signed the Pledge on behalf of his entire list of candidates, bringing 81 new signatures to the Dementia Pledge. Alzheimer Europe would like to express its gratitude to Mr Bellamy and all the candidates from Les Républicains for supporting the Pledge and for putting dementia firmly on their agenda as a policy priority.



The Dementia Pledge 2024 is a commitment which all candidates standing for election in the European Parliament were invited to sign, pledging their support in prioritising dementia in the areas of health, research, disability policy and informal carers and pledging to join the European Alzheimer's Alliance, upon election.

9 JUNE

Alzheimer Europe's Dementia Pledge 2024 campaign draws to a close after EU elections



Following the European Parliament elections between 6 and 9 June, Alzheimer Europe's #DementiaPledge2024 campaign has drawn to a close. With 304 candidates signed up to the pledge, Alzheimer Europe broke its record of 230 candidates signed up in the run-up to the 2019 elections.

We would like to say a huge thank you to all of the associations who supported the campaign, contacted candidates and played an integral part in making the campaign such a success! Additionally, we would like to thank the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) for their contributions to the campaign, helping us send strong messages to candidates that dementia needs to be a priority during the next parliamentary term.

In the coming weeks, Alzheimer Europe will write to elected candidates, asking them to follow up on their commitment, as well as asking members to make contact to establish a closer connection between MEPs and national Alzheimer's organisations.

Alzheimer Europe will also work during the summer to re-establish the European Alzheimer's Alliance (EAA) and will announce the new group. Following the Pledge campaign and the election results, we currently expect upwards of 70 members for this new incarnation of the EAA, which is a multinational and cross-party group that brings together MEPs to support European citizens living with Alzheimer's disease or another form of dementia, as well as their supporters/carers.

For a detailed breakdown of the MEPs elected in each country, more information is available on the European Parliament website: <https://election-results.eu/>

Our EU campaign does not end here, as we continue to seek endorsements from national and European organisations for our Helsinki Manifesto and the support of members of the public for our Call to Action. This campaigning will continue until December 2024 and the policy work emerging from our Helsinki Manifesto will continue for the next five years. Find out more about the campaign, here: <https://www.alzheimer-europe.org/policy/campaign/alzheimer-europe-election-campaign-2024>

ALZHEIMER EUROPE

28 MAY

Alzheimer Europe hosts online Alzheimer’s Association Academy meeting on Partnering in Research projects and welcomes attendees from 18 nations



On 28 May 2024, Alzheimer Europe welcomed representatives from 18 member organisations to its most recent Alzheimer’s Association Academy meeting, a forum which enables sharing of updates, experiences, challenges and good practices in policy developments and campaign activities at both a national and European level. Dianne Gove, Director for Public Involvement and Ethics, moderated the session. She noted that Anne Rita Øksengård was unable to attend the meeting and had recorded her session entitled “Partnering in European research consortia as a national patient organisation” for attendees to watch at a later date. Other topics included:

- “Recent European projects for patients with cognitive problems and their caregivers in Greece-Hellas”: Magda Tsolaki, founder and chair of the Panhellenic Federation of Alzheimer’s disease and related disorders (Alzheimer Hellas, Greece) gave an overview of the Erasmus+ and European projects that they were involved in from 2016-2024, highlighting their Dementia Rights programme as well as the AD-GAMING programme, a set of games designed to improve the quality of life of people with dementia. These games have been translated into five languages and are available to everyone. She shared that, since she works in several universities, she was able to invite graduates and post-graduates to do their ‘practicals’ (internships) in the programme. This group of around 100 people was what made the coordination and management of all of the projects possible.
- “Experiences from the Brain Health Armenia project”: Jane Mahakian, founder of Alzheimer’s Care Armenia, then discussed her organisation’s Brain Health Armenia project with its six aims which include early detection, building workforce capacity and dementia education to reduce stigma. She detailed what worked and what did not, noting that thinking outside the box in terms of securing funding and utilising volunteers to fill roles within

the project have helped make the project sustainable and successful, noting the importance of a legacy plan and partnerships. She spoke of the fear and stigma that still exists, noting that there is a lot of work still to be done in educating the public and healthcare professionals.

- “Collaboration of Alzheimer Europe in EU-funded research projects”: Angela Bradshaw, Director for Research at Alzheimer Europe, then shared the ways in which Alzheimer Europe collaborates in EU-funded research projects, through Public Involvement (91%), communications (91%), stakeholder engagement (41%), and ethical (75%) and policy reflections (8%). She shared that the areas of project research involvement were in platforms for brain research (EPND and eBRAIN-Health), AI for detection, diagnosis and care (ADIS, Al-Mind & PATTERN-COG), dementia screening, diagnosis and management (AD-RIDDLE, PREDICTOM, PROMINENT & RECOGNISED) and dementia risk reduction and brain health (LETHE and Multi-MeMo). Ana Diaz, Public Involvement Lead at Alzheimer Europe, continued the presentation by clarifying what Public Involvement (PI) entails for Alzheimer Europe, sharing how the organisation structures its PI work with the projects in which Alzheimer Europe is involved.

Closing the Academy meeting, Dianne Gove thanked all the speakers for their presentations and the audience for their contributions and engagement with discussions. The next Academy session will take place on 16 July 2024.

12 JUNE

The European Working Group of People With Dementia and supporters gathered online for a last meeting of the current term of the group and a farewell to departing members



On 12 June, members of the European Working Group of People with Dementia (EWGPWD) and their supporters gathered online. This heartfelt meeting marked the end of the current term of the group and provided an opportunity to say goodbye and express gratitude to those leaving the group: Petri, Bernd and Stephen. Marguerite, who had left the group earlier in the year, was also thanked for her contributions.

The meeting began with a warm welcome from Dianne (Director for Public Involvement and Ethics). Daphné (Public Involvement Officer) then presented a slideshow of photos showing members at various events, conferences and social gatherings, both online and in-person. Ana (Public Involvement Lead) gave a special thank you to Petri, acknowledging his contributions to Alzheimer Europe and the EWGPWD, particularly in raising awareness of frontotemporal dementia. She read out some of his words from an email since he was not able to attend. Soraya (Public Involvement Officer) and Dianne expressed their gratitude to Stephen and Bernd respectively, highlighting Stephen and Bernd's invaluable contributions to the working group and the organisation's activities, and wishing them success in their future endeavours. Daphné also shared a few words in appreciation of Marguerite. Bernd and Stephen also spoke, expressing how much they had enjoyed their time with EWGPWD. Their sentiments resonated with other members who expressed sadness at their departure but also reflected on all the cherished moments created together. Dianne and Ana then thanked Chris for his role as Chair and Vice-Chair of the EWGPWD. They thanked him for his essential role in fostering cohesion in the EWGPWD and his constant eagerness to help out and assist with all activities. Soraya, Sarah (Public Involvement Officer) and Dianne concluded the meeting with final words of appreciation for the EWGPWD. Chris closed the meeting by thanking AE staff for their support and expressing his gratitude again to the departing EWGPWD members and all EWGPWD supporters for their essential roles.

14 JUNE

Programme for the 34th Alzheimer Europe Conference in Geneva is now online!



Alzheimer Europe, Alzheimer Schweiz Suisse Svizzera and Alzheimer Genève would like to thank everyone who submitted an abstract for the 34th Alzheimer Europe Conference (34AEC) that will take place in Geneva from 8 to 10 October 2024. We received a record number of abstracts for 34AEC, with a total of 578! All of them have been reviewed and we have now sent responses to everyone. If you have not received information about your abstract submission, please contact us via: info@alzheimer-europe.org. Following the abstract review, we are pleased to announce that we have included a detailed programme for the conference on our website: <https://www.alzheimer-europe.org/conferences/2024-geneva/detailed-programme>

We would also like to remind you that our conference registration portal is open. You can take advantage of the Early Bird registration fees until 15 July 2024, to join us in Geneva. Register with these Early Bird rates and benefit from the reduced registration fees.

A 25% discount is available for participants from low and middle income countries. Special rates are also available for people with dementia, students and member associations of Alzheimer Europe.

See here for more information: <https://www.alzheimer-europe.org/conferences/2024-geneva/registration-fees>

We look forward to seeing you in Geneva at 34AEC!

17 JUNE

Alzheimer Europe presents the 45th edition of Dementia in Europe magazine

It is with great pleasure that we introduce the 45th edition of our Dementia in Europe magazine, which contains many important updates on European and national policy developments in the dementia field, as well as touching on areas related to dementia research, care and awareness-raising.

We open the Alzheimer Europe section with a look back at the capacity-building Alzheimer's Association Academy workshops that we organised earlier this year and which focused on artificial intelligence (AI) and modifiable risk factors. Turning to projects in which our organisation is involved, we introduce the newly-launched AD-RIDDLE project, which will look at how to improve the prevention, detection and diagnosis of dementia; the REBALANCE project, which is exploring the use of focused ultrasounds as a novel approach for the treatment of Alzheimer's disease (AD); and we examine the progress of the AI-MIND project as it reaches its mid-term point, with promising results in both the generation of new data and the development of digital AI tools for screening brain connectivity and dementia risk estimation. In our policy section, we are delighted to feature an article with the Maltese Minister for Health and Active Ageing, Dr Jo Etienne Abela (pictured, right) and Parliamentary Secretary for Active Ageing, Dr Malcolm Paul Agius Galea (pictured, left), who outline the country's new National Dementia Strategy, called "Reaching New Heights". Additionally, we are pleased to hear from Anthony Scerri, Vice-Chair of the Malta Dementia Society, who shares the organisation's response to the new strategy. With the EU elections taking place this month, the following article takes stock of the progress of Alzheimer Eu-



Europe's election campaign, including a recap of our highly successful European Parliament Reception in Brussels. It has been fantastic to see the engagement across the different branches of our campaign (Helsinki Manifesto, public Call to Action, and Dementia Pledge for MEP candidates) and especially amongst our members. This work will continue well past the elections and is vitally important in providing a strong foundation for us to continue our policy work into the second half of 2024 and beyond. Staying at the EU level, we then hear from Katarina Ivanković-Knežević from the European Commission about the new European Disability and Parking Cards, and what this important development in European disability policy means for people living with dementia. The final article in this section provides a brief overview of some of the fruitful and constructive discussions which took place at the most recent meeting of the European Group of Governmental Experts on Dementia.

In the third and final section of the June 2024 edition of our magazine, *Dementia in Society*, we start with an article featuring people living with dementia, discussing a topic not often talked about: What it is like for a person with dementia to take on the role of carer themselves. We spoke to Petri Lampinen, Lieselotte Klotz and Helen Rochford Brennan about their experiences of supporting close family members in need of care. The next article explores an exciting collaboration between our Spanish member, Confederación Española de Alzheimer y otras demencias (CEAFA), and Momentum Spain, using the popular video game Fortnite and famous gamers to help raise awareness of dementia among younger people. We then highlight an important new book entitled "Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia", edited by Fiona Maclean, Alison Warren, Elaine Hunter and Lyn Westcott. The book features contributions from professionals, as well as from people with lived experience, including members of our European Working Group of People with Dementia, Chairperson, Chris Roberts and Vice-Chairperson, Margaret McCallion. In the penultimate article, Füsün Kocaman of the Turkish Alzheimer Association outlines an innovative Erasmus+ project with the Turkish Ministry of the Interior, developing training materials to enhance the skills and knowledge of search and rescue personnel in cases involving people with dementia. The closing article of this edition takes a look "behind the headlines", with Betty Tijms and Pieter Jelle Visser of the EPND (European Platform for Neurodegenerative Diseases) project, who share their work categorising five biological sub-types of AD – a vital development in improving our understanding of the condition. We hope you find this edition both interesting and useful. *Dementia in Europe* magazine issue 45 can be downloaded, here: <https://bit.ly/DementiaInEurope45>

18 JUNE

Alzheimer Europe organises a Company Round Table meeting in Luxembourg



On 18 June 2024, Alzheimer Europe hosted a Company Round Table meeting in Luxembourg. The meeting was a hybrid event, with many participants attending in person and some joining remotely. It was attended by company representatives from Biogen, Danone (Nutricia), Eli Lilly, Novo Nordisk, Prothena Biosciences, Roche, Terumo Blood & Cell Technologies, members of the Alzheimer Europe staff and Board. During the meeting, seven Alzheimer Europe speakers provided updates on recent policy and research developments.

Cindy Birck (Project Officer) gave an update on our Clinical Trials Watch, an online database providing accessible and up-to-date information on clinical trials that are investigating drugs for Alzheimer's disease and/or dementia.

Owen Miller (Policy Officer) shared some updates on recent policy developments and on our European Parliament election campaign.

The next presentation was given by Angela Bradshaw (Director for Research) and Lukas Duffner (Project Officer), who updated the delegates on a project aiming to identify general public perceptions and expectations, and experiences of research participants, in the context of dementia research.

Following a short break, a presentation on some of the EU projects in which Alzheimer Europe is a partner was delivered by Angela Bradshaw, Dianne Gove (Director for Public Involvement and Ethics) and Daphné Lamirel (Public Involvement Officer).

The meeting was moderated by Jean Georges (Executive Director) who also gave the final presentation of the meeting, informing

participants about Alzheimer Europe's activities in 2024 and the upcoming Annual Conference to be held from 8 to 10 October in Geneva, Switzerland, under the motto "New horizons – Innovating for dementia".

We would like to thank our sponsors and members for participating in this meeting and we look forward to welcoming them to the next Company Round Table meeting, which will take place online, on 18 September.

18-19 JUNE

The European Dementia Carers Working Group meet in Luxembourg for a final in-person meeting of the current group



On 18 and 19 of June, the European Dementia Carers Working Group (EDCWG) met in Luxembourg. Dianne Gove (Director for Public Involvement and Ethics), Ana Diaz (Public Involvement Lead) and Public Involvement Officers Soraya Moradi-Bachiller, Sarah Campill and Daphné Lamirel also attended the meetings.

The first session on 18 June centred on the REBALANCE project. This EU-funded research initiative is investigating a non-invasive treatment for Alzheimer's disease called 'focused ultrasound'. Two researchers from the University of Latvia, who are looking into the social and ethical issues of the REBALANCE project, joined the discussion. They conducted focused group discussions, asking members their thoughts on 'preclinical research' and how people with dementia and their carers might be involved in this type of research. Members also reflected on their concerns and hopes regarding the translation of preclinical studies to clinical research.

The second session on 18 June was about the AI4Hope project, an EU project focused on developing and testing AI-based palliative care tools for dementia. In small groups, Dianne and Daphné asked members about their understanding of the term 'palliative care', whether it is a useful and relevant concept for dementia and their experiences with accessing palliative care for people with dementia at different stages of the condition. Daphné then presented information about a new tool developed by the project, a 'video recording diary system', and Dianne gathered the group's opinions on using such a tool for people with dementia.

The meeting on 19 June started with a farewell to Filomena, Magnus and Paola, who are ending their terms of office with the group. Dianne, Ana and Soraya thanked them warmly for their valuable contributions over the past two years. Sonata (Chair of the EDCWG), Trevor (Vice-Chair of the EDCWG)

and the other members expressed gratitude for the great times shared together and wished all the best for the future.

The remaining part of the EDCWG meeting was dedicated to the INTEREST project. Martina Roes and Rene Thyrian from the German Centre for Neurodegenerative Diseases (DZNE) joined the discussion and members were invited to share their experiences and perspectives about social health, inequalities, intersectionality and unmet needs in dementia care.

Overall, the meetings were a valuable opportunity for members of the EDCWG to share their opinions on a variety of EU research projects that Alzheimer Europe is currently involved in. A big thank you to all members for your enthusiasm and active participation during the two days!

19 JUNE

Alzheimer Europe organises Public Affairs meeting in Luxembourg bringing together member organisations from 21 countries across Europe



On 19 June 2024, Alzheimer Europe was delighted to welcome representatives from member organisations from 21 countries to its Public Affairs meeting, which took place in Luxembourg. These meetings provide a forum which enables sharing of updates, experiences, challenges and good practices in policy developments and campaign activities at both a national and European level. The meeting started with a warm welcome from Maria do Rosário Zincke dos Reis, Chairperson of Alzheimer Europe (Portugal) and a *tour de table* of introductions. This was followed by presentations from Alzheimer Europe staff and member organisations.

The first part of the meeting was focused on the recent European Parliament elections and on Alzheimer Europe's campaigning with members. From Alzheimer's side, an overview of campaign outcomes and a discussion of next steps was provided by Kate Boor-Ellis (Director for Communication and Policy), Chris Bintener (Project Communications Office) and Owen Miller (Policy Officer). Following this, Johan Karlman presented the successful campaigning done by Demensförbundet (Sweden) in the run-up to the EU elections of 6-9 June, and Maria do Rosário Zincke dos Reis followed, presenting the great campaigning by Alzheimer Portugal.

Anti-amyloid treatments in Europe were the topic of the next presentation, in which Angela Bradshaw (Director for Research) gave updated Alzheimer Europe's member associations on recent regulatory developments.

Following a short break, Jean Georges (Executive Director) discussed the future directions of Alzheimer Europe and asked members for their feedback on a new strategic plan for 2026-2030. He then closed the meeting with thanks for the great engagement and contributions of participants.

The next Public Affairs meeting will take place on 11 December in Brussels (Belgium).

21 JUNE

Alzheimer Europe Board of directors elected and 2023 Annual and Financial Report approved during Annual General Meeting in Luxembourg



Alzheimer Europe is pleased to announce its new Board of directors and to present its 2023 Annual and Financial Report. These are just two of the important outcomes from the organisation's Annual General Meeting (AGM), which took place this week in Luxembourg. At the AGM, held on 18 June 2024, 32 full members out of 36 were present or represented, ensuring the meeting had quorum. Two of Alzheimer Europe's provisional members were also in attendance, as were the staff and Executive Director of the organisation, together with various other guest observers.

Chairperson Rosário Zincke dos Reis (Portugal) moderated the meeting and the agenda included an in-depth review of the 2023-2024 activities and projects of Alzheimer Europe, as well as the finances of the organisation. As has been the case since the beginning of 2022, our core activities in 2023 were funded by an operating grant awarded by the European Commission's Citizens, Equality, Rights and Values (CERV) programme, ensuring we can continue providing a voice to people with dementia and their carers, making dementia a European priority, changing perceptions and combating stigma, raising awareness of brain health and prevention, strengthening the

European dementia movement, and supporting dementia research.

AGM delegates reviewed and unanimously adopted Alzheimer Europe's 2023 Annual and Financial Report and the report is now available on our website, as a PDF publication. Printed copies will be available at our Annual Conference in Geneva in October.

Read our 2023 Annual and Financial Report, here: <https://bit.ly/AE2023AnnualReport>

The AGM also discussed and voted on a number of other matters related to membership fees and decisions, the appointment of auditors, Alzheimer Europe's statutes, rules and regulations, and our 2025 Work Plan and Budget, which was unanimously adopted.

On the agenda, too, were the elections for the Board of directors. Following these elections, the Board remains largely unchanged, with one big difference: Charles Scerri (Malta), who has served on the Board for 16 years, announced that he was stepping down from his position as Vice-Chairperson. Jean Georges, Executive Director, thanked Charles on behalf of Alzheimer Europe and its Board, for his vital contributions to the organisation over the years and for his friendship. He will be truly missed by us all!

Following Charles Scerri's departure, Mario Possenti (Italy) who was the Honorary Secretary from 2022 to 2024, has been voted in as the new Vice-Chairperson of the organisation. Lorène Gilly (France), a member of the Board since 2022, replaces him in the role of Honorary Secretary. The new Board of Alzheimer Europe:

Office bearers

- Chairperson: Rosário Zincke dos Reis (Portugal)
- Vice-Chairperson: Mario Possenti (Italy)
- Honorary Secretary: Lorène Gilly (France)
- Honorary Treasurer: Marco Blom (Netherlands).

Members

- Stefanie Becker (Switzerland)
- René Friederici (Luxembourg)
- Andy Heffernan (Ireland)
- Martina Mátlová (Czech Republic)
- Mary-Frances Morris (Scotland, United Kingdom)
- Katariina Suomu (Finland)
- Jochen René Thyrian (Germany).

Congratulations to all of them!

The new terms of office of the European Working Group of People with Dementia (EWGPWD) and of the European Dementia Carers Working Group) have begun following the 2024 AGM, and the members, chairpersons and vice-chairpersons of both groups will be announced in the coming weeks. Both



the chairperson of the EWGPWD and chairperson of the EDCWG will become *ex-officio* members of the Alzheimer Europe Board, with full voting rights.

Chris Roberts (Wales, United Kingdom), current Chairperson of the EWGPWD and Sonata Mačiulskytė (Lithuania), current Chairperson of the EDCWG each gave a speech at the AGM, sharing the excellent work of their respective working groups over the past year and thanking Alzheimer Europe for its support and its commitment to ensuring the voices of people with dementia and carers are heard at the European level. Chris Roberts informed delegates that this would be his last AGM as

Chairperson of the EWGPWD, as he is stepping down from his position, after eight year in the group and four years as Chairperson. He will be sorely missed and we wish him and his wife and supporter Jayne Goodrick all the very best for the future.

A big thank you to our national member associations for attending our 2024 AGM in Luxembourg, for having such great discussions and for using their votes, thus helping to shape the future of our organisation and ensure our important collaborative work continues.

AE NETWORKING

3-4 JUNE	Gwladys went on a site inspection for the 35 th Alzheimer Europe Conference with representatives of Federazione Alzheimer Italia and Alzheimer Uniti (Bologna, Italy)
3-4 JUNE	Ange, Lukas, Ana and Sarah attended the AD-RIDDLE kick-off meeting (Stockholm, Sweden)
4-5 JUNE	Chris and Soraya attended the ADIS General Assembly meeting (Regensburg, Germany)
5-6 JUNE	Lukas and Daphné attended the AI4Hope consortium meeting (Helsinki, Finland)
6 JUNE	Ana and Sarah met with the members of the LETHE Advisory Board
9-11 JUNE	Angela participated in the Global Alzheimer's Leadership Series workshop (Paris, France)
12 JUNE	Jean and Owen attended an OECD workshop on long-term care
12 JUNE	Alzheimer Europe organised an online farewell for some members of the European Working Group of People with Dementia (EWGPWD)
12 JUNE	Owen attended a WHO Europe engagement session on developing a non-state actor engagement plan
13 JUNE	Jean met with representatives of the EFPIA Alzheimer's disease platform
14 JUNE	Jean met with the Executive of the European Alzheimer's Disease Consortium
17 JUNE	The Alzheimer Europe Board met (Senningerberg, Luxembourg)
18 JUNE	Alzheimer Europe organised a company round table meeting with sponsors and members (Senningerberg, Luxembourg)
18 JUNE	Alzheimer Europe organised its Annual General Meeting (Senningerberg, Luxembourg)
18 JUNE	Lilly organised an information meeting for Alzheimer Europe members and staff (Senningerberg, Luxembourg)
18-19 JUNE	Alzheimer Europe organised consultations with the European Dementia Carers Working Group (EDCWG) (Senningerberg, Luxembourg)
19 JUNE	Alzheimer Europe organised a Public Affairs meeting with members (Senningerberg, Luxembourg)
19 JUNE	Owen attended the closing meeting of the SOUND project
21 JUNE	Jean met with Novo Nordisk

26 JUNE	Ana and Soraya participated in consultations with the ADIS Advisory Board (Senningerberg, Luxembourg)
26 JUNE	Jean met with Otsuka
26-27 JUNE	Ana, Dianne, Daphné, Sarah and Soraya participated in the online gatherings of the EWGPWD and EDCWG
27-28 JUNE	Gwladys, Jean and Cristina organised a site inspection for the 34 th Alzheimer Europe Conference (Geneva, Switzerland)




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EU PROJECTS

30 MAY

Multi-MeMo publishes its first project newsletter



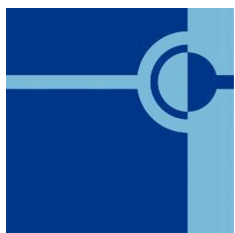
On May 30, the Multi-MeMo project marked its first anniversary by releasing its inaugural external newsletter. Launched in May 2023, Multi-MeMo is a collaborative research initiative looking at multimodal interventions for the prevention of dementia, aiming to develop an improved multimodal intervention model supporting the combination of lifestyle changes and pharmacological treatments that have the potential to enhance each other's effects. Ultimately, this is expected to lead to more timely and personalised interventions to effectively prevent and/or delay the development of Alzheimer's disease and related dementia.

Funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND), the three-year project involves six partners and three external collaborators. The newly released newsletter offers readers the latest project updates, highlights significant advances and major achievements and features an interview. Additionally, it includes an update on the first online meeting of the Multi-MeMo Advisory Board, which consists of members of the public with and without cognitive impairment from seven European countries.

https://www.multi-memo.eu/welcome-to-the-first-multi-memo-newsletter/

30 MAY

New results from MIND-AD randomised controlled trial are out



The MIND-AD trial was a 6-month multinational (Sweden, Finland, Germany, France) proof-of-concept randomised controlled trial. Participants were 60–85 years old, had very early (prodromal) Alzheimer's disease and not-well managed vascular/lifestyle risk factors. New results from MIND-AD have recently been published in the Alzheimer's translational research journal, Alzheimer's Research and Therapy. The trial was supported by the EU Joint Programme – Neurodegenerative Disease Research (JPND) and the following JPND projects EU-FINGERS and Multi-MeMo.

MIND-ADmini builds on the successful results and experience of the pioneering FINGER study, which earlier showed cognitive benefits from a multidomain lifestyle intervention in at-risk older people from the community. In parallel, the LipiDiDiet trial highlighted clinical benefits of medical food (Fortasyn

Connect) in people with prodromal Alzheimer's disease. However, the feasibility and impact of multidomain interventions combining lifestyle with medical food in prodromal Alzheimer's disease has not been studied earlier.

The multinational MIND-ADmini trial demonstrated for the first time that a multidomain lifestyle intervention, alone or combined with medical food, is feasible and beneficial for persons with early (prodromal) Alzheimer's disease. The intervention was safe, well-adhered, with the lifestyle+medical food group showing a reduced rate of cognitive-functional decline after 6 months.

"MIND-AD has been a natural next step to combine two successful approaches – non-pharmacological and medical food – and test their feasibility and potential synergy in people who already experience cognitive symptoms due to Alzheimer's disease. The encouraging results of MIND-AD pave the way to design larger clinical trials investigating longer-term cognitive and other health benefits of combined non-pharmacological and pharmacological approaches." says Professor Miia Kivipelto from Karolinska Institute and FINGERS Brain Health Institute, who led both MIND-AD and FINGER trials, and is the scientific leader of both the World-Wide FINGERS network and the EU-FINGERS project.

"These findings add to the growing body of evidence that moderate multimodal lifestyle changes may help reduce the risk of Alzheimer's disease or slow its progression, and also suggest that more intensive multimodal lifestyle changes may have additional benefits for improving cognition in people with early Alzheimer's disease", pointed out Professor Alina Solomon from the Brain Research Unit at University of Eastern Finland, Scientific Coordinator for the MIND-ADmini trial and Multi-MeMo project coordinator.

https://doi.org/10.1186/s13195-024-01468-x

3 JUNE

The EPAD project launches a brand-new website

The European Prevention of Alzheimer's Dementia (EPAD) project is pleased to announce the launch of its new website. It's more user-friendly, packed with updated information and easier to navigate.

The EPAD project was driven by the idea that early, targeted intervention focused on the initial stages of disease would be more effective than efforts to tackle established disease processes. With gratitude to the Innovative Medicines Initiative (IMI) for funding (2015-2020), EPAD was an interdisciplinary research initiative established to overcome the major hurdles hampering drug development



for secondary prevention of dementia due to Alzheimer’s disease. It also pioneered a novel, flexible approach to clinical trials.

Over 2,000 research participants were recruited into the four-year EPAD Longitudinal Cohort Study exploring new ways to better understand the early stages of Alzheimer’s disease and prevent dementia before symptom onset. The data, bio sample and neuroimaging generated from this study are available for researchers studying the brain and neurodegenerative diseases around the world. We invite you to explore the new website to find further information on how to request access. <https://ep-ad.org/>

3 JUNE

AD-RIDDLE project has been kicked-off in Stockholm



The kick-off meeting of the AD-RIDDLE (“Real-World Implementation, Deployment, and Validation of Early Detection Tools and Lifestyle Enhancement”) project took place in Stockholm on 3 and 4 June 2024. Recent advances in the areas of multi-domain lifestyle interventions and pharmacological treatments call for a transformation of Alzheimer’s disease clinical pathway. AD-RIDDLE sets out to improve this pathway by means of developing a modular toolbox, offering instruments for risk-reduction, early detection, diagnosis and intervention. Specifically, digital cognitive assessment tools, blood-based biomarkers and lifestyle-based intervention protocols shall be optimised and streamlined into one digital portal, to optimise the clinical pathway of Alzheimer’s disease. During the kick-off meeting in Stockholm, representatives of 24 partners from academia, healthcare, industry and non-profit organisations met to discuss different work packages, facilitate partnerships and set the stage for effective collaboration throughout the five-year project.

Within the consortium, Alzheimer Europe leads two work packages concerning facilitation of the real-world implementa-

tion of AD-RIDDLE (e.g., ethical, policy, health economic considerations) as well as communication and public involvement. Angela Bradshaw (Director for Research), Ana Diaz (Public Involvement Lead), Sarah Campill (Public Involvement Officer) and Lukas Duffner (Project Officer) joined the kick-off meeting on behalf of Alzheimer Europe.

The AD-RIDDLE project has received funding from the Innovative Health Initiative 2 Joint Undertaking (JU), under grant agreement No 101132933 (2024-2029). The JU receives support from the European Union’s Horizon Europe research and innovation programme and COCIR, EFPIA, EuropaBio, MedTech Europe and Vaccines Europe, with Davos Alzheimer’s Collaborative, Combinostics OY., Cambridge Cognition Ltd., C2N Diagnostics LLC, and neotiv GmbH.

4-5 JUNE

ADIS Partners meet for General Assembly in Regensburg (Germany)



On 4-5 June, ADIS project partners met in Regensburg (Germany) and online for their biannual General Assembly, hosted by the Fraunhofer Institute for Toxicology and Experimental Medicine (ITEM-R). The meeting began with opening remarks by the project coordinator Holger Fröhlich Fraunhofer Institute for Algorithms and Scientific Computing (SCAI). Next, Vanessa Lage-Rupprecht (SCAI) reported on project progress and underlined a dissemination milestone, achieved with the publication of the first project paper, accessible [here](#).

Christophe Bintener (Alzheimer Europe) then gave an update on the communication activities. The following presentation was given by Neus Falgàs from Fundació Clínic per a la Recerca Biomèdica (FCRB). She provided an overview of the clinical data and biosample acquisition process, which has been finalised. After a lunch break, Holger Fröhlich gave an overview of the recently launched Innovative Health Initiative funded “PREDICTOM” project. The afternoon focused on agent-based modelling with a presentation by Uri Nevo (Tel Aviv University).

The next presenter was Sophia Krix (SCAI) explaining the different possibilities to analyse the data generated at FCRB using Artificial Intelligence and statistical modelling. Last but not least, Soraya Moradi-Bachiller (Alzheimer Europe) spoke about the consultations with the young ADIS Advisory Board focusing on a brain health campaign that was extensively discussed with the project partners.

The second day started with a guest speech by Rainer Spang, who gave an overview of research on single-cell data and modelling progressive diseases. The consortium partners then had a lively discussion on the brain health campaign and how it could be organised. They also discussed the format and timing of a public event. Holger Fröhlich then closed the meeting, thanking all attendees for the constructive exchanges and contributions.

5 JUNE

AI4HOPE project holds first in-person project meeting in Helsinki



The AI4HOPE (Artificial Intelligence Based Health, Optimism, Purpose, and Endurance in Palliative Care for Dementia) project held its first in-person project meeting in Helsinki on 5 and 6 June 2024. AI4HOPE aims to unite artificial intelligence, physiological measures and psychosocial interventions in a palliative-care ecosystem, in order to support people with dementia and their carers. This first in-person meeting was attended by representatives from academia, industry, clinical practice and patient organisations who discussed the steps that need to be taken for technical implementation and set the tone for effective collaboration in the upcoming years (AI4HOPE will run until 2028). Daphné Lamirel (Public Involvement Officer), Dianne Gove (Director for Public Involvement and Ethics) and Lukas Duffner (Project Officer) attended on behalf of Alzheimer Europe and took part in workshops regarding the technical aspects of the project, data protection and discussions with clinical partners. They also presented Alzheimer Europe’s work and communication channels.

Throughout the lifecycle of AI4HOPE, Alzheimer Europe will be leading the Public Involvement activities, involving members of both the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG), and will contribute towards all communication activities. AI4HOPE receives funding from the European Union’s Horizon Europe research and innovation programme (grant agreement no. 101136769).

10-11 JUNE

Members of INTEREST meet in Amsterdam



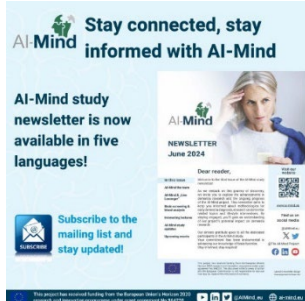
On 10-11 June, members of the INTEREST (Innovations in diversity and equity in social health research in dementia) project attended a two-day hybrid meeting in Amsterdam. INTEREST is funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND), and is looking at the topics of inequity and unmet needs in dementia care in Europe, with a special focus on social health and intersectionality. The group is led by Dr Louise Hopper (Dublin City University) and consists of international experts with interdisciplinary backgrounds. Alzheimer Europe is leading the Public Involvement (PI) activities of the project.

During the meeting, researchers leading the different workstreams provided an update on their work and discussed the plans for coming months including the social health framework; the review of unmet needs of people with dementia and carers, of effective psychosocial interventions and use of technology in dementia care; and the policy and communication activities.

The PI activities include face-to-face and online meetings with members of the European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG). The meeting with members of the EWGPWD already took place in March, in Brussels, and had a focus on unmet needs and health disparities experienced by people with dementia. The meeting with the EDCWG is planned in June, in Luxembourg. Ana Diaz, Public Involvement Lead, attended the meeting on behalf of Alzheimer Europe.

11 JUNE

AI-Mind's third study newsletter is available in five languages



On 11 June, the AI-Mind project released the third issue of its study newsletter in five different languages (English, Norwegian, Finnish, Italian and Spanish).

This newsletter provides valuable updates on the latest advancements in dementia research and offers insights into

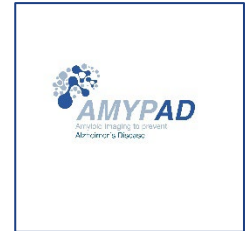
the progress of the AI-Mind project. Released periodically, this informative newsletter keeps subscribers informed about innovative methodologies for early dementia diagnosis, recent dementia-related studies and lifestyle interventions to enhance overall well-being. To ensure inclusivity and engagement, the newsletter is shared with AI-Mind study participants who are keen to learn about the study's progress in various countries. In this third issue, readers can explore key moments from the last AI-Mind General Assembly and an exhibition dedicated to ageing. The newsletter also provides valuable insights into brain screening methods and the benefits of blood analysis, among other topics.

<https://www.ai-mind.eu/blog/ai-minds-study-newsletter-is-now-available-in-five-languages/>

17 JUNE

Paper on amyloid-PET imaging predicting functional decline published by AMYPAD researchers

On 17 June, an international team of researchers from the amyloid imaging to prevent Alzheimer's disease (AMYPAD) project published a new paper titled "Amyloid-PET imaging predicts functional decline in clinically normal individuals" in the journal Alzheimer's Research & Therapy.



There is good evidence that elevated amyloid- β ($A\beta$) positron emission tomography (PET) signal is associated with cognitive decline in clinically normal individuals. However, it is less well established whether there is an association between the $A\beta$ burden and decline in daily living activities in this population. In this study, authors used data from the AMYPAD Prognostic and Natural History Study, a large European amyloid-PET dataset phenotyping longitudinally individuals at risk of Alzheimer's disease progression. The primary aim of the study was to assess the natural history of functional decline and relate it to individuals' baseline $A\beta$ burden. The authors concluded that amyloid-PET quantification supports the identification of clinically normal individuals at risk of functional decline. We would like to congratulate Lisa Quenon, first author of the paper and all authors who contributed to this work. One of the authors, Cindy Birck, is Project Officer at Alzheimer Europe and Alzheimer Europe is delighted to have been involved in authoring this article.

<https://doi.org/10.1186/s13195-024-01494-9>

SPONSOR OF THE MONTH

Alzheimer Europe would like to express its gratitude to a new sponsor for its 2024 activities:



Read more about sponsorship opportunities here:
<https://www.alzheimer-europe.org/about-us/governance/finances/2024-sponsorship-opportunities>

Help us give a voice to people with dementia

Donate



EU project acknowledgements



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon 2020, Horizon Europe, the Innovative Medicines Initiative 2 (IMI2) Joint Undertaking (JU), or the Innovative Health Initiative (IHI) JU. Projects funded through the IMI2 or IHI JU receive support from EU Research & Innovation programmes, as well as industry federations and other contributing partners. Please visit the project website(s) listed below for specific details on the organisations, federations and funders providing support for individual projects.

The projects in this newsletter are:

AD-RIDDLE – grant agreement 101132933 (<https://ad-riddle.org/>)
 AI4HOPE – grant agreement 101136769 (<https://www.ai4hope.eu/>)
 AI-MIND - grant agreement 964220 (<https://www.ai-mind.eu/>)



The **ADIS** project is supported by the Luxembourg National Research Fund (INTER/JPND21/15741011/ADIS) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu

The **Multi-MeMo** project is supported by the Luxembourg National Research Fund (INTER/JPND22/17107181/Multi-MeMo) under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu

MEMBERS OF THE EUROPEAN ALZHEIMER'S ALLIANCE



Currently, the total number of MEPs in the Alliance stands at **96**, 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):

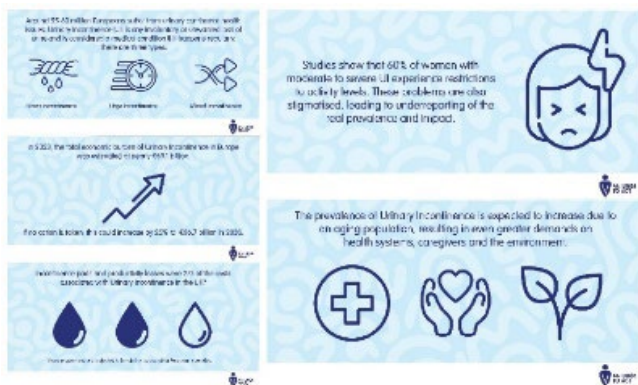
Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium:** Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria:** Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D). **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 Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Patricia Chagnon (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Marie Dauchy (I&D); Geoffroy Didier (EPP); Catherine Griset (I&D); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Jean-Lin Lacapelle (I&D); Pierre Larrourou (S&D); Eric Minardi (I&D); Nadine Morano (EPP); Philippe Olivier (I&D); 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 (Renew Europe); Deirdre Clune (NI); Ciarán Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Petras Auštrevičius (Renew); Vilija Blinkevičiute (S&D); Liudas Mažylis (EPP). **Luxembourg:** Marc Angel (S&D); Charles Goerens (Renew Europe); Tilly Metz (Greens, EFA); 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:** João Albuquerque (S&D); Sara Cerdas (S&D); Maria da Graça Carvalho (EPP); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Cláudia Monteiro de Aguiar (EPP). **Romania:** Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Klemens Grošelj (Renew Europe); Irena Joveva (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA). **Sweden:** Peter Lundgren (ECR).

EU DEVELOPMENTS

17 JUNE

European Association of Urology marks World Continence Week with a series of infographics and highlights two important publications



World Continence Week is being observed this year from 17 to 23 June. The European Association of Urology is marking this awareness-raising week with a series of specially-created infographics and is also using this week as a platform to highlight two important publications:

The first is a manifesto for policy reform on Continence Health in Europe, called "An Urge to Act". The manifesto was launched at the first Continence Health Summit in Brussels, in November 2023, and was endorsed by Alzheimer Europe alongside 22 other scientific, professional, patient and non-profit organisations. The manifesto aims to raise awareness among EU and national policymakers of continence health problems and to instil the need for action. It calls for concrete policy changes to face the challenges posed by the report and makes ten high-level recommendations to European and national policymakers to recognise the importance of patient-centred continence care. It also promotes a holistic understanding of the intricate links between continence health and healthy ageing, women's health, as well as disease areas like

cancer, mental health, neurological problems and several other comorbidities such as obesity. This will require increased funding for continence health research.

Read the manifesto, here: https://d56bochluxqnz.cloudfront.net/media/109857_EAU_Urge-To-Act_Manifesto_A5-folder.pdf

A report commissioned by the European Association of Urology, and conducted by Triangulate Health Ltd, on the socio-economic and environmental costs of continence health problems. This research on the economic burden of urinary incontinence reveals that the cost of continence care will reach an estimated EUR 69.1 billion in 2023. These costs include the impact of incontinence on individuals' health, the costs of medical consultations and products such as continence pads, incontinence-related absenteeism at work, nursing home admissions, and the environmental impact of incontinence care. If no action is taken to support continence health, the economic burden could rise by 25% in 2030, to EUR 86.7 billion. This economic burden becomes considerably higher when including caregiver costs.

Read the report, here: https://d56bochluxqnz.cloudfront.net/media/Socio-economic_report_UrgetoAct.pdf#as-set:4080543@1

Find out more about "An Urge to Act": <https://uroweb.org/an-urge-to-act>

19 JUNE

European Commission reports on European Semester process

The European Commission has reported on the 2024 European Semester Spring Package, providing guidance on policy coordination. This includes implementation of NextGenerationEU and the Recovery and Resilience Facility (RRF), as well as Cohesion Policy programmes. The Euro-



pean Semester cycle also provides updated reporting on progress towards the delivery of the Sustainable Development Goals and identifies investment priorities for the upcoming mid-term review of the EU's Cohesion Policies.

The country reports identify key challenges, with a particular focus on competitiveness, and priority reforms and investments. Additionally, the Commission proposes country-specific recommendations (CSRs) to provide guidance to Member States on how to tackle key challenges that are only partially or not addressed in Member States' RRP. The country-specific recommendations are divided into:

- A recommendation on fiscal policy, including fiscal-structural reforms, where relevant

POLICY WATCH

27 MAY

Alzheimer Scotland's Active Voice members participate in launch of "Future of Long-Term Care" report



Alzheimer Scotland's Active Voice includes both the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN). Dementia Awareness Week 2024, which took place from 27 May to 2 June, started with both groups being well represented at the launch of a report which provides recommendations on the Future of Long Term Care in Scotland. This radical report was produced by a 'commission' which was specifically set up in 2022 to review options in relation to long-term care.

Members of both SDWG and NDCAN have been key members of the commission from its outset and indeed, contributed to the content of the report. In recognition of their involvement, Kenny (pictured, right) from SDWG and then Bill (pictured, left) from NDCAN gave a presentation at this well-attended event and both outlined what long-term care means to them, and why the recommendations of this new report are so important. Read more about the report, here:

<https://www.alzheimer-europe.org/news/alzheimer-scotland-publishes-long-term-care-findings>

- A recommendation to continue or accelerate implementation of the national recovery and resilience plans and Cohesion Policy programmes
- Where relevant, further recommendations on outstanding and/or newly emerging structural challenges, with a focus on improving competitiveness.

In this Semester cycle, the Commission has carried out for the first time a two-stage analysis of employment, skills and social challenges in each Member State, based on the revised Social Scoreboard and the principles of a Social Convergence Framework. All documents relating to the Semester are available at:

https://ec.europa.eu/commission/presscorner/detail/en/ip_24_3290

13 JUNE

UNCPRD Committee elects new members

The United Nations Committee on the Rights of Persons with Disabilities has elected nine new members to support its work in the review process of the UN Convention on the Rights of Persons with Disabilities (UNCPRD).



During this election, the European Union, acting as a regional integration body, presented a candidate to the UN's human rights treaty body. Inmaculada Placencia-Porrero is a Senior Expert on Disability at the European Commission and has led work on the rights of persons with disabilities, including the development of several policies and legislation, such as the European Accessibility Act.

Ms Placencia-Porrero was elected to the Committee and will serve her term, along with the other members, between 1 January 2025 and run until the end of 2028. Further details on the new members are available at: <https://www.ohchr.org/en/events/events/2024/seventeenth-conference-states-parties-and-2024-elections>

19 JUNE

UK dementia organisations issue joint election manifesto

UK dementia organisations have joined forces to publish a new dementia manifesto ahead of the General Election on 4 July 2024. The Alzheimer's Society, Alzheimer Scotland, Dementia UK, Alzheimer's Research UK and the UK Dementia Research Institute have published "Dementia: a manifesto", calling on the next UK Government to make dementia a priority.



The joint manifesto calls on the next UK Government to make dementia a priority, highlighting that there are currently 982,000 people living with dementia in the UK and that many do not have a formal diagnosis, resulting in a lack of care, support and the treatment opportunities. Additionally, the manifesto notes that there is no cure and that existing care and

treatment options are often disjointed, inaccessible and inadequate for people with dementia and their families and carers. The organisations call on the next UK Government to:

- Better understand how to prevent, reduce and delay dementia
- Increase access to diagnosis and treatment
- Help people living with dementia navigate support systems
- Create a care system that works for everyone
- Invest in the future of dementia research.

The full manifesto can be downloaded at: <https://www.alzheimers.org.uk/news/2024-06-19/uk-organisations-release-new-dementia-manifesto-ahead-general-election>

SCIENCE WATCH

20 MAY

The use of an Artificial Intelligence-powered tool to predict the needs for amyloid-PET scans



On 20 May, researchers published an article about a tool to improve the diagnosis of Alzheimer's disease (AD) in the journal PLOS ONE. While new guidelines recommend the use of a brain imaging technique called amyloid-PET to help diagnose AD, patients find these scans burdensome, they are expensive and not widely available. Identifying patients that would benefit from a scan is therefore valuable.

Bringing together expertise from patient care as well as Artificial Intelligence (AI), the team developed a new method to improve the diagnosis of AD. The computerised decision support approach used machine learning to classify 286 people based on neuropsychology, APOE, and MRI.

These were participants from the Amsterdam Dementia Cohort, consisting of 286 participants of comprises of 135 healthy participants, 108 people living with AD due to dementia, 33 people with frontotemporal dementia as well as 10 people living with vascular dementia. For uncertain cases, hypothetical amyloid-PET results were added to increase diagnostic certainty. If certainty improved, the actual PET result was used.

Results showed that the computerised method recommended amyloid-PET for 21% of patients, achieving diagnostic certainty for 66%. This approach was better than three comparison scenarios: no amyloid-PET (54%), amyloid-PET according to appropriate use criteria (55%), and amyloid-PET for all (54%).

This method selected 21% of memory clinic patients for amyloid-PET without compromising diagnostic performance, and promoted a cost-effective implementation. In addition, it aids clinicians in decision-making during evaluations.

<https://doi.org/10.1371/journal.pone.0303111>

22 MAY

Otsuka terminates development of AVP-786 for AD agitation

On 22 May, Otsuka Pharmaceutical has announced the termination of development of its compound AVP-786, which was under investigation as a therapy for agitation associated with dementia.

The decision follows the recent top-line results of a Phase 3 trial, which evaluated the efficacy, safety and tolerability of AVP-786 for the treatment of agitation in people with dementia of the Alzheimer's type. The experimental drug failed to meet the primary efficacy endpoint, showing no significant difference from placebo in the change from baseline to week 12 in the Cohen-Mansfield Agitation Inventory (CMAI) total score. The multicentre, randomised, double-blind, placebo-controlled study's top-line results were initially released in February, with Otsuka subsequently conducting a detailed analysis of the data from the completed trial.



Following this detailed analysis, the company announced the decision to stop its clinical programme for AVP-786.

As a leading company in the central nervous system field, the company said that it will continue research and development efforts to meet unresolved medical needs and will continue to focus on addressing agitation associated with Alzheimer's disease.

https://www.otsuka.co.jp/en/company/news-releases/2024/20240522_2.html

22 MAY

A Narrative Review Study on End-Of-Life Care For People With Dementia And Comorbid Cancer



Clair Surr and Laura Ashley's (2024) narrative review study on end-of-life (EOL) care for individuals with dementia and comorbid cancer underlines the complexity of providing effective EOL care to this demographic and identifies significant research gaps.

In their paper, the authors examine key findings from recent studies. Some of these findings include the notable lack of research focused on

EOL care for people with dementia and comorbid cancer as well as the limitations of the available research, which is mainly based on American or Asian retrospective examination of routine datasets. Other findings suggest that individuals with both cancer and dementia are at risk of worse EOL care outcomes than people with cancer without dementia. An example of these possible worse EOL care outcomes is poor pain management. This group, along with their families, face more complex EOL care needs and may experience high levels of unmet needs for practical and psychosocial support. Those diagnosed with dementia, at or after their cancer diagnosis, are at a higher risk of receiving aggressive EOL care that fails to meet their evolving needs, including their dementia-related needs.

The authors conclude that there is a need for studies collecting primary data (using prospective and longitudinal designs and employing mixed methodologies) and emphasise the importance of understanding what constitutes good care for individuals with dementia and comorbid cancer and how it can be effectively delivered by specialist palliative and EOL care teams.

Please follow the link to read the paper by Clair Surr and Laura Ashley: <https://pubmed.ncbi.nlm.nih.gov/38841908/>

6 JUNE

New study suggests that vigorous physical activity may affect cognition in people with high-risk hypertension



Hypertension is an established risk factor for cardiovascular and cerebrovascular diseases and it also represents a key modifiable risk factor for the development of cognitive impairment.

Physical activity, by itself, is associated with a lower risk of decline in cognition, however, the optimal volume and intensity of exercise to benefit cognition is still unclear.

In a new study published in the journal *Alzheimer's & Dementia*, a team of researchers led by Dr Richard Kazibwe from the University School of Medicine, North Carolina (US) investigated the association of self-reported vigorous physical activity (VPA) with the risk of developing cognitive impairment among 7,670 individuals aged ~70 years (34.5% women) with high-risk hypertension undergoing blood pressure control.

In the study, participants were asked about the frequency with which they engaged in VPA (i.e. activities that would make the person sweat, increase their heart rate, or increase their breathing) over the past 12 months. According to the self-reported VPA, researchers classified participants into two groups; the high VPA category and the low VPA category, where the former refers to participants engaging in VPA once or more than once per week and the latter states the VPA frequency to be less than one session per week.

After a maximum follow-up of 7.4 years, the risk of cognitive impairment outcomes was analysed. The incidence of MCI and dementia among participants with high-risk hypertension who reported engaging in VPA with a frequency of one or more sessions per week had a lower risk of MCI and probable dementia than those who engaged in less than one session of VPA per week.

Researchers also adjusted the results for alcohol consumption, depression, and cardiovascular risk factors, which had a minimal effect on the link between VPA and cognition. Although the researchers showed the role of VPA as a preserver of the cognitive function in people with hypertension, further studies with longer observational periods, a diverse population of participants, and objective measures of physical activities are needed to confirm these findings.

<https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/alz.13887>

10 JUNE

FDA external advisors recommend approval of donanemab for AD



On 10 June, the Peripheral and Central Nervous System Drugs Advisory Committee convened to advise the US Food and Drug Administration (FDA) on the safety and efficacy of the drug donanemab from Eli Lilly, which is being considered for approval.

During the meeting, advisors comprehensively reviewed the data of the TRAILBLAZER-ALZ 2 trial Phase 3 study, which evaluated the efficacy and safety of donanemab in early symptomatic Alzheimer's disease (AD) -MCI or mild dementia due to AD- with the presence of confirmed Alzheimer's disease neuropathology. The trial enrolled 1,736 participants, across eight countries, selected based on cognitive assessments in conjunction with amyloid plaque imaging and tau staging by positron emission tomography (PET) imaging.

In its discussion, the FDA had asked the panel to consider some unique aspects of Lilly's trial, especially that study participants stopped taking the drug as soon as their amyloid was cleared and the study's inclusion of participants based on tau levels. The 11 committee members voted unanimously in favour of the monoclonal antibody donanemab, being effective for people with an early stage of AD and that the drug's benefits outweigh the risks. The panel, however, raised concerns about certain safety risks and insufficient representation of underrepresented group like Hispanic and Black people in the Phase 3 trial.

The FDA will soon decide on donanemab's marketing authorisation. The FDA is not compelled to follow the recommendation of the independent panel of experts but it often does so. <https://www.science.org/content/article/fda-panel-backs-new-alzheimer-drug-despite-risks-uncertainties>

16 JUNE

Study assesses return on investment of European Commission-funded Alzheimer's disease research

Alzheimer's disease (AD) is among the non-communicable chronic diseases (NCDs) placing the highest burden on people living with the disease, carers, healthcare systems and society. Throughout the last two decades, the European Commission (EC) has funded research projects across all facets of AD, throughout five funding cycles. A recent study published in the journal BMC has examined the return on investment of such funding actions, in terms of scientific, public health, policy and economic impact. In particular, the impact generated



across these domains is assessed by fourteen indicators and comparisons with two other NCDs, breast cancer and prostate cancer, are drawn.

The authors note that EC AD research funding has been growing steadily over the years (the study examines the timeframe between 1999 and 2019), both in terms of volume and allocated financial resources, though the introduction of the Horizon 2020 (H2020) funding scheme came with a minor decrease in funding for AD, as compared to other NCDs. EC-funded AD-related projects generated a total of 6584 publications. AD-related projects funded resulted in 68 patent applications and 28 projects focussing on the development of new diagnostic tools. Notably, only a few funded attempts were made to increase the efficiency of established psychological and neurological diagnostic tools. AD-research funding by the EC has also informed several regulatory and policy measures and created a high number of education, training and learning opportunities for researchers and students.

However, the authors outline that the ratio between investment and achievement may be less beneficial in AD as compared to breast cancer, mainly owing to the comparatively lower translational success concerning drug development. They also underline the substantial economic and public health benefits of early detection and prevention across different NCDs.

<https://resource-allocation.biomedcentral.com/articles/10.1186/s12962-024-00540-5>

17 JUNE

New study provides insights on palliative care for early dementia

A recent scoping review, published in the Journal of Pain and Symptom Management, aimed to map the current research on palliative care during the early stages of dementia. The review, carried out by Karen de Sola-Smith and colleagues, encompassed scientific literature from databases such as PubMed, CINAHL, EMBASE, Cochrane, PsycINFO and Web of Science, focusing on studies published in English over the last decade until March 2022.



The review revealed that, out of the 77 reviewed papers, only a few specifically focused on palliative care for the early stages of dementia. The key findings were first, that the term "early" palliative care lacks a clear definition in the literature. However, the evidence suggests that palliative care needs emerge at or before diagnosis and continue throughout the disease trajectory. The authors also highlight 'tipping points,' which are critical moments when providing or adapting palliative care is essential. These moments can occur when there are changes in symptoms, functional status or caregiving needs.

According to the review results, early-stage dementia palliative care needs encompass several key aspects. These include advocating for future care that aligns with the goals of the person with dementia, providing reassurance to prevent feelings of neglect and abandonment, planning for future care scenarios (covering practical, personal and relationship needs) and establishing long-term relationships with trusted care providers. Effective palliative care for early dementia might include having open discussions about care goals and guiding families to build support networks. It can also cover the provision of helpful tools and resources for families, personalised care that considers the individual's needs and ensuring that dementia-care providers are well prepared.

The authors conclude that there is a significant lack of evidence on palliative care provision in the context of early-stage dementia. They recommend that future research focuses on developing tools to determine the best timing for palliative care in early dementia. New research and tools should also focus on better understanding the needs of people with dementia and their families during the early stages, and training caregivers and families to maintain clear communication about care goals and future plans.

<https://pubmed.ncbi.nlm.nih.gov/38848792/>

MEMBERS' NEWS

15 MAY

Greek dance-movement action "To terponon meta tou ofelimou" applied to people with dementia



On 15 May, the Hellenic Alzheimer's Disease Association of Larissa (E.E.N.A.L.) participated in a social solidarity event, with the dance-movement action: "To terponon meta tou ofelimou". The Association applies dance kinetics to elderly people and people with dementia, in the context of healthy ageing and healthy cognition, through musical rhythm and its transformation into movement. The purpose of this event was to showcase an original and innovative action, to highlight the abilities of the beneficiaries and to increase their self-confidence for equal participation in social events.

The choreo-kinetics was presented by a ten-member female group, under the guidance of the choreographer Madalena Koutoula, in the central square of Larissa. The repertoire included the songs "Pes mou mia lex" by Manos Hatzidakis and "Kalimera" by Nektarios Vasileiou. With the performance of the choreographies, the women's group achieved the connection of mind and body, expressed emotions, which they depicted with harmonious and complex movements. The large audience and the city's institutions were amazed by the courage, enthusiasm and the transmission of emotions and messages they conveyed.

Particularly surprising was the participation of Despina (85-year-old), who performed the choreographies with confidence, enthusiasm and joy. The presentation of the dance movement ended with applause and many cheers from the audience. The Association encourages participants to show their skills to the public and encourages participation to help reduce ageism and stereotypes.

15 MAY

Alzheimer Scotland's Active Voice members participate in awareness session with social care students at City of Glasgow College

Alzheimer Scotland's Active Voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), have a shared priority to

support workforce knowledge and development, to help ensure that health and social care staff working with people living with dementia, their families and carers have opportunities to achieve appropriate knowledge and skills in their roles, informed by people with personal experience.



Group members regularly participate in sessions with existing and future workforce, sharing their experience to inform policy and practice. At the beginning of May 2024 SDWG members Stuart Dougall (pictured, front right) and Margaret McCallion (pictured, front left), and NDCAN member Marion Ritchie participated in an awareness session with social care students at City of Glasgow College, as part of a learning unit focussed on caring for people living with dementia.

The members shared their personal experiences with and answered questions from the students, helping them work towards achieving their learning outcomes which included identifying the strategies and skills required to meet the needs of people with dementia; and, explaining the ways to assist the carer in coping with the stresses associated with caring for people with dementia.

Both Margaret and Stuart emphasised the importance of person-centred care with Margaret speaking about the importance of “seeing the person as a person”, whilst Stuart highlighted the tagline of previous Alzheimer Scotland campaign he had fronted, that “dementia is one thing, not every thing” about a person. Stuart stressed that his “life may have changed, but it’s certainly not over”.

Marion spoke about her experience of receiving help from professional carers at home, in hospital, and in care home settings throughout the time she cared for her husband, Dave, who had a diagnosis of vascular dementia. She shared the stresses she experienced as a carer, and the feelings she had in relation to accepting that she required the support of professional carers, and of receiving that support.

Importantly, Marion highlighted some of the ways professional carers can assist a family carer to accept help by working with them in partnership in the provision of care. She offered suggestions for providing care in hospital that can help alleviate the distress of the person with dementia and the worries of the family carer. And, she shared points to consider when providing care in a care home setting. Finally, she told the students considering a career as a carer that “you are life savers”. The feedback following the session was very positive.

22 MAY

Politicians in the dementia experience café - there is a long way to go before the uniformity of social services across Estonia observes NGO Living with Dementia



NGO Living with Dementia held an "Experience Café" on 22 May in Tallinn with the candidates of the political parties in the European Parliament elections. The Experience Café is a meeting place for the members of the NGO, people with dementia, their relatives, specialists in the field and other interested parties.

At the event, the joint discussions revolved around how to ensure the dignity of people with dementia and what the legal system can do to protect the rights of people with dementia both in Europe and in Estonia.

Seven European Parliament candidates from seven different political parties took part in the discussion: "Is it only in their own interest to represent people with dementia?".

The discussion was chaired by Sirli Peepson, a member of NGO Living with Dementia.

As an introduction, Chris Ellermaa (pictured, right), member of the European Dementia Carers Working Group and Board member of NGO Living with Dementia in Estonia, opened with the scope of the dementia topic in Europe and Estonia:

- By 2025, there will be 9.1 million people living with dementia in Europe.
- By 2050, this number is estimated to reach 14.3 million.
- According to the World Health Organization (WHO), it is the third leading cause of death in Europe and the seventh in the world.
- According to the WHO, the cost of dementia in Europe in 2019 was EUR 392 billion.
- An estimated 23,000 people with dementia lived in Estonia in 2019, which is 1.74 percent of the Estonian population.
- By the year 2050, the number of people with dementia in Estonia will increase to an estimated 35,394 people.

All the candidates who participated in the discussion agreed on the importance, scale and number of dementia diagnoses and related issues that need to be addressed. By the introductory part of the discussion it became clear that everyone in the hall had their own personal experience and story with dementia.

Participants emphasised that in the case of dementia, not only the people living with dementia need support, but also their families and loved ones. The role of the patient advocacy organisation cannot be underestimated and is very important so that people are not left alone. It was brought up many times during the discussion that dementia is also a big financial cost for society and for the family. Despite the fact that awareness of dementia is growing, the topic should be dealt with more systematically. According to the UN Convention on Persons with Disabilities, countries have an obligation to deal with this topic on the one hand, but also there is a great need among all kinds of "invisible disabilities". From the country's point of view, there is a need to find bottlenecks and specific laws needed to be changed. At the same time, some important actions have already been taken, like the amendment to the law concerning long-term incapacity for work. The amendment also applies to dementia, in that the employer can keep a person working part-time.

During the discussion it was agreed that the day-care centres are the minimum level that municipalities can manage relatively easily. The day-care centres should exist as a structure and if those can keep the loved ones going to work, the personal income tax back will be paid back to the state budget. "A person with dementia is a normal person who just needs to be observed and interacted with. It is possible to make life with dementia dignified for both carers and people, so that they are not socially isolated. At the same time, the availability of social services varies greatly across Estonia, and there is still a long way to go before harmonisation", says Chris Ellermaa.

The participants unanimously agreed that legal issues must also be dealt with in relation to dementia: how to ensure that there are intermediate stages before the loss of legal capacity, when a person can participate in decision-making with the help of a representative of their choice. Dementia is a long-term and slow-moving disease, and supported decision-making, step-by-step representation, is an important issue for all loved ones in this area.

Social welfare and medicine are not organised at the EU level, it is up to each Member State. The use of public sector money could be more effective if we knew more about this disease, said Chris Ellermaa.

As a final comment, one candidate stated that guardianship for people living with the dementia must be "dignified and European".

28 MAY

New strategic partnership agreement is signed for Alzheimer Scotland Centre for Policy and Practice



National Dementia Carers Action Network (NDCAN) members Joanna and Marion were proud to represent Alzheimer Scotland's Active Voice at the signing of a new strategic partnership agreement in relation to the Alzheimer Scotland Centre for Policy and Practice (ASCPP) at University of the West of Scotland (UWS). By combining their expertise, UWS and Alzheimer Scotland, through the ASCPP, are making a significant difference in the lives of families affected by dementia and improving standards of care. As members of NDCAN, Joanna and Marion have formed strong ties with colleagues at the ASCPP. Indeed, lived experience has been central to the work of the ASCPP since its inception in 2013, and the involvement of both the Scottish Dementia Working Group (SDWG) and NDCAN members has been key to the success.

Pictured: Alzheimer Scotland Chief Executive Henry Simmons (left) & former First Minister Henry McLeish (right)

1 JUNE

Spominčica organised a theatre play to support people with dementia and their caregivers

Spominčica (Alzheimer Slovenia) fulfils its mission of helping people with dementia and their caregivers through various activities and is always open to cooperate with



different associations and new innovative approaches to support them. In May, Spominčica, in cooperation with the Red

Noses Association and the National Gallery, organised a lecture on the early signs of dementia and a theatre play titled "Let's Go to the Seaside" adapted for people with dementia. The aim of the play is to offer support through the art of clowning and to bring laughter and give hope to those facing difficult challenging health issues. The event was attended by people with dementia, their caregivers and family members, and the general public.

4 JUNE

UK research call launched to improve end-of-life experience for people with dementia



Recent evidence suggests that by 2040 there will be 1.4 million people with dementia in England and Wales. Dementia is

the UK's biggest killer, yet there are currently significant gaps in both evidence and service provision for people dying of, or with, dementia, meaning that many are not receiving the right care and support to have the best possible experience at the end of their lives.

Alzheimer's Society has partnered with Marie Curie to fund GBP 1 million (EUR 1.18 million) for new, impact-focused research that can improve the end-of-life experience for people with dementia and those who care for and support them. The GBP 1 million fund is available through Alzheimer's Society and Marie Curie. The objective of the call is to understand and address the unique needs of people with dementia, and to provide the right care and support which will improve the end-of-life experience for people with dementia and their carers.

Research proposals should be impactful and have well-specified and feasible pathways to involve policy and decision makers, people with relevant lived experience, and other key stakeholders. Both Alzheimer's Society and Marie Curie are committed to funding research which considers issues around equity, diversity and inclusion. Therefore, careful consideration should be given to project design and delivery, involving a diverse range of voices with lived experiences to help inform an inclusive research project. Applications opened on 4 June 2024 and the deadline for receiving expressions of interest is 30 July, while the deadline for full applications is 28 October. Applicants will be notified of the outcome in March 2025.

Find out more via: <https://www.alzheimers.org.uk/research/researchers/grants/marie-curie-research-grants-scheme>
 Apply via: <https://www.mariecurie.org.uk/research/information-researchers/marie-curie-research-grants-scheme>

6-7 JUNE

Conference "Dialogues in Neurodegenerative Disorders" takes place in Slovenia

On 6-7 June, the international conference "Dialogues in Neurodegenerative Disorders" took place in the Union Hall of the Grand Hotel Union in Ljubljana (Slovenia). Spominčica – Alzheimer Slovenija was co-organiser of the event and approximately 250 participants



from 20 different countries attended the conference. The ceremonial opening of the international conference brought together top experts, researchers, healthcare professionals, and representatives of social work to discuss the latest achievements and challenges in the field of neurodegenerative diseases.

The conference, held under the honorary patronage of the President of the Republic of Slovenia, Dr Nataša Pirc Musar, represented an important step towards better understanding and addressing these diseases. The keynote speakers at the opening ceremony were the President of the National Assembly of the Republic of Slovenia, Mag. Urška Klakočar Zupančič, the President of the National Council, Marko Lotrič, and the Minister of Health of the Republic of Slovenia, Dr Valentina Prevolnik Rupel. All government representatives emphasised the importance of the new Strategy for Dementia Management in Slovenia until 2030.

The conference focused on bridging the gaps between science, healthcare and caregiving, therapeutic programmes and social care, and people with neurodegenerative diseases and their caregivers. Participants were presented with cutting-edge research, innovative solutions to problems arising from neurodegenerative diseases, and best practices in care. Additionally, the conference provided an opportunity for people affected by neurodegenerative diseases to share their life stories and experiences, further connecting the academic and medical community with the public. As an example of good practice, the residents of the Fužine home for the elderly were presented. At the conference, Tomaž Gržinič shared his experience as a person with dementia and member of Spominčica – Alzheimer Slovenija.

Numerous international and domestic experts shared their insights and experiences. The "Dialogues in Neurodegenerative Disorders" conference represented a key event for raising awareness and promoting collaboration among various sectors dealing with neurodegenerative diseases. The organisers

hope that the conclusions and recommendations from the conference will contribute to improving the quality of life for patients and their families.

14 JUNE

Dementia-Friendly Point is opened at the Ministry of Health of the Republic of Slovenia



On 14 June, our Slovenian member opened a “Dementia-Friendly Point” at the headquarters of the Ministry of Health in Ljubljana, Slovenia. The Dementia-Friendly Point was jointly opened by the Minister of Health, Dr Valentina Prevolnik Rupel and the President of Spominčica – Alzheimer Slovenija, Štefanija Lukič Zlobec. At the event, Ms Zlobec presented the Minister with a certificate for the Dementia-Friendly Point, and together they placed the Dementia-Friendly Point sticker at the entrance of the Ministry and answered questions from the media.

On this occasion, the Minister of Health emphasised that her Ministry is aware and recognises the crucial importance of Dementia-Friendly Points for improving the quality of life of people with dementia and their families. Dementia represents one of the greatest challenges of an ageing society, therefore, they are striving for better understanding, acceptance, and support for people facing dementia, as well as their families and loved ones. Prof. Dr Zvezdan Pirtosek, neurologist and president of

the professional council of Spominčica and Dr Nožidar Voljč, member of the professional council of Spominčica, attended the opening.

Spominčica – Alzheimer Slovenija is pleased that important stakeholders are joining the network of Dementia-Friendly Points as they are an excellent example of good practice, contributing to maintaining dignity, independence, and integrity of people with dementia, as well as reducing the stigma associated with the condition. The network of Dementia-Friendly Points established by Spominčica now includes 433 different organisations across Slovenia and this will contribute to creating a dementia-friendly society in Slovenia.



LIVING WITH DEMENTIA

20 MAY

Pia Knudsen, member of the European Working Group of People with Dementia, talks about the Royal Run in her home town, Aarhus



When I was 22 years old I met the current King of Denmark, at the time he was Prince Frederik. He went to university in Aarhus, where I live, and occasionally came to the Casablanca Cafe, a place where many of us hung out. Despite him being always closely followed by his bodyguards, we occasionally talked and shared opinions about different things. Frederik has always spoken very positively about his stay in Aarhus, which we are proud of, and makes us feel somewhat connected to him and somewhat important. I have followed him ever since, from the side-lines of course! and loved him and his family ever since, just like almost all Danes do.

On 20 May 2024, I, along with three other people with dementia, were invited to take part in the “Royal run”, a popular run that takes place, every spring, in different places in Denmark. In Aarhus alone, 22,000 people participated in the run. It was a very sunny day and a fantastic experience, a huge party with different races for people of all ages. I was invited as a person with dementia because I work with one of the councillors in Aarhus.

When I had run my one mile, had pictures taken, and was on my way home, King Frederik and I saw each other, nodded to each other, looked each other in the eye and smiled. It only lasted a short moment, but a moment that was so fine that I hope I will never forget it. I live for such experiences, and the many other good things I experience. I collect them and I survive difficult times by remembering wonderful experiences.

Pictured: King Frederik X of Denmark at the Royal Run in Aarhus

LIVING WITH DEMENTIA – SPECIAL FOCUS ON DEMENTIA AND EMPLOYMENT

Up next, we have two articles in our Living with dementia section, focusing on the topic of dementia and employment. One is written by a member of the European Dementia Carers Working Group, Barry Northedge (Scotland, UK), and looks at the launch of a new film about dementia in the workplace, for which Barry and his wife Margaret, who is living with dementia, were interviewed. The second article is a personal account written by Pia Knudsen (Denmark), member of the European Working Group of People with Dementia, about her experience of losing her job after her diagnosis.

29 MAY

Dementia in the Workplace - “Guidance for Life, Work and Career”

Barry Northedge, member of the European Dementia Carers Working Group, writes about participating in a new film about dementia in the workplace, together with his wife Margaret.

Scotland’s Dementia Awareness Week saw the launch of the film, Dementia in the Workplace - “Guidance for Life, Work and Career”. This was the culmination of a co-production research project, funded by the Alzheimer’s Society, which aimed to explore the issues people faced when getting a diagnosis of dementia whilst still in employment, particularly pertinent to people diagnosed with Young Onset Dementia (YOD). Margaret, my wife, was just 54 when she was diagnosed with YOD, she was still working in a job that she loved but that soon came to an end as her employer did not understand the problems she was trying to deal with. This research was personal!



The co-production team consisted of six people living with dementia, two carers, six professionals from career guidance and health and social care and two academics from the University of the West of Scotland, all meetings were conducted on line and all meetings were recorded by a visual artist capturing the essence of discussions. There is no doubt that the lived experience of dementia was both central to the research and absolutely valued by all involved. There is also no doubt that those with lived experience appreciated the opportunity to be fully involved and to have their experiences, views and suggestions equally valued. On more than one occasion it was commented that 'being involved in the research was like being back at work', something sorely missed.

Many people diagnosed with dementia whilst still working have negative experiences hence there is clearly a need to create support for them to make and take decisions about their future whether that be remaining in employment or about a new direction for their 'career'. This is where the links with the career guidance professionals on the team were vital. They were able to take a person-centred approach to developing coping strategies, looking at reasonable workplace adjustments or in taking the decision to leave work for other opportunities. Opportunities

which needed a non-traditional view of career. We needed to accept that continuing work may not be a reasonable option for everyone but a diagnosis should not stop people from contributing in other ways such as volunteering or joining groups such as the Scottish Dementia Working Group, which members repeat 'is just like work'!

The project outlined the potential for career guidance to make a positive difference to the lives of people diagnosed with dementia if we accept a definition of career being about much more than paid employment. So, that brings us back to the film. Using the personal testimonies and experiences of people living with dementia, the research makes a compelling argument to address the issues of dementia and employment in a positive way through guidance and support. The film is available to view here: <https://youtu.be/glFAYkUByFg> Look out for the presentation in Geneva! This research was funded by the Alzheimer's Society.

Pictured: Members of the Scottish Dementia Working Group and National Dementia Carers Action Network attending 'Dementia in the workplace' film launch (with Barry and Margaret attending virtually)

26 JUNE

Pia Knudsen, member of the European Working Group of People with Dementia, writes about life after diagnosis and about her experience of dementia and the employment market

Unfortunately, it is a widespread myth that dementia is a consequence of old age. I am an example of how this is not the case. My name is Pia and I am 60 years old. I was diagnosed with Alzheimer's dementia four years ago. It is an early age to get a fatal disease, but it is not unique, my younger sister, who is 53 years old, has also been diagnosed. I currently live by myself in a house in Aarhus. My son lives in Barcelona, and my daughter is in the process of setting up her new life in Copenhagen. When I received the diagnosis, my boyfriend left and I was fired from my beloved job. It was very hard to cope with, and to recognise as my life. How to create meaning, when you lose your identity and your everyday life?

I have been a high school teacher throughout my working life, and in this way, I have made a difference to many people. I taught visual arts and design. After the diagnosis, my employer wanted someone who could work full-time, so I was fired, because I wasn't able to do that. The part-time jobs that the municipality offer are almost exclusively targeted at unskilled people, but what I need is to contribute as what I have been educated and trained to be, a teacher. And I need a job in which I feel I can contribute and create something for society and other people.

It is a shame and it makes me very sad that there are no meaningful employment offers for people with early-onset dementia who have a long-term education. It is very important to have a job that is meaningful. It creates meaning in an existence where one can quickly lose perspective and the joy of living. This problem will only grow in the future as more people will be diagnosed earlier. Therefore, I would like to make a call for politicians to create space and opportunities in the job market for people with dementia at working age, with any level of education. An opportunity like this would have enabled me to maintain my job and my identity as a college teacher, and to feel that I am still a person of value, instead of being someone with a diagnosis of dementia who is a burden, both for society and my relatives. I remain hopeful that this will happen, but after four years, in which I have applied for jobs as a teacher and have been rejected because of my diagnosis, hope is fading.



NEW PUBLICATIONS AND RESOURCES

17 MAY

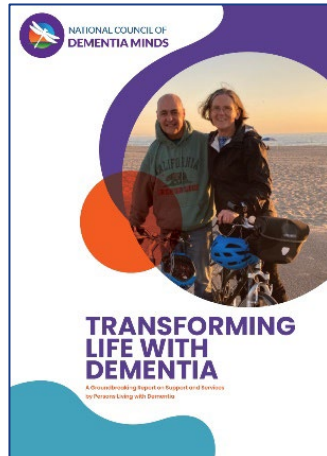
National Council of Dementia Minds in USA launches "Transforming Life With Dementia" reports

The National Council of Dementia Minds in the USA launched their "Transforming Life With Dementia" reports on 17 May 2024.

The first is a ground-breaking needs-analysis report of what people diagnosed felt they needed upon hearing a dementia diagnosis: <https://dementiaminds.org/dementia-needs-analysis-report-download/> (the 131 recommendations can also be seen on this page, at the bottom).

The second is a booklet version with photos of people living well with dementia. It gives a Top Ten version of what is needed upon diagnosis: https://dementiaminds.org/dementia-needs-analysis-report-download/#flipbook-df_1517/1/

The National Council of Dementia Minds is a non-profit organisation founded and governed by persons living with dementia.



Buzzword or not, the time for a digital transformation of aged care is now. The digitalisation of European aged care urgently needs a boost. Ageing, staff shortages and older people's quality of life require new methods of delivering aged health and social care services and a smart, wise and cost-effective transition in the sector. The ageing population in Europe is growing rapidly, creating a higher demand for innovative solutions to support older adults and their caregivers. The primary concerns for care recipients are enhancing independence, improving quality of life, and ensuring safety and wellbeing. There is a need for tools, and their implementation, to assist carers and informal caregivers in providing effective and personalised care while also reducing their workload. The digital transition of aged care in Europe seems to stumble behind other care sectors like hospitals and primary care.

The EAN found a lack of vision and underlying strategy, a lack of funding and insufficient skills and training as the main reasons for this gap. Age-tech is booming across Europe. The concept of Age-tech comprises a wide range of digital technologies, products and solutions that particularly address the needs and demands of the ageing population and can support aged care providers and support older adults to live a healthy, active and independent life. Age-tech solutions include teleconsultation, emergency response systems, tracking devices, home safety, and security. Other Age-tech areas are mobility devices e.g. walkers, scooters, power-assisted wheelchairs, in-car technologies such as parking assistance or GPS navigation; aids for vision/hearing impairment and other assistive technologies. Equally importantly, Age-tech devices can help both formal and informal caregivers to perform their services more effectively, safely and efficiently.

Read the publication, at: <https://www.ean.care/en/publications>

13 JUNE

European Ageing Network publishes report on "Accelerating the Digital Transition" for sustainable elderly care in Europe



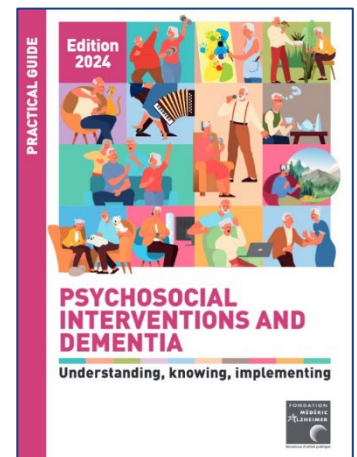
The European Ageing Network (EAN) is the European trade association of aged care and service providers. Following its vision on aged care in 2030, The EAN strives for better quality of life of older adults, while maintaining a high quality of care. In line with that vision, The EAN recognises the importance of digitalisation and Information and Computer Technology (ICT) in high quality care provision and its positive effects on quality of life. To better understand challenges and to further take advantage of ICT and digitalisation, The EAN has set-up a working group 'Digital Care'.

22 JUNE

Fondation Médéric Alzheimer publishes new guide on psychosocial interventions

The Fondation Médéric Alzheimer has published a new edition of its guide 'Psychosocial interventions and dementia: Understanding, knowing, implementing' on its website.

In this new version, the chapters have been updated by the initial authors and summary tables have been added. This new version also completes certain chapters by highlighting



specific interventions or devices (e.g. theatre, tango-therapy and the PARO seal cub robot). One section is dedicated to digital devices, which are increasingly being used in psychosocial interventions (such as virtual reality, augmented reality and animal-like robots).

The guide is targeted at professionals working directly or indirectly with people with dementia. It aims to improve their knowledge and understanding of psychosocial interventions designed to maintain and/or improve cognitive, psychological, social and physical functioning and, more globally, quality of life of people with dementia. The relationship and interaction between the person providing the intervention and people living with dementia are central to the support they provide. The interventions described in the guide were developed to be either therapeutic or recreational.

You can download the guide free of charge at the following address: https://www.fondation-mederic-alzheimer.org/wp-content/uploads/2024/06/guide-inm-2024-psychosocial-interventions-and-dementia_english.pdf

25 JUNE

TouchNEUROLOGY publishes new edition of its journal touchREVIEWS in Neurology

The latest edition of touchREVIEWS in Neurology is full of topical content that highlights the current landscape and future directions in neurological research and treatment. Explore touchREVIEWS in Neurology Volume 20, Issue 1, 2024, here:

<https://touchneurology.com/journals/touchreviews-neurology/touchreviews-in-neurology-volume-20-issue-1-2024/>



AE CALENDAR 2024

DATE	MEETING	AE REPRESENTATIVE
2-3 July	EMA Patients' and Consumers' Working Party meeting (Amsterdam, the Netherlands)	Angela
9 July	European Academy of Neurology meeting on "Economic Burden of Neurological diseases in Europe"	Jean
11 July	Consultation with the ADIS Young Adults Advisory Board	Soraya
15 July	eBRAIN-Health General Assembly meeting	Daphné and Angela
16 July	Alzheimer's Association Academy on Palliative Care	AE members and staff
28 July	WW-Fingers Network Meeting (Philadelphia, USA)	Jean
29 July	International AD/ADRD Research Funders Consortium (Philadelphia, USA)	Jean
30 July	CEOi luncheon (Philadelphia, USA)	Jean
28 July-1 August	Alzheimer's Association International Conference (Philadelphia, USA)	Jean

CONFERENCES 2024

DATE	MEETING	PLACE
28 July-1 August	AAIC 2024 – A global forum to advance dementia science, https://aaic.alz.org/	Philadelphia, USA and online
18-20 September	20 th EuGMS Congress - "From Healthy Ageing to Complex Needs in Older Adults", https://eugms2024.com/	Valencia, Spain
25-27 September	IPA 2024 International Congress - Crossing Oceans and Connecting People to Improve Mental Health for Older Adults, https://www.ipa-online.org/events/2024-international-congress	Buenos Aires, Argentina
8-10 October	34 th Alzheimer Europe Conference – New horizons – Innovating for dementia, https://www.alzheimer-europe.org/	Geneva, Switzerland
29 October – 1 November	17 th Clinical Trials on Alzheimer's Disease (CTAD), https://www.ctad-alzheimer.com/	Madrid, Spain

34th Alzheimer Europe Conference

New horizons – Innovating for dementia

Geneva, Switzerland

8 - 10 October 2024 #34AEC

www.alzheimer-europe.org/conferences

