



Alzheimer's Disease
International

The global voice on dementia

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Global Perspective

A newsletter for Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.



On the 23 May, ADI led a side-event to the 71st World Health Assembly in Geneva. ***Mobilising Society: Inspiration for developing national responses to dementia*** was a particularly significant event for dementia advocacy and the advancement of dementia on the global agenda, as it was the only event at the WHA this year dedicated to highlighting dementia as a global health challenge.

It also marked two important occasions: the one-year anniversary of WHO's *Global action plan on the public health to dementia 2017-2025*, and the launch of ADI's new report: *From plan to impact: Progress towards targets of the Global plan on dementia 2017-2025*.

We were joined by an expert panel of speakers who presented on the experience and effect of dementia in their country, creating a national plan and targets for the future. On the panel sat Paola Barbarino, ADI

CEO, Dr Shekhar Saxena, former Director of the Department of Mental Health and Substance Abuse at World Health Organization, a representative of the governments of the Netherlands, Japan, Australia and the UK, and Kate Swaffer, Co-Founder and CEO of Dementia Alliance International.

The event facilitated a diverse group of panellists and audience members to share experiences, to learn, and to inspire mobilisation for the creation of more national plans.

Paola Barbarino concluded the event by saying, "We have a huge challenge ahead of us, which would see us need at least 15 new plans a year to hit the 2025 target. Governments must act now as national plans take time to develop and set in place and are essential in achieving tangible actions for the benefit of people with dementia and their families and care partners who don't have time to wait."



Alzheimer's Disease International

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of *Global Perspective* to arrive by 1 October 2018.

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Editorial

Paola Barbarino, CEO

As ever, the team has been frantically busy since my last editorial in Spring 2018. One of the highlights was the publication of *From Plan to Action*. As I said at the very start of my tenure, so often nations produce action plans but then take no action. One year since the approval of the *WHO Global Action Plan on Dementia* we positioned ADI firmly as the organisation who praises governments who are working hard to transform plans into reality while questioning those governments who don't. At a packed side event in the Palais de Nations in Geneva, I was joined by the Mental Health Department of WHO - which launched its excellent guide to creating a national action plan - and representatives of Japan, the UK, the Netherlands and Australia, as well as Dementia Alliance International, to discuss everything good that has come from their countries on dementia in the last year.

The Alzheimer University on Policy in London saw representatives of 12 member associations coming together to analyse how to push their governments into action for the benefit of people with dementia and their families. The Training of Trainers initiative in Jakarta was a resounding success with many members taking part. The STRIDE project kicked off in earnest with many successful gatherings of participating members. Two important WHO regional meetings also took place, in Brazzaville and Lebanon, to discuss the implementation of national plans with government representatives. The former saw limited member participation but hopefully some new interest from nations not yet in the ADI network.

Also of note was ADI participation at events and meetings in Argentina, Bolivia, Mexico, the Philippines, Bosnia and Herzegovina, Spain, Switzerland, Sweden and the joint launch with OECD of the excellent 'Care needed' report.

We were very disappointed to learn of France's decision to discontinue reimbursement of four Alzheimer's drugs. This also gave us an opportunity to launch our pledge to get anti-dementia drugs onto the WHO list of essential medicines because, if we do not do it, this could become a serious issue for us all in the future.

We launched our new series of webinars for members and many took part. This follows the results of our membership survey last year and we hope it will become a regular way to exchange news and information more interactively between us all. We also hope it will make us stronger and better informed in our tireless work.

I lastly wanted to highlight Chicago. It has been an honour and a pleasure to work on the conference this year. The programme includes new sessions and topics never before aired. We have worked very hard on all sessions and, in the Entrepreneurship and Innovation session, we are pleased that IKEA will join us to speak of their new range of their furniture designed with dementia in mind. So far delegates from 58 nations have registered, confirming the uniqueness of the ADI conference in the global landscape both for breadth of topics and attendees.

As you know there won't be another ADI Global conference until 2020. My advice is to make the most of Chicago!

News & Meetings

From plan to impact: ADI's latest report

At the side-event to the 71st World Health Assembly, ADI launched a new report, *From plan to impact: Progress towards targets of the Global plan on dementia 2017-2025*.

The report contains an update on dementia plans adopted and in development around the world, including progress towards target one of the Global plan: for 146 WHO Member States to develop plans, policies or other frameworks on dementia by 2025. To date, national plans have been developed by 28 WHO Member States, with 30 plans currently in development.

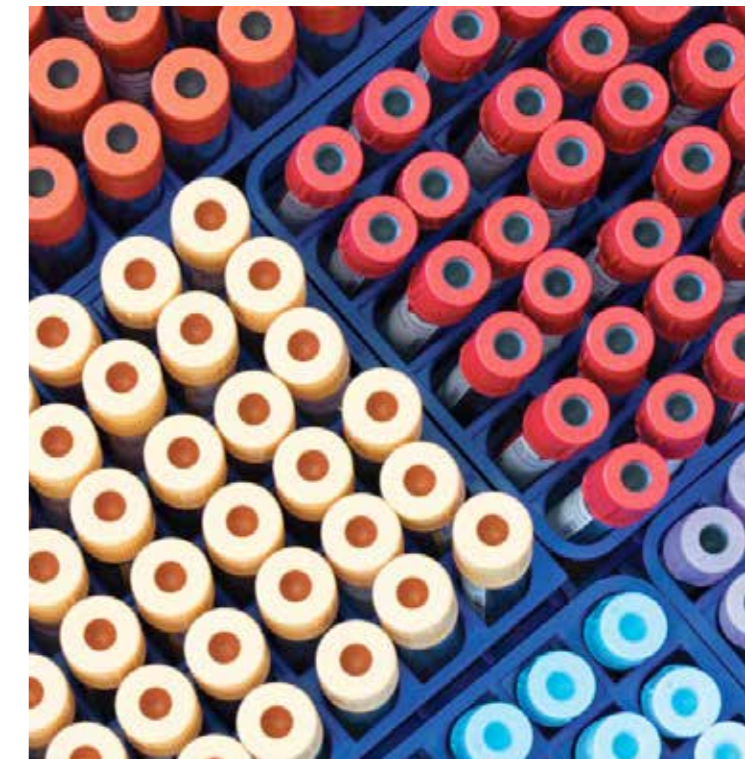
However, the report finds that progress is far too slow. To hit the 2025 target set out by the Global plan, over 15 plans would need to be created each year. Only two plans have been created since 2017. Moreover, the report also calls for greater funding from governments to be devoted to plans.

The event also saw the unveiling of a new publication from the WHO, *Towards a Dementia Plan: A WHO guide*. ADI welcomed this document which aims to assist governments, civil society and others to create effective dementia action plans. It sets out steps and methods to prepare for, develop and implement plans, including identifying priorities, stakeholder engagement and allocating budget.

To read the report, visit: www.alz.co.uk/plantoimpact



Bill Gates Diagnostic Accelerator



On July 17 Bill Gates announced his next investment in Alzheimer's research is in a new fund called Diagnostics Accelerator. This project of the Alzheimer's Drug Discovery Foundation (ADDF) "aims to accelerate bold new ideas for earlier and better diagnosis of the disease".

Bill Gates explained that since becoming involved in dementia research, one of the biggest things he believes we can do right now, is to develop reliable, affordable, and accessible diagnostic tools.

Bill Gates is joined by a number of other donors, philanthropists and foundations in committing more than \$30 million to help launch Diagnostics Accelerator. He is positioning the fund as "venture philanthropy" aiming to bridge the gap between government and charitable investment, "fantastic for generating new ideas and cutting-edge research" but which doesn't always create usable products, and venture capital, which is more likely to develop a test that will reach patients "but its financial model favours that will earn big returns for investors"

Read Bill Gates' blog post on this new fund at www.gatesnotes.com/Health/A-better-way-of-diagnosing-Alzheimers

■ News & Meetings

New report from ADI & Karolinska Institutet



On 4 July, ADI and Karolinska Institutet launched a timely report focussing on global estimates of informal care.

In this report we estimate that the annual global number of informal care hours provided to people with dementia living at home was about 82 billion hours in 2015, equating to 2,089 hours per year or 6 hours per day. This is the equivalent of more than 40 million full-time workers in 2015, a figure that will increase to 65 million full-time workers by 2030.

As 60% of people with dementia live in lower and middle-income countries (a proportion that continues to increase), and as almost all (96%) of people with dementia in lower and middle-income countries live at home, this has a significant impact on the global distribution of caregiver time.

The report also reveals the continued disproportionate impact of dementia on women. Women contribute to 71% of the global hours of informal care, with the highest proportion in low-income countries.

To read or download the full report visit www.alz.co.uk/reports

Updated conference programme

Our 33rd International Conference in Chicago is fast approaching. The final conference schedule is available online, including details of our expert speakers, plenaries, symposiums and parallel sessions.

The main plenary sessions will be: National and International Policy; Scientific Progress; Technology, Innovation and Entrepreneurship; Care; and Psychosocial Interventions. This covers a broad scope of issues within the dementia field, from care and the social impact of dementia, to the state of the art of dementia research and future innovation.

Alongside the plenaries, there will be a diverse range of other presentations taking place, including women and dementia; diverse populations; dementia-friendly communities and many more. The Exhibition Hall will also feature poster presentations, as well as providing an excellent space for networking.

People with dementia and those from low and middle income countries can benefit from significantly reduced rates.

Find out more at www.adi2018.org



■ News & Meetings

New report from OECD finds countries failing to diagnose dementia

A new report from the Organisation for Economic Co-operation and Development (OECD) shows that part of the reason for the gap in dementia care provision is that physicians are failing to diagnose the condition.



Care needed: Improving the lives of people with dementia provides an in-depth look at ways that OECD countries have tried to improve people's lived experience with the condition, and areas in which they must continue to improve.

They found that despite primary care services often being the first port of call, physicians average just 12 hours of dementia training during medical school and primary care doctors only correctly identify around 50-75% of dementia cases. Fewer than 40% of OECD member countries can estimate diagnosis rates nationally, and only two countries (the United Kingdom and Denmark) have set specific targets to improve their diagnosis rates.

As populations continue to age, the number of people with dementia is expected to rise to 41 million by 2050 in OECD countries, and globally to 152 million by 2050.

The report was launched at an event in London, jointly organised by OECD and ADI. It brought together experts, practitioners, people living with dementia, carers and policymakers to discuss how the quality of care for people with dementia can be improved, and how health systems can better prepare to tackle dementia in the coming years.

NCD Alliance #Enough campaign



In preparation for the High Level Meeting on NCDs (non-communicable diseases) that will take place in September, NCD Alliance launched their #Enough campaign to raise awareness, promote voices of people living with NCDs, and call on governments to deliver assertive action.

ADI supported this campaign by putting out a message on social media that dementia is a major NCD, and people can reduce their risk of developing dementia, as well as other NCDs, through activities such as exercise and by not smoking. We continue to work towards influencing the outcome document in September and for the explicit inclusion of dementia.

ADI pledges to register anti-dementia medication on WHO list of essential medicines

In June, the Ministry of Health and Solidarity in France announced its decision to discontinue reimbursement for four Alzheimer drugs.

This was disappointing, particularly to have occurred so shortly after the first anniversary of WHO's Global action plan on the public health response to dementia 2017-2025.

As a result, ADI announced its intention to apply to register anti-dementia drugs onto the WHO Model List of Essential Medicines.

Paola Barbarino, ADI's CEO said: *"We will insist that these drugs are made available to everyone. We hope one day there will be more treatments and urge governments to be prepared so that the public will have access to those."*

Helping people with dementia to live well requires a multi-faceted approach, and access to anti-dementia drugs is an important component.

■ News & Meetings

Sweden commits to developing a dementia strategy



The Swedish government have announced their commitment to launch a national dementia strategy, an outline of which is expected in October 2018 and will run until June 2022.

It is estimated that 150,000 people are living with dementia in Sweden. The Swedish Government expects this figure to increase by over 50% by 2050. The number of individuals aged over 80 years is also expected to increase substantially, accounting for 15% of the total population, or a million people, by 2030.

Krister Westerlund, President of Alzheimer Sverige, said, "Working for Alzheimer Sweden, I am delighted to see our that government has taken this decision! I was happy to read that they put emphasis on a health-system competence-build with a long-term focus, and in that process, that the Swedish government are opening up to a European and International school of thought about neuro-degenerative diseases."

The association is also urging that the strategy includes attention to quality of life through all the stages of dementia.

Wendy Fleming made a Companion by Royal Society Te Apārangi



Congratulations to Wendy Fleming on being made a Companion by Royal Society Te Apārangi, New Zealand. Wendy Fleming has been elected as a Companion in recognition of her outstanding contributions to the promotion of dementia research in New Zealand. She has raised public awareness about the impact of Alzheimer's disease and dementia on quality of life and the necessity for world-class scientific research to help give hope to people with dementia. As well as her roles in New Zealand, Wendy is a previous Vice Chair of ADI and now an ADI Honorary Vice President.

■ News & Meetings

Jakarta hosts Training of Trainers course

In 2016, ADI Asia Pacific Regional Office launched its Dementia Care Skills (DCS) Training of Trainers, aimed at low and middle income countries with the long-term objective of building "self-reliance" in dementia care training. This has since been rolled out in Bangladesh (4 training sessions), Indonesia (7), Malaysia (15), Brunei (4) reaching approximately 800 family caregivers and care-workers in the Asia Pacific region.

In April 2018, the ADI Asia Pacific Training of Trainers course was conducted for the first time in Jakarta, Indonesia. The training was supported by ADA (Singapore), Dementia Australia, Alzheimer's Indonesia (ALZI) and Atma Jaya Catholic University of Indonesia, and hosted by ADA's Koh Hwan Jing and ALZI's Dr Yuniar Soenarko.

Participants from 12 countries in Asia Pacific attended the training, including observers from Iran, TADA Chinese Taipei and Japan. It is expected that each new trainer will go on to train 1,000 family caregivers and care-workers per year in each respective country, resulting in 12,000 caregivers and care-workers trained by 2019.

DY Suharya, ADI Asia Pacific regional director, explained: "The objective is to encourage and support more individuals in these countries that have the capacity to assist and improve quality life of people with dementia and their carers in the region."

Philippines News

From April 2018, Alzheimer's Disease Association Philippines (ADAP) officially welcomed their new President, Dr Michelle Anlacan. Dr Soccoro (Corrie) Martinez remains on the ADAP Board.

DY Suharya visited ADAP in May 2018. There, she initiated a Global Dementia Action Plan National Response stakeholder meeting which was attended by representatives from WHO WPRO, the National Institute on Ageing, the University of the Philippines and ADAP.

In the same week, the Department of Health in the Philippines confirmed that they have submitted a position paper to WHO supporting the Global action plan on dementia and have committed to publish a draft of their national dementia plan by the end of 2018.

Madagascar Alzheimer celebrates 25 years of supporting people with dementia



In May, Madagascar Alzheimer celebrated its 25th birthday. To mark the occasion and to continue raising awareness, the association arranged a motorcade and a 3km solidarity march to Ankadiefajoro, where they plan to set up a day care centre.

Local artists and entertainers animated the event from the beginning to the end and were in charge of delivering some key messages about dementia.

At the event, Madagascar Alzheimer were joined by around 100 people who enjoyed the entertainment, heard testimonials from people living with dementia and became more aware of dementia in Madagascar. After the event, Madagascar Alzheimer report receiving many more calls and emails from people needing information and support. With more sustained funding, they would hope to set up a more permanent helpline service.

■ Events

22-26 July 2018
Alzheimer's Association International Conference (AAIC)
Chicago, USA
Email: aaic@alz.org
Web: www.alz.org/aaic

24-26 October 2018
11th Alzheimer Iberoamerica Congress
Guatemala City, Guatemala
Email: emerita.alzheimerguatemala@gmail.com
Web: http://alzheimeriberoamerica.org

TBC 8-10 November 2018
ADI Asia Pacific Regional Meeting
Colombo, Sri Lanka
Email: alzheimers@alzlanka.org
Web: www.alzlanka.org

26-29 July 2018
33rd Conference of Alzheimer's Disease International
Chicago, USA
Email: conference@alz.co.uk
Web: www.adi2018.org



29-31 October 2018
28th Alzheimer Europe Conference: "Making dementia a European priority"
Barcelona, Spain
Web: www.alzheimer-europe.org



■ News & Meetings

Mexican Federation Conference



May saw the Mexican Alzheimer Federation's (FEDMA) 23rd conference take place in Aguascalientes, Mexico. The conference hosted 51 exhibitors and 42 different activities, from talks and meetings to symposiums, with designated spaces for medics and health professionals, carers, people with dementia and the general public. Lecture topics were chosen by representatives of the associations and presented to this large audience.

Staff changes

James Smith, Communications and Policy Officer, recently left the ADI London team. James has been an asset to the team for the past two years, including strengthening ADI's communications, and assisting the impact of ADI through events and collaboration with the WHO, UN and other organisations. James will be replaced in August by Annie Bliss.

STRiDE

STRiDE – the Strengthening Responses to Dementia in Developing Countries research project – had its launch event in March 2018. Funded by Research Council UK's Global Challenges Research Fund, STRiDE aims to build and strengthen the capacity of researchers in seven low and middle income countries: Brazil, India, Indonesia, Jamaica, Kenya, Mexico and South Africa. The research team is led by Martin Knapp and Adelina Comas-Herrera from the London School of Economics and Political Science (LSE), UK.



Since March, STRiDE has held Theory of Change workshops in Brazil, India, Indonesia, Kenya and Mexico. The Theory of Change approach works from an end goal – in this case full, nationwide support for people living with dementia and their families – to understand what needs to happen for this to be achieved. This also allows indicators to be identified which help to evaluate the ongoing impact of the project. In STRiDE, Theory of Change workshops were held with local partners including researchers, NGOs and stakeholders such as people living with dementia and their carers.

Elizabeth Mutunga from Alzheimer's and Dementia Organisation Kenya said: *"The STRiDE theory of change workshop was informative. The caregivers input on what they go through from misdiagnosis, lack of information on the disease and the general care of people living with dementia came out clearly. Most of them explained how they had lost their livelihoods and how they were affected financially, psychologically and emotionally."*

The workshop was very important for Kenya as Government officials attended from the Ministry of Health, Ministry of Labour and the private sector. There was unison in awareness creation and making sure the information is disseminated in the rural areas to decrease loss of lives as some of the elderly have been burnt as they are deemed witches."

STRiDE research will play an important role in improving advocacy and research capacity in the field of dementia in low- and middle-income countries.

■ News & Meetings

Alzheimer University



In May, ADI hosted another successful Alzheimer University in London, this time on the theme of Advocacy. We were joined by colleagues from 11 countries: Jamaica, Kenya, Mauritius, Namibia, Nigeria, Romania, Sweden, Slovakia, South Africa, Trinidad and Tobago and the UAE.

Alzheimer University programmes are a powerful way of helping equip organisations to make the most impact in advocacy and support for dementia in their countries. They cover the entire scope of running a successful NGO, from creating strong business plans and transparent accounting, corporate communications to service provision, advocating for people with dementia and carers, and fundraising. The next Alzheimer University will run in September in London for Emerging Associations.



Online support groups

DAI members facilitate and provide online support groups for people with dementia through online video conferencing. Online support groups are ideal for those who cannot drive to their local "in person" support group or who live in isolated areas with limited access to services. People with dementia can join DAI at www.joindai.org. Anyone can subscribe to DAI blogs and newsletters at www.infodai.org. Find out about our support groups at www.dementiaallianceinternational.org/services/online-support-groups/

■ Research update

Proposed Alzheimer's diagnostic framework offers improvements in research

A new research framework proposed by the US National Institute of Aging and Alzheimer's Association could offer significant improvement in the results of clinical trials, say researchers.



The framework proposes a shift from the current method of diagnosis for Alzheimer's disease based on evaluating symptoms and behaviour, to a biological model like that used in the diagnosis of other conditions such as diabetes and cancer.

Although not recommended for primary care practice, this has potential to enable clinical trials to be targeted more effectively to exclude those who do not clinically have the disease but are often recruited due to presenting with similar symptoms.

If proven to have prognostic validity, these biomarkers to identify Alzheimer's disease pathology could be used far earlier than current diagnosis, which is often made when a person is already experiencing symptoms that interfere with their usual activities in daily life - symptoms such as changes in thinking, reasoning, communicating, spatial awareness or memory.

In future, earlier diagnosis of dementia could mean that individuals have longer to benefit from support and treatment, including potential new treatments.

Alireza Atri, MD, PhD, Vice-Chair of ADI's Medical and Scientific Advisory Panel, commented: *"This is a seminal conceptual research advance. It allows classification of early biological changes in the Alzheimer's disease pathway that can now be measured, using advanced technologies, many years prior to the potential development of clinical symptoms."*



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present the preview of
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THREE
SECONDS**

**a documentary film about Alzheimer's Disease International
and global dementia.**

Saturday 28 July 17:30 – 19:30
Plenary Hall, Room 190 of McCormick Place
Join us for an evening of drinks, snacks and networking