



**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.



WHO Executive Board, 24 January 2019 – 1 February 2019, Geneva

The 114th session of the WHO Executive Board took place from 24 January until 1 February 2019 with an exceptionally packed schedule.

Alzheimer's Disease International (ADI)'s Chris Lynch (Deputy CEO and Policy, Communications & Publications Director), Annie Bliss (Communications & Policy Officer) and Birgitta Martensson (Board Member) attended the

meeting in Geneva to ensure that dementia was kept on the agenda.

In the absence of a specific dementia programme, ADI delivered two important statements on Non-Communicable Diseases (NCDs) and Universal Health Coverage (UHC), focusing on the challenges of dementia in these two areas. Many thanks to Birgitta Martensson for stepping up to help cover the last-minute programme changes.

Continued on page 6.



Alzheimer's Disease International

The global voice on dementia

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Send us your comments

If you have any comments about or items for the newsletter, please contact the Secretariat.


Want to contribute?

We welcome your contributions. Please get in touch to have your news and stories included in future issues.

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Notes from ADI

Paola Barbarino, Chief Executive Officer

From global to local

It's been a busy start to 2019 at ADI. In January, we raised the profile of dementia at the WHO (World Health Organization) Executive Board in Geneva with statements on Non-Communicable diseases (NCDs) and Universal Health Coverage (UHC).

We then held the second in our series of global webinars on dementia research and clinical trials at the beginning of February (more on page 4). We were thrilled to see such a positive interaction with this important and complex issue and hope that you will all be able to join us for our third webinar on 10 May 2019. You can catch up on the series [on our website](#) and make sure you are signed up to our [newsletter](#) for details of how to register for the next one.

Our focus then shifted to the Asia Pacific region, including presenting at a major symposium for the Korean National Institute of Dementia (KNID) in Seoul, plus a series of association and governmental meetings in Singapore and Malaysia. I was delighted by the opportunity to be interviewed live on BBC World News and Channel NewsAsia. My colleague Chris Lynch (Deputy CEO and Policy, Communications & Publications Director) also visited the region to attend the first of a series of G20 preparation meetings in Tokyo with our Japanese member, Alzheimer's Association Japan. Read more about our involvement in the KNID symposium on page 3 and look out for updates on the G20 in the March e-Newsletter.

I'm also pleased to say that preparations for our [Singapore conference in March 2020](#) are well underway. Keep an eye on social media and our email updates for more information.

Finally, I hope you enjoy the features in this edition of *Global Perspective*. Please remember to share your contributions with us, particularly for our new 'Innovations' segment (page 9) where we shine a light on a selection of innovative interventions for people living with dementia and their care partners from around the world.



Paola Barbarino speaking with Dr Kwak Sook Young, Director General of the Korean Ministry of Health and Welfare at the International Conference on Global and National Strategies against Dementia (ICSAD)

Thanks to everyone for your continued support and we wish you all the very best.

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News

ADI release two translations of recent reports

At the beginning of 2019, ADI released important translations of two recent ADI reports. *The World Alzheimer Report 2018: The State of the art of dementia research: New Frontiers* has now been translated into Spanish. The report features interviews with some of the leading lights in dementia research from around the world, including Dr Ricardo Allegri, Head of Cognitive Neurology, Neuropsychology and Neuropsychiatry, Fundación para la Lucha contra las Enfermedades Neurológicas (FLENI).

ADI's Regional Director for the Americas Joost Martens noted the importance of Spanish translations in the region, saying: "Translating key ADI documents and messages into Spanish is essential for the associations in Latin America to have good access to the information, but also to enable sharing it with their members and dependencies."

A summary of our report, *Dementia in sub-Saharan Africa: Challenges and opportunities*, highlighting data on the impact of dementia in sub-Saharan Africa, the experiences of those living with dementia and the urgent need for governments to act to improve understanding and access to health services and social protection, is now available in French.

You can access all our reports and their translations on the [ADI website](#).

ADI in Asia Pacific

Out of the 50 million people diagnosed with dementia globally, 50 per cent of those live in the Asia Pacific Region. In February 2019, ADI's CEO Paola Barbarino and Asia Pacific Regional Director DY Suharya attended a series of governmental and association meetings in Malaysia, Singapore and South Korea, as well as a major symposium for the Korean National Institute of Dementia (KNID) in Seoul, to raise awareness in the region.

At the International Conference on Global and National Strategies against Dementia (ICSAD), Paola Barbarino gave a keynote speech, providing a global perspective in several areas, including creating a dementia friendly society at local, regional and national levels. She encouraged the government of Korea to involve more people living with dementia and their caregivers in their work and to be more active on the international research scene. Other speakers included Director General of the Ministry of Health in Korea, Kwak Sook Young, who outlined the commitments of Korea's third national dementia plan, acknowledging the role of the World Health Organization (WHO) and ADI in global advocacy.

While some countries have struggled to develop and fund dementia strategies, Korea is leading the way with a national dementia plan that's been updated and improved three times. The country has 256 dedicated dementia care centres and delivers a nationwide dementia awareness education programme in primary and secondary schools. The Republic of Korea provides an example to other countries of a government, successfully providing and funding effective initiatives to raise awareness in response to the increasing prevalence of dementia.

After the event, Paola Barbarino said, "It was fascinating to hear from all the speakers at the KNID symposium, particularly about the sophisticated and people-centred approach put in place by the Korean government to provide guardianship for people in lower-income households who have been diagnosed with dementia." She urged Korea to share its knowledge and initiatives with the rest of the world, stressing the importance of global collaboration.

Read more about national dementia plans on the [ADI website](#).



ADI CEO Paola Barbarino gives her presentation on global and local efforts to raise dementia awareness at the International Conference on Global and National Strategies against Dementia (ICSAD), organised by the Korean National Institute of Dementia (KNID) in Seoul

News

Let's Talk About Dementia Research: ADI hold second webinar on global barriers and access to clinical trials

On Friday 8 February, ADI held the second in a series of global webinars – *Let's Talk About Dementia Research: Global Barriers and Access to Clinical Trials*. The series aims to provide an open discussion on dementia research and clinical trials and a forum for debate between professionals and the public. Picking up on questions from our previous webinar around stigma, the debate drilled down into the barriers and enablers for accessing dementia research and clinical trials in low- and middle-income countries (LMICs) compared to high-income countries (HICs).

We welcomed back Professor Craig Ritchie (Chair of Psychiatry of Ageing at the University of Edinburgh and Director of the Centre for Dementia Prevention) who co-chaired the debate alongside ADI's CEO Paola Barbarino. We were also grateful to be joined by Dr Jill Rasmussen (Primary Care Specialist in psychiatry, neurology and learning disability and Independent Consultant in CNS Research), Professor Miia Kivipelto (Professor in Clinical Geriatrics at the Karolinska University Hospital, Stockholm), Silvia Ríos Romanets (Specialist in Behavioural Neurology and Movement Disorders, Medical Director and Deputy, API Colombia), Elizabeth Kasimu Mutunga (Carer and Chairperson, Alzheimer's & Dementia Organization Kenya), and Rochelle Amour (Assistant Director of Alzheimer's Jamaica and the co-founder of the Age Caribbean Consultancy).

During the discussion, we asked participants which types of dementia research they would like to see prioritised. Whilst the answers were relatively split, it was interesting to see that over half of respondents (53%) supported multi-domain approaches,



Webinar panellists (L-R): Jill Rasmussen, Craig Ritchie, Miia Kivipelto and Paola Barbarino. Also pictured on laptop screen: Rochelle Amour, Silvia Ríos Romanets and Elizabeth Kasimu Mutunga

closely followed by new therapies and innovation (33%). Other discussion points included how, in LMICs, to fund research and ensure it takes place.

Rochelle Amour highlighted an important consideration of dementia research in LMICs - something she termed 'implementation science'. She encouraged those involved in research to carefully consider the question: "How is this [research] going to end up in the health systems we are working with in this country?"

We were pleased to once again reach a wide global audience, extending to more than 50 countries. Thank you to everyone who joined us. If you weren't able to watch live, recordings of both webinars in the series are available on the [ADI website](#).

Stay tuned for our next webinar, taking place on 10 May 2019. Sign up to our [mailing list](#) for more information.

■ News

Roche remain committed after discontinuing CREAD programme

Pharmaceutical company Roche has recently announced that they are discontinuing their CREAD Phase III studies into the effects of crenezumab, a possible new drug treatment for Alzheimer's disease. Crenezumab was discovered by Swiss biotechnology company AC Immune SA and developed by Roche.

The Alzheimer's Prevention Initiative (API) and Roche will continue to investigate crenezumab in familial Alzheimer's disease. While this is disappointing news, we are assured that Roche and AC Immune remain committed to find treatments that will improve the lives of people with dementia.

The recently announced additional investment into the clinical development of tau therapeutics in later stage Alzheimer's disease reflects the companies' commitment.

Read our full response, as well as press releases by Roche and AC Immune [here](#).



Thailand commit to donepezil funding



ADI were pleased to learn that the Thai government have recently committed to funding donepezil treatment for people with mild to moderate dementia (FAST stages 4-6) and have included the drug in Thailand's national drug list.

Although there have not been any new pharmacological breakthroughs in dementia in 20 years, it is vitally important for the 50 million people living with dementia around the world – a large proportion of which are living in the Asia Pacific region – that they know there is some form of medical treatment alongside care and community interventions.

ADI's CEO Paola Barbarino wrote: "I am greatly encouraged by this action and applaud the Thai government's ongoing commitment to achieving universal health coverage by pursuing sustainable financing solutions, which will make the treatment available to the entire country."

We would like to thank our member Alzheimer's and Related Disorders Association of Thailand for their essential advocacy work.

Find out more about Alzheimer's and Related Disorders of Thailand [here](#).

ADI & GADAA Dementia & Humanitarian Settings Report

ADI has been working with the Global Alzheimer's & Dementia Action Alliance



Global Alzheimer's and Dementia Action Alliance

(GADAA) on a Dementia and Humanitarian Settings Report, which will investigate humanitarian emergency responses to protect and support people living with dementia. As part of the external review, ADI's Communications and Policy Officer Annie Bliss attended a stakeholder engagement meeting in Geneva on Older Persons in humanitarian emergencies organised by the UN Independent Expert on the enjoyment of all human rights by older persons and the UN High Commissioner for Human Rights (OHCHR). The report will be released in April.

Please contact a.bliss@alz.co.uk for more information.

■ Meetings and Conferences

WHO Executive Board cont'd

Speaking of the importance of attending these events, ADI's Chris Lynch said: "It is so important that we keep the profile of dementia as high as possible. We speak loudly and we repeat our message at gatherings like the WHO Executive Board. Even though we have the Global action plan on dementia we cannot rest. The unique challenges of dementia mean it needs profile and consideration, especially when it is being discussed under broader areas like NCDs, UHC, Age and Mental Health. It's our goal and duty to ensure dementia is on the agenda."

We were delighted that the Governments of Canada and Poland highlighted dementia in their interventions, which emphasises the importance of the support and engagement of our members. Thanks to all our members for their hard work and continued support. We will be reaching out again soon to assist in the preparation for the World Health Assembly in May, including the launch of our updated *From Plan to Impact* report.

Read the [ADI blog](#) for more about how Annie Bliss, ADI's Communications & Policy Officer, got on at her first WHO Executive Board.

ADI attend ICHRoP 2018 in Vienna

In November 2018, Michael Lefevre, ADI's General Manager, attended the [International Expert-Conference on Human Rights of older Persons \(ICHRoP\)](#) in Vienna. The meeting, attended by UN experts, representatives from UN member states and non-governmental organisations, discussed the implications of robotics, automation, digitalisation and education for the human rights of older people.



ADI General Manager Michael Lefevre

A declaration from the meeting emphasised that a rights-based and participatory approach needs to be embedded in the research, design and implementation of technologies and called for steps to eliminate the barriers that older people face in accessing technology and education.

The declaration stopped short of calling for a new convention to clearly set out the rights of older people, which ADI believes would be an important step. The outcomes of the conference will be taken forward to the UN Open-ended Working Group on Ageing.

Read the conference report [here](#).

■ Events

26-31 March 2019
AD/PD™ 2019, the 14th International Conference on Alzheimer's and Parkinson's Diseases
Lisbon, Portugal
 Website: www.adpd.kenes.com/2019

20-28 May 2019
72nd World Health Assembly
Geneva, Switzerland

8-9 June 2019
International Forum on Women's Brain and Mental Health
Zurich, Switzerland
 Website: www.forum-wbp.com/

14-18 July 2019
Alzheimer's Association International Conference (AAIC)
Los Angeles, USA
 Website: www.alz.org/aaic

16-18 August 2019
ADI Asia Pacific Regional Conference
Kuala Lumpur, Malaysia
 Website: www.adfm.org.my/adi-asia-pacific-regional-conference-2019
 Email: office.adfm@gmail.com

16-18 October 2019
Alzheimer IberoAmerica Conference Ecuador
 Website: www.alzheimeriberoamerica.org

7-10 November 2019
ADI Caribbean Regional Conference
Kingston, Jamaica
 Email: alzheimerja@cwjamaica.com

22-25 November 2019
Alzheimer Europe Conference
The Hague, Netherlands
 Website: www.alzheimer-europe.org/Conferences/The-Hague-2019
 Email: info@alzheimer-europe.org

March 2020
International Conference of Alzheimer's Disease International
Singapore
 Website: www.adi2020.org
 Email: info@alz.co.uk

■ Dementia Alliance International Update



Dennis Frost (DAI member and advocate) at the ADA Singapore World Alzheimer's Month conference in September 2018

DAI's advocacy and presence continues to grow in many countries, with DAI supporting many ADI members around the world to empower themselves and develop self-advocates.

To highlight the growth of the voices of people with dementia, whether as part of global advocacy groups, or simply by sharing their stories and getting involved in local initiatives, we felt it interesting to highlight this growth with a list of currently known National or Regional Dementia Working or Advisory Groups (DWG's) around the world:

- **Dementia Advocacy Support Network International (DASNI)**
- **Scottish Dementia Working Group (SDWG)**
- **Alzheimer's America Early-Stage Advisory Group (EAG)**
- **Highlands Dementia Working Group (HDWG)**
- **European People with Dementia Working Group (EUPDWG)**
- **Dementia Australia Dementia Advisory Committee (DADAC)**
- **Irish Dementia Working Group (IDWG)**
- **Dementia Alliance International (DAI)**
- **Japan Dementia Working Group (JDWG)**

- **Southern (Kiama) Dementia Advisory Group (DAG's)**
- **NZ Dementia Advisory Committee (NZDAC)**
- **Ontario Dementia Advisory Group (ODAG)**
- **Dementia Advocacy Awareness Team (DAAT)**
- **3 Nations Dementia Working Group (3NDWG)**
- **Finnish Dementia Working Group**

This year new advocacy groups will also be started in TADA Chinese Taipei and Singapore.

Individuals all around the world are all making a difference, too, and it is also important to acknowledge DAI's pioneer advocates and Board Members James McKillop and Carole Mulliken. These individuals, as well as many other people living with dementia, make it clear that it is possible to live a positive, productive - and often much longer life than we are told to expect - after a diagnosis of dementia. Working together, or individually, we are all making a difference.

For more information, please visit the [DAI website](#).

■ Technology and Dementia



Mike Belleville at the ADI Chicago conference, July 2018

At ADI's 33rd International Conference in Chicago last July, we aimed to showcase some of the leading innovations in dementia research, including product designs from large creative companies like IKEA and new ideas from researchers in China, Switzerland and the UK. We were also joined by Mike Belleville, patient advocate and Board Member for **Dementia Alliance International (DAI), who spoke in our plenary session on technology, innovation and entrepreneurship about how people with dementia use new technology. Mike previously worked as a technician for Verizon and his interest in technology has led him to advocate for innovative products for people living with dementia. We asked him to share with us some of the advancements in technology that have had the greatest impact on his own life since his diagnosis and what he would like to see developed in the future.**

Hello, my name is Mike Belleville and I live in a town called Bellingham in Massachusetts, USA. I've been happily married for nearly 38 years and have three children and five grandchildren. At the age of 52, I was diagnosed with younger onset Alzheimer's, a diagnosis which was then changed to Lewy Body Dementia three years ago. I am living well with my disease and, through my work with DAI, am dedicating my time to changing harmful stereotypes

around people living with dementia. One of the most important ways that I'm trying to do this is through technology.

My background in tech has led me to investigate the kinds of products available to assist people living with dementia. I am most interested in looking at smart home technology and the ways that existing smart products can be adapted to respond to changes in the body and changes in the environment to help people's everyday lives.

I already use a smart watch that has in-built sensors and smart home technology to control things such as indoor temperature, lights and appliances. What if this kind of technology could be enhanced to detect things that it doesn't currently and trigger automatic responses?

Nearly every day my anxiety will kick into overdrive and lead me to become very agitated and frustrated. What if my smart watch had a sensor that could detect my anxiety levels and send a signal to my smart home which would then ease my anxiety? This could be through playing a video of my wife talking to me to help calm me down, or by connecting to a Bluetooth speaker to play my favourite music. Perhaps it could also send my wife a text message alerting her of my agitation, and she could then call me herself?

The possibilities really are endless, and the technology would of course need to be customisable to an individual's need. Imagine, for example, a wearable sensor that detects when a person is cold and could automatically turn up the heat in their house. Imagine if it were able to find things for us in our own home. Imagine if items that are most valuable to us had small sensors that could be registered with the smart home so that when we misplace something, we only need to ask our smart homes where it is located.

Technology is always getting faster, smaller and smarter. There are so many ways that existing technologies could be adapted to help people live more comfortably. What we are lacking is enough research in this area. I truly believe all the pieces are already here that could accomplish this. We are simply waiting for somebody to put all the pieces together.

Read more about innovation on [page 9](#)

■ Innovations

Six out of ten older people in Santo Domingo de Heredia have some type of cognitive dysfunction

A pilot study conducted by the Costa Rican Association of Alzheimer's and Associated Dementias (ASCADA), using the 10/66 analysis tool, has found that six out of ten older people have cognitive dysfunction.

The results showed that 60.4% have some type of cognitive dysfunction. Of these, 5.5% have mild cognitive impairment and 5.5% have already moderate cognitive impairment.

The study, which considered 101 people between 65 and 98 years of age, is the first of its kind in Central America and forms part of Costa Rica's National Plan for Alzheimer's Disease and Related Dementias 2014-2024. The objective was to test the 10/66 analysis tool and see if the research can be extended across the nation. Work is already projected into next phases, including further analysis of the data and projections to carry out the research in other regions.

Find out more about the 10/66 Dementia Research Group [here](#).

Republic of Korea's Dementia-Free Index (Defri)

The Republic of Korea has developed an app which gives people a score based on how well they take steps to reduce their risk of dementia. The app looks at basic health factors (including gender, age, education, diseases), cognition levels and quantitative measurements of adherence to behaviours known to prevent dementia. Individuals can use the app on their mobile phone to review their diet, exercise levels, smoking/drinking habits, and are encouraged to check their Dementia-Free Index (Defri) score every week.

ADI's CEO Paola Barbarino said, "This is a great example of how a simple idea can be effectively and holistically implemented at the national level. This project should provide inspiration to other countries in how to scale up projects successfully, which is so often a challenge for governments."

Learn more about Defri [here](#).



Dementia Dog project



Billy – Scotland's first Dementia Community Dog

Dementia Dog is a pioneering intervention programme, in collaboration with **Alzheimer Scotland** and **Dogs for Good**, which involves Dementia Community Dogs and Handlers working alongside healthcare professionals to help people with dementia feel more independent, confident and connected.

From opening doors to fetching medication pouches, the Assistance and Community Dogs undergo two years of specialised training to learn key skills to help structure routine and social connections for people living with dementia – both at home and in the community. Dementia Dog currently has 12 dogs working in Scotland.

According to a recent project evaluation report, participants reported increased confidence to engage in social activity, improved emotional wellbeing and increased physical activity. Care-partners who have taken part in the project also reported improved emotional wellbeing and reduced burden.

The dementia assistance dog programme currently only exists in Scotland and Australia, through Dementia Dog's collaboration with **Assistant Dogs Australia**, **HammondCare** and the **Dementia Centre, Sydney**.

Visit the **Dementia Dog website and read the **research evaluation report** to learn more about how this project is supporting families living with dementia.**

■ Research update

ADI-INDUCT collaboration

Continuing the collaboration between ADI and INDUCT (Interdisciplinary Network for Dementia Using Current Technology), Sophie Gaber, a Marie Curie early-career researcher based at the Karolinska Institutet,



Sophie Gaber, early-career researcher at Karolinska Institutet

Sweden, will be seconded to the ADI team until May. INDUCT aims to improve technology and care for people living with dementia. Sophie's research explores the way in which Everyday Technologies that we encounter at home and within public space, from the humble kettle, to smartphones, ATMs, public transport ticket machines, and more complex online banking or eHealth, may be both a help and a hindrance.

Within an increasingly technological society, access and the ability to use Everyday Technologies is a prerequisite to participate in many activities and places however studies from the **CACTUS (Cognitive Accessibility and Technology Use when aging in home and Society)** research group indicate that people with dementia may experience increased challenges with Everyday Technologies. This highlights the role of Everyday Technologies as a potential catalyst to exclusion or stigma for people with dementia that are unable to access or use it. Sophie will contribute to a number of ADI's projects including the World Alzheimer Report 2019 and our global dementia research webinar series.

Read more about INDUCT [here](#).

STRiDE Update: Focus on India



STRiDE team in Bangalore with Dr Radha Murthy (Nightingales Medical Trust), Adelina Comas-Herrera, Meera Pattabiraman, Wendy Weidner, Suvarna Alladi, Narendhar Ramasamy (L-R)

Last December, Adelina Comas-Herrera (Assistant Professorial Research Fellow, LSE, and co-leader of STRiDE [Strengthening Responses to Dementia in Developing Countries]) and Wendy Weidner (ADI's Research and Policy Project Lead) joined team members from STRiDE-India at the **AAIC Satellite Symposium** in Bangalore.

Meera Pattabiraman, Chairperson of **Alzheimer's and Related Disorders Society of India (ARDSI)**, welcomed delegates and gave an overview of ARDSI's critical advocacy work to ensure continued momentum after India's Minister of Health committed to developing a national dementia plan back in September.

Adelina Comas-Herrera and Suvarna Alladi (Professor of Neurology at the National Institute of Mental Health and Neurosciences (NIMHANS) and STRiDE-India's senior researcher) presented a summary of STRiDE's key goals for research and impact in India and Saadiya Hurzuk (STRiDE-India's early career researcher) presented her research poster. Wendy Weidner presented how ADI's research undertakings complement our global advocacy work and support the development of national dementia plans.

Post-symposium, the STRiDE team met face-to-face to discuss ongoing work, including the situational analysis for India and the gaps in service provision it revealed. It was great opportunity to enrich collaboration on key work packages and demonstrated the unique and valuable combined contribution that the researchers and ARDSI make to the success of STRiDE.

Keep up to date with STRiDE [here](#).



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