



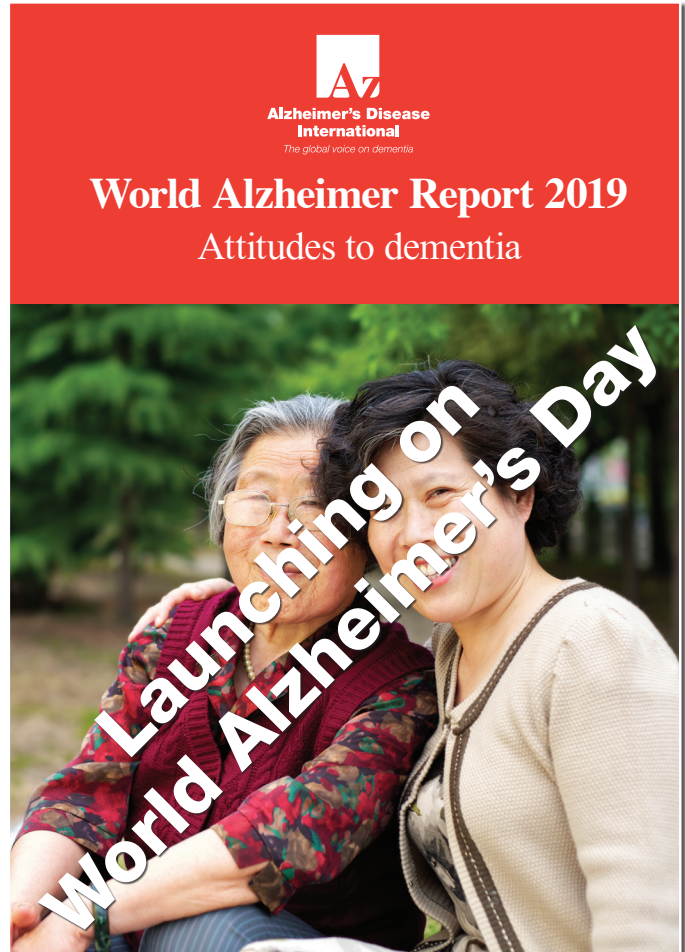
Alzheimer's Disease
International

The global voice on dementia

July 2019, Volume
29, No. 2

Global Perspective

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



World's biggest survey on attitudes around dementia

Over the past two months, ADI have been carrying out a **global survey on attitudes around dementia**. The response from members, partners and the general public has been remarkable, with almost **70,000 people across more than 140 countries** completing the survey.

Translations into 32 languages by volunteers from all over the world enabled a truly global reach, which will increase the effectiveness of follow-up policy and advocacy opportunities on both a national and international level.

ADI would like to extend a huge thank you to everyone who completed the survey and helped spread the word; to ADI members and partners; to the London School of Economics (LSE), who ADI commissioned to create the survey; to the journalists and members of the press who helped share the survey; and to all volunteers who supported with translations.

The survey is now in the analysis stage with the team at LSE, while ADI is in the process of shaping the World Alzheimer Report 2019.
Continued on page 4.



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

DY Suharya, Regional Director - Asia Pacific

A month of action in Asia Pacific

The ADI Asia Pacific Regional Office (APRO) continues to support a membership of 19 associations across the region, encouraging member countries to become self-reliant, readily support one another and reach out to non-member countries to encourage them. During April and May, I have had the privilege to visit four of these members in Nepal, Tonga, Singapore and Japan in my capacity as Regional Director for APRO.

The visits started in April, hosted by Alzheimer and Related Dementia Society (ARDS) Nepal, involving the government, international agencies and care providers. This offered the opportunity for empowerment and strengthening collaborations to effectively contribute to the improvement of quality life of people with dementia and caregivers in Nepal.

In May, we had the privilege of assisting our new member, Huelo Tonga, at The Dementia Friendly Tonga Workshop, which was supported by Asian Development Bank and Ministry of Internal Affairs Tonga. This was with the support of our members in The Pacific sub-region, Dementia Australia and Alzheimer's New Zealand. The government and Huelo Tonga have committed to make dementia a national priority, as evidenced by a recent follow up visit by the Tongan Delegates to Dementia Australia's Sydney office in June. I look forward to learning more about Tonga's first World's Alzheimer's Month event in September and congratulations to Tonga for recently becoming the first member of ADI in the Pacific sub-region.

After the Pacific, I had the privilege of facilitating a Dementia Friendly Community discussion at the International Ageing Asia Innovation Forum in Singapore. Accompanied by our member from Alzheimer's Association Japan (AAJ), Noriyo Washizu, we presented our work on ADI's DFC principles at a Dementia Friendly Symposium in Osaka, Japan hosted by Asahi Shimbun who also organized media interviews (they have 4 million subscribers!). We also had the chance to present ADI's work at the C20 G20 pre-summit event, explore potential collaborations on the Caravan Dementia Friends project and had a productive meeting with Dr Kenji Toba, the Chair and Dementia Advisor to the Ministry of Health Japan in Tokyo.

Looking ahead, the most exciting upcoming event is the ADI Asia Pacific Regional Meeting and Regional Conference hosted by Alzheimer's Disease Foundation Malaysia (ADFM) at Hotel Istana, KL Malaysia in August 2019. (see page 6 for further details)

I hope you enjoy the features in this edition and please share your stories with us. Thank you to all for your commitment and support, we wish you all the very best!



DY Suharya and Noriyo Washizu, Alzheimer's Association Japan, at a Dementia Friendly Symposium in Osaka, Japan

News

ADI prepares for World Alzheimer's Month



With September fast approaching, ADI and its members are preparing for World Alzheimer's Month 2019 under the theme of **Let's talk about dementia: End the stigma**. Last year, the campaign extended to over 80 countries, with events and social media campaigns reaching millions of people. ADI has prepared a *Guide to planning a successful World Alzheimer's Month Campaign*, which contains guidance on topics including: organising events; engaging with the government; tips for media and social media; and how to measure the success of a campaign.

The guide is available to download from the World Alzheimer's Month [campaign website](#), where new materials will be added in the coming months in various languages.

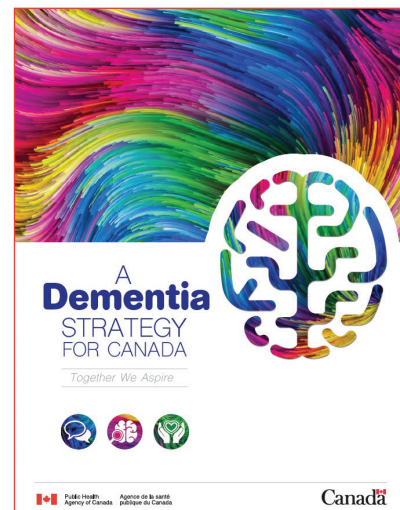
Let us know what you are doing to raise awareness and challenge stigma for World Alzheimer's Month this year and we will add your event to our [World Alzheimer's Month Events webpage](#).

ADI and the Pan American Health Organization (PAHO) are working together to plan and deliver a regional dementia awareness campaign for the Americas. The campaign coincides with the end phase of the PAHO regional action plan on dementia and will run during September to complement World Alzheimer's Month. The campaign will be adapted for five languages: English, Spanish, Portuguese, French and Dutch.

Download the [World Alzheimer's Month campaign guide](#).

Canadian government launches national plan to tackle dementia

On 17 June, the government of Canada officially adopted a national plan on dementia. The plan, *"A Dementia Strategy for Canada: Together We Aspire"*, is the 32nd to be adopted worldwide, and includes key targets for improving awareness, access to care, support and treatment, research and risk reduction of dementia by 2025.



It is estimated that over half a million people in Canada are living with dementia, resulting in a combined healthcare system and caregiver cost of over \$10 billion every year. These economic and social costs are set to drastically increase as the number of Canadians living with dementia is estimated to increase by 66 per cent by 2031 to 937,000. The plan follows a rigorous multi-stakeholder consultation process including the Alzheimer Society of Canada and people living with dementia. Crucially, the plan includes a budget of \$3 million in 2019 and \$12 million in each of the following four years.

Paola Barbarino, CEO of Alzheimer's Disease International welcomed the adoption of the plan. She said: *"We have been eagerly awaiting the launch of this plan, Canada is a nation which has the means and capacity to implement a plan which can serve as a beacon of excellence to inspire others. The way so many stakeholders, including people living with dementia, were consulted throughout the process is an example for inspiration. We hope this multisectoral engagement continues in the implementation and monitoring of what could become a seminal plan."*

National dementia plans remain the single most powerful tool to transform dementia care and support people living with dementia and their care partners. The adoption of a [Global plan on dementia](#) by the World Health Organization (WHO) in May 2017 targets 146 of the 194 Member States to develop a national response to dementia by 2025. Currently the global response is just 15% of the target and the timely launch of Canada's plan should stimulate others to follow suit.

Read the full story on the [ADI website](#).

News

Risk reduction webinar



RISK REDUCTION OF COGNITIVE DECLINE AND DEMENTIA
WHO GUIDELINES

Risk Reduction of Cognitive Decline and Dementia

Featuring Paola Barbarino, Neerja Chowdhary and other guest speakers involved in the development of the guidelines

Watch online now!

www.alz.co.uk/adi-who-webinar-risk-reduction

World Health Organization

Alzheimer's Disease International
The global voice on dementia

On Friday 21 June, ADI and the World Health Organization (WHO) held a webinar on an important area of research: **Risk Reduction of Cognitive Decline and Dementia**. As we continue to advocate for a disease modifying treatment, risk reduction is one of the key areas where governments, health care systems and individuals can make a real difference.

ADI's CEO Paola Barbarino chaired the event and was joined by a panel of global experts, all of whom were involved in the development of the new **WHO risk reduction guidelines**: Neerja Chowdhary, Technical Officer in the Department of Mental Health and Substance Abuse, (WHO); Professor Miia Kivipelto, Professor in Clinical Geriatrics at the Karolinska Institute; Professor Kaarin Anstey, Senior Principal Research Scientist at Neuroscience Research Australia (NeuRA) and Fellow of the Academy of the Social Sciences in Australia, and Kate Swaffer, Chair, CEO & Co-founder, Dementia Alliance International (DAI).

The panel discussed a range of pertinent topics included the differences between dementia prevention and risk reduction, and the importance of not allowing risk reduction evidence to increase stigma by attributing every case of dementia to lifestyle factors. Professor Miia Kivipelto summed up one of the key takeaways in saying: "We should make societies not only dementia friendly but dementia prevention friendly, and this involves the whole community".

Thank you to all the panelists and participants who joined us live. For those unable to join on the day, a full recording is available to watch for free on the ADI website.

Watch the recording.

Survey cont'd:

The report will feature survey results alongside expert essays and case studies will be released in September 2019, during World Alzheimer's Month.

ADI's Deputy CEO and Policy, Communications & Publications Director, Chris Lynch said: *"The findings of the global attitudes to dementia survey will form core of the World Alzheimer Report 2019, alongside essays and case studies from experts and key contributors. We will explore global, national and local response to awareness raising and stigma and take a look at how some truly fascinating groups are tackling issues including indigenous populations, marginalised or seldom heard from groups and shine a light on advocacy and working groups of people living with dementia and carers."*

Read more about the World Alzheimer Report 2019.

ADI staff changes

ADI welcomes Taylor Paatalo as part-time Communications and Administration Assistant. This is after Jenni McGowan, who worked on ADI's regular newsletters, social media since September 2018, recently left the ADI team to take up a full-time role at an arts charity in London. We wish Jenni the very best with her future career.



Sophie Gaber, PhD student at the Karolinska Institutet, will also be leaving ADI, having completed her secondment with ADI. **Read more about her experience on page 12. View a full list of staff on the ADI website.**

■ News

Dementia and ageing given prominent focus at the G20

Dementia was specifically recognised as a global health priority by G20 leaders in the declaration of the Osaka Summit, June 2019.

This followed months of advocacy and partnership working, specifically with HelpAge International and NCD Alliance and as part of the C20 global health working group, with Japan taking a lead on healthy ageing.

The key extract from the declaration reads: *"We will implement comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers."*

This was a truly collaborative effort by the entire ADI team and members. Noemi Medina from ALMA, our Argentinian member, triggered the opportunity as Argentina passed the G20 presidency to Japan.

Chris Lynch, Deputy CEO, supported by Noriyo Washizu from Alzheimer's Association Japan attended 6 days of meetings in February and April in Tokyo, speaking with government ministers and parliamentarians and resulting in dementia being specifically included in the presentation of the C20 policy pack to Prime Minister Abe.

ADI is now finalising its strategy for the follow up meeting of G20 Ministers of Health in October, to ensure that G20 countries take a significant leadership role in ensuring that we work towards global and national solutions to dementia.

Read the full story [here](#).



ADI blog: Research and Collaboration

Why is research collaboration so important? We spoke to senior researcher Professor Julie Williams from Cardiff University to hear her view.



"For the last 25 years my team at Cardiff University has been focused on trying to find genes that affect a person's risk of developing Alzheimer's disease.

Over the years we have formed ever larger collaborations, first within the UK and then with colleagues in Europe and the USA. This partnership work has led to the discovery of over 40 susceptibility genes, giving us a much clearer understanding of Alzheimer's disease.

There is no doubt in my mind that we could have achieved these results more quickly if there was a global mechanism for funding research, or even networks or collaborations that bring researchers together.

What we need is an organisation that could fund the nuts and bolts of international collaborations – the meetings, administrative structures and perhaps most importantly the sharing of data."

Julie Williams is Professor of Neuropsychological Genetics at Cardiff University and the Chief Scientific Adviser for Wales since 2013. She is one of the world's leading contributors to Alzheimer's research. A pioneer of working collaboratively, having recognised early the complexity of Alzheimer's disease genetics, and having participated in many world-wide, powerful consortia, the consortium she leads, GERAD (Genetic and Environmental Risk in Alzheimer's Disease), plays a dominant role in the field, focusing on developing larger, more powerful studies.

Read the full blog piece.



34th International Conference of Alzheimer's Disease International

19 - 21 March 2020
Singapore

Hope in the age of dementia

New science; New knowledge; New solutions

Topics include

Dementia as a public health priority
Awareness & friendliness
Research & innovation
Risk reduction
Diagnosis, treatment, care & support
Support for dementia carers
Data & information systems

Abstract submissions now open!

www.adi2020.org

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■ Meetings and Conferences

Innovative Medicines Initiative (IMI) Stakeholder Forum



Left to right: Emilio Merlo Pich, Vice President, Takeda Pharmaceuticals; Paola Barbarino, CEO, Alzheimer's Disease International; Donata Kurpas, Associate Professor, Wroclaw Medical University; Magali Haas, CEO & President, Cohen Veterans Bioscience; Viktor Jirsa, Director of the Institute de Neurosciences des Systèmes & Director of Research CNRS, Aix-Marseille University; Corinne de Vries, Head of Science and Innovation Support, European Medicines Agency; Michelle Lax, Vice President Imaging, IXICO.

In June 2019, ADI's CEO Paola Barbarino was invited to speak on the panel at this year's Innovative Medicines Initiative (IMI) Stakeholder Forum in Brussels. The theme of the forum was "Brain health and disease in the digital era – 2020 & beyond" - a heartening title given the recent lack of inclusion of brain research in Horizon Europe. The Director General for Research and Development of the European Commission announced a public consultation on innovation **"Have your say"**.

Paola spoke alongside representatives from research and civil society on the question of how digital technologies can be used to facilitate timely and accurate diagnosis of brain diseases. Paola said: *"There is a huge gap in diagnosis of Alzheimer's disease and dementia. The vast majority of governments are failing to address the diagnosis challenge. Digital diagnostics could be a real gamechanger, particularly in lower- and middle-income countries where getting a timely and accurate diagnosis remains an enormous challenge."*

As we develop digital and online tools for diagnosis, we need to ensure that there is sufficient dissemination of information and sufficient post-diagnostic support for people living with dementia."

Watch a recording of the panel discussion.

ADI hold first online council meeting

On 11 June 2019, ADI held its first online council meeting, attended by over 90 participants from 48 countries.



ADI's Events and Administration Coordinator Katie Bingham said, *"It was truly wonderful to see so many attendees engaging in the meeting. I would like to thank all of those who joined and hope you too felt it was a very successful meeting."*

Following this meeting, we are proud to announce that ADI now has 100 members. This is thanks to the approval of the applications for associations in Bonaire, the British Virgin Islands, Ecuador, Qatar, Saint Kitts and Nevis, Suriname, and Tonga. Congratulations to all staff and volunteers for the hard work leading to this great achievement.

ADI CEO Paola Barbarino praised members for their hard work and commitment: *"While it is not about the numbers of member associations but their quality - each member association demonstrates resilience and energy to the cause, many thanks to scores of selfless volunteers - this is an important milestone for ADI. Together we are stronger and can advocate better."*

We are also delighted that Kate Swaffer has been re-elected as Board Member, John Grosvenor has been elected to the Nominations Committee, and Alireza Atri will become the new MSAP Chair.

Serge Gautier, outgoing Chair of the MSAP, said: *"The ADI MSAP is a powerful force in acquiring and sharing new knowledge with the Alzheimer societies around the world. I wish the new Chair Dr Alireza Atri a successful term on the ADI Board"*.

**Is there an association in your country?
View the full list on the **ADI website**.**

■ Meetings and Conferences

ADI hold first virtual Alzheimer University

During the first two weeks of April, ADI ran a trial virtual Alzheimer University with participants from Albania (Alzheimer Albania), Burundi (Alzheimer Community Support of Burundi - ACSB), Georgia (Georgian Alzheimer's Association) and Uganda (Uganda Alzheimer Association) officially joining ADI's Membership Development programme. Alzheimer University programmes involve a series of workshops for staff and volunteers from national Alzheimer associations to help them strengthen their organisations.

Speakers at this first online Alzheimer University included ADI staff members, Dr Nori Graham, Honorary Vice President of ADI, speakers from Alzheimer's Society (UK), NCD Alliance and the Alzheimer Society of Ireland.

Dr. Paul Kiwanuka-Mukiibi, Uganda Alzheimer Association said: *"The appropriateness and relevance of the content was 'spot on', in that it applied just as much to participants versed and experienced in the topic, as to those who weren't. Personally, in cases where I already had some form of knowledge-base and experience, the content and the way it was delivered served not only as a refresher, but also as a 'thought provoker' that broadened my perspective. The content was very effective in eliciting 'real-life' responses that greatly enriched discussions, as well as the cross-cultural learning experience."*

Read more about ADI's Alzheimer University programme.

Women's Brain Project

On 8-9 June 2019, ADI joined international leaders from the global health community for the 2nd International Forum of Women's Brain and Mental Health in sunny Zurich. The forum was organised by the **Women's Brain Project**, a non-profit organisation calling and acting for a precision approach to brain disease and mental health with respect to sex and gender.

ADI's Research and Policy Project Lead Wendy Weidner joined a panel, alongside specialists from Microsoft, the World Health Organization (WHO), the Organisation for Economic Co-operation and Development (OECD), Global Brain Health Initiative (GBHI), and The Mauli House Project in India, to discuss socioeconomic risk factors through a gender lens. On the panel, Wendy spoke about the disproportionate impact of dementia on women, not only in terms of numbers living with the condition, but also as caregivers (read more in our 2018 report, **Global estimates of informal care**).

The two-day interactive forum included diverse topics such as sex differences in the brain; the predisposition of women's brains to certain neurological and mental diseases; the need for precision medicine; and the importance of enrolment and retention of women in research and clinical trials. The forum culminated in a lively discussion about leveraging artificial intelligence to address gender bias with a special visit from Sophia the Humanoid Robot, who took questions from the audience! **Position papers and blogs from the forum will follow shortly at the Women's Brain Project website.**

■ Events

14-18 August 2019
Alzheimer's Association International Conference (AAIC)
Los Angeles, USA
Website: <https://www.alz.org/aaic/overview.asp>

16-18 August 2019
ADI Asia Pacific Regional Meeting and Regional Conference
Hotel Istana, KL Malaysia
Website: <http://adfm.org.my/aprc2019/>
Email: office.adfm@gmail.com

27 September 2019
3rd Middle East and North Africa Regional Conference of ADI
Beirut, Lebanon
Email: executive5@trustandtraders.com

23-25 October 2019
Alzheimer Europe Conference
The Hague, Netherlands
Website: <https://www.alzheimer-europe.org/Conferences/The-Hague-2019>

12-14 November 2019
Alzheimer Iberoamerica Conference
Ecuador
Website: www.alzheimeriberoamerica.org

19-21 March 2020
International Conference of Alzheimer's Disease International
Singapore
Website: www.adi2020.org
Email: info@alz.co.uk

■ Meetings and Conferences

UN open ended working group on ageing

In April 2019 ADI, through its regional director for the Americas, Joost Martens, participated in the 10th annual session of the **UN Open-Ended Working Group on Ageing (OEWGA)** in New York. This working group, with participation from Member States, UN agencies, national human rights institutions and civil society organisations, was established by the General Assembly in 2010 in order to “consider the existing international framework of the human rights of older persons and identify possible gaps and how best to address them”. In other words, the working group goes through the process of working towards a UN Convention on the Rights of Older People.



Joost Martens and Rosita Kornfeld

During the three days, the focus was on lifelong education and social security and protection, with attention also given to legal elements that must shape the drawing up of such a UN Convention. This followed on from previous years' sessions, which covered the themes of long-term care and palliative care; independence and autonomy; violence, abuse and neglect.

ADI's Joost Martens presented a short statement to the plenary session, highlighting the need for social protection, not only for older people and people living with dementia, but just as much for their care partners, especially the many women that take on this role.

With age being the main risk factor for dementia, and long term care for older people in the majority of cases meaning care for people with dementia, ADI calls for greater collaboration between organisations from the ageing movement and organisations that work on dementia, particularly in this process towards a UN Convention on the Rights of Older People.

Read more about the 10th Open Ended Working Group on Ageing.

Citizen Encounters on Dementia in Chile



This year, the Alzheimer Chile Corporation held two public events in Santiago and Valparaíso to highlight the role of care partners of people living with dementia, with close to 300 and 500 family caregivers in attendance, respectively.

The first event in May featured a diverse programme, including a photographic exhibition, “The Faces of Alzheimer’s”, with pictures of people living with dementia alongside their family care partners to highlight the ‘invisible’, unpaid healthcare workforce and the need for public policies to support them.

Joining the event by video feed, ADI's CEO Paola Barbarino commended Chile on being a regional example, while also acknowledging the current limitations of implementing Chile's national dementia plan.



Former national congress building, Santiago

■ Meetings and Conferences

Dementia in Chile cont'd:

Speakers across the two events included well-known Chilean actresses Elena Muñoz and Paulina Urrutia, who gave their testimonies as care partners of people living with dementia; Member of Parliament, Juan Luis Castro; Senator Juan Ignacio Latorre; Carolina Marzán of the Commission of Family and Senior Adults; Noemí Medina of AIB (Alzheimer Iberoamerica); Paola Maeso of AUDAS (Uruguayan Association of Alzheimer's); well-known Chilean journalist, Amaro Gómez Pablos; and Joost Martens, ADI's Regional Director for the Americas.

These meetings have strongly increased visibility and empowerment of family members of people living with dementia across the country.

Just one week after the second meeting, the Minister of Health announced that Alzheimer's and other dementias will be incorporated into the national system of Universal Access with Explicit Guarantees (AUGE), thus guaranteeing the similar priorities in care and allocation of resources as other pathologies.

Read more about Chile's national dementia plan.

DAI host side event at the UN Convention on the Rights of Persons with Disabilities

At the 12th Session of the Conference on State Parties (COSP) to the Convention on the Rights of Persons with Disabilities (CRPD) at the United Nations in New York, Dementia Alliance International (DAI) hosted a side event on dementia as a disability. This was the first time that dementia has been formally represented in a side event at the COSP.

The overarching theme of the event was social inclusion and health; two key determinants of well-being, both of which are being systematically denied to people with dementia all around the world.

DAI Chair and CEO Kate Swaffer said: *"Our disabilities may be more invisible than many others, but we are still, even in 2019, being stigmatised and discriminated against on a daily basis. We hope this event will be the start of change for the more than 50 million people currently living with dementia globally."*

Read more from Kate on [the DAI blog](#).

DAI would like to thank the UN and the World Health Organization (WHO) for supporting this important side event, and acknowledge our co-sponsors: Alzheimer's Disease International (ADI) the Australian Government, the International Disability Alliance, Human Rights Watch, the Global Rehabilitation Alliance and the World Hospice and Palliative Care Alliance. We also thank our two sponsors, ADI and Boehringer Ingelheim.

A special thanks also to Ms. Catalina Devandas Aguilar, the UN Special Rapporteur on the rights of persons with disabilities, for her opening remarks, and all other speakers. It was a rich discussion about dementia as a disability, and the rights of all to rehabilitation, services and full and equal access to the CRPD.

Watch a recording of the side event.



Left to right: Antony Duttine (Adviser, Pan American Health Organization), Christine Thelker (Board Member, Dementia Alliance International), Kate Swaffer (Chair and CEO, Dementia Alliance International), Bethany Browne (Researcher, Human Rights Watch), Arlene Pietranton (CEO, American Speech-Language-Hearing Association) and Jan Monsbakken (Board Member, Global Rehabilitation Alliance)

■ Partners in research



Howard Gordon speaking at ADI's third webinar on research participation, alongside Professor Craig Ritchie (middle) and ADI's CEO Paola Barbarino (right)

On 10 May 2019, ADI held the third in our global webinar series: *Let's Talk about Dementia Research: Maintaining hope when trials end*. The webinar built upon themes of our previous webinars in the series - including why we need clinical trials and the key barriers and enablers to participation around the world - and asked the important and timely question: how do we maintain hope when clinical trials end?

The webinar featured a panel of global experts, including Pippa Kelly (author, dementia writer and public speaker); Dr Martin Traber (Roche), Dr Philipp von Rosenstiel (Biogen), Dr Eliezer Masliah (National Institute on Aging), Professor Craig Ritchie (Centre for Dementia Prevention, Psychiatry of Ageing, Edinburgh University) and Howard Gordon, activist for dementia and rights.

As a global advocate for the rights of people living with dementia, we asked Howard to tell us why it is essential for people living with dementia to be part of the discussion around dementia research.

"Recently, I travelled to London to take part in ADI's webinar series: *Let's Talk About Dementia Research*. On a personal level, it was a wonderful experience to be part of the panel. However, more significantly, as a person living with dementia, it is important to be seen not just as participants in research, but as partners. Too often things are done for rather than with people living with dementia and it is to ADI's credit that they have involved people living with dementia in this series.

By *partners* in research, I mean that people with dementia (in the earlier stages of dementia and depending on abilities) can and should be involved

in the design, development, running, reporting and publishing of dementia research. This is important because it could have a positive effect on the perceptions of people living with dementia and send a message to someone getting a diagnosis today that it is not the beginning of the end but the end of the beginning. Our lives change after a diagnosis, but there is much we may be able to do within the limits of our diagnosis, and research can be one of those things.

I am currently involved in a project called Dementia Enquirers, facilitated by the Dementia Engagement and Empowerment Project (DEEP) and funded by the National Lottery Community Fund. The project will fund 12-month research projects run by DEEP groups around the United Kingdom. I am on the Pioneers Group, a group comprised solely of people living with dementia, working alongside an advisory group of academics and researchers who are there to support but not to take part in the research themselves. The project is a wonderful example of how people living with dementia can lead research and determine its priorities.

Away from the Dementia Enquirers project, I have been involved in over 20 research projects in the last 18 months. Some have been as simple as completing a questionnaire, some have involved discussions about different aspects of life with dementia, and one involved a blood test and a year-long study looking at the effects of taking the prescription medicine losartan (most commonly used to treat high blood pressure).

There can be many reasons for taking part in research. Initially, it got me out of the house at a time when I had no support and was struggling to cope with my diagnosis. It gave me back a feeling of self-worth and doing something positive.

As time has passed, it is still a positive in my life, but I also realise that there is only a small chance that these research studies will benefit me. For me, the main benefit of current research will be for my children, grandchildren and those that follow; a sort of small legacy I may leave for their future, hopefully making a difference to their lives, which to me is priceless."

Find out more about ADI's global webinars on research participation, and hear more from Howard Gordon on [his blog](#).

■ Research update

Interview with ADI secondee, Sophie Gaber



As Karolinska Institutet PhD student Sophie Gaber finishes up her secondment, we asked her to reflect on her time at ADI:

Q. What brought you to ADI?

A. ADI are partners with the **INDUCT** (Interdisciplinary Network for Dementia Using Current Technology) project that I am working with. My knowledge of ADI, however, began years ago through the annual World Alzheimer Reports, which are essential reading every year.

Q. What were your responsibilities during the secondment?

A. From the beginning of my time at ADI, I was invited to collaborate on various projects and I particularly enjoyed this diversity of opportunities. Highlights have included the series of global webinars aimed at demystifying dementia research, as well as helping with the development of the first innovation showcase at the 33rd Annual Conference of ADI in 2018. More recently, I have collaborated with ADI on the world's biggest survey on attitudes around dementia which will form part of the World Alzheimer Report 2019 (read more on page 1).

Q. How has the secondment influenced your future research?

A. This secondment has opened my eyes to the vast opportunities available globally in the field of dementia research. It has been a pleasure to work with a team who are so passionate about improving the lives of people with dementia and I am grateful for how welcoming everyone at ADI have been. I have learned a lot under the supervision of Wendy Weidner (ADI's Research and Policy Project Lead), particularly about the interconnectedness of dementia research and the ways in which my small piece of research can provide a meaningful contribution to the big puzzle. I hope to keep in contact with the ADI team and look forward to the upcoming World Alzheimer Report 2019!

Thank you to Sophie for all her work during her secondment. We wish her the very best for the future!

ADI attends Lundbeck 6th #1VoiceSummit

On 25 – 26 June 2019, ADI attended the 6th #1VoiceSummit at Lundbeck's Headquarters in Copenhagen. The summit was an opportunity for international and national advocacy associations working across all areas of brain disease, to gather and share information and expertise.

ADI's Head of Development Nikki Bayliss was invited to attend as a panelist, discussing fundraising and membership in relation to World Alzheimer's Month.

Many thanks to Lundbeck for hosting and for the opportunity to hear from delegates around the world working in different disease areas within the brain.

Read more about [Lundbeck #1VoiceSummit](#).

STRiDe update: Greetings from Brazil

In March, Adelina Comas-Herrera, Assistant Professorial Research Fellow, London School of Economics (LSE), and co-leader of STRiDE (Strengthening Responses to Dementia in Developing Countries) and ADI's Research and Policy Project Lead Wendy Weidner joined team members from STRiDE-Brazil at the **AAIC Satellite Symposium** in São Paulo.

Rodrigo Schultz, President of FEBRAZ, the Federation of Brazilian associations, welcomed delegates as the first official act of the organization. Adelina and Dr Jerson Lacks (Universidade Federal do Rio de Janeiro) presented a summary of STRiDE's key goals for research and impact in Brazil. Wendy presented on how STRiDE's research undertakings complement ADI's global advocacy work and support the development of national dementia plans. There were also important contributions from Dr Cleusa Ferri, Deborah Oliveira, Elaine Mateus, and Fabiana da Mata from the STRiDE-Brazil team.

The STRiDE team took full advantage of being together, starting with a site-visit to a Primary Care Centre. The STRiDE-Brazil team held their first National Advisory Group meeting, with key stakeholders from health, social care, WHO, academia, and the community. It was an invaluable opportunity that showcased the close collaboration between researchers and FEBRAZ that will contribute to the success of STRiDE. **Keep up to date with [STRiDE](#).**