



Alzheimer's Disease  
International

*The global voice on dementia*

February 2021  
Volume 31, No. 1

# Global Perspective

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



## ADI holds first virtual international conference

**F**rom 10 – 12 December, ADI hosted its first ever virtual international conference and 34th global gathering of the dementia community. The 3-day event welcomed close to 1600 delegates from 130 countries. Under the theme of 'Hope in the Age

of Dementia', the conference was structured around the World Health Organization (WHO)'s Global action plan on dementia and featured state of the art scientific and non-scientific speakers and content.

**Continued on page 8.**



## Alzheimer's Disease International

*The global voice on dementia*

The views stated in *Global Perspective* are personal and do not necessarily reflect the views of ADI. Published by Alzheimer's Disease International, London, United Kingdom. Editors: Taylor Paatalo. Design: David O'Connor. Copyright © Alzheimer's Disease International. All rights reserved. ADI is a not for profit organisation registered in the State of Illinois, USA.

### 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.

### Secretariat

#### New Address

Alzheimer's Disease International  
57a Great Suffolk Street  
London  
SE1 0BB  
Tel: +44 (0)20 7981 0880  
Email: [info@alzint.org](mailto:info@alzint.org)  
Web: [www.alzint.org](http://www.alzint.org)

### Keep in touch



[www.facebook.com/alzheimersdiseaseinternational](https://www.facebook.com/alzheimersdiseaseinternational)



[www.twitter.com/AlzDisInt](https://www.twitter.com/AlzDisInt)



[alzint.org/LinkedIn](https://alzint.org/LinkedIn)



[www.youtube.com/user/alzdisint](https://www.youtube.com/user/alzdisint)

**SUBSCRIBE**  
TO OUR MONTHLY NEWSLETTER



## Notes from ADI

### Looking back at 2020 and forward to 2021

**It is my great pleasure to introduce you to another great issue of the Global Perspective. Never before has the title of our newsletter felt so relevant. 2020 was certainly the year in which the importance of having 'global perspectives' and knowledge really came to the fore.**

Last year, we were challenged by the series of events unfolding before our eyes. 2020 could have been unsurmountable were it not for the help, advice and support we all shared with one another. You have been our source of inspiration and your passion and resilience has made us want to do even more for our community. In a way, not having to travel has enabled us to focus on the delivery of some very important content - a lot of which has been influenced by your positive feedback.

We are not yet done with COVID-19 by any means, and as we embark into promising territory of vaccination programmes, the possible inequalities that this may expose are coming starkly to the fore. These inequalities are also coming strongly out of research and clinical trials. With the possibility of a disease modifying therapy on the horizon, how can we ensure that everyone, including those in low- and middle-income countries, benefit? Our first two webinars of the year, one on Biogen's aducanumab data and another on vaccines, the latter taking place on 24 February, tackle these two big topics. Throughout the year, we will continue to put together programmes that are timely, impactful, courageous and topical, as well as reflecting on broader issues underpinning our policy environment.

In the turbulence of last year, we somehow also managed to run our global conference online. Despite wading into unknown territory in deciding to host it online, it turned out to be a huge success with close to 1600 attendees from 130 countries. In the closing ceremony, there was real commotion in our team as we started to realise how many of you were singing along with us from your homes and offices to the wonderful notes of 'It's a Wonderful World', performed by the great Noriyo Washizu of Alzheimer's Association Japan (AAJ).

So many of you helped us make ADI 2020 unique, displaying an array of knowledge and insight that inspired many attendees. The challenge ahead is now how to make sure the next conference will incorporate some of your insightful feedback and make ADI 2022 even better.



Paola Barbarino, CEO of ADI



## Notes from ADI

As you can tell, the activities for ADI are only set to increase in 2021. Our publication programme is continuing unabated with From plan to impact IV to remind us how far we are from hitting the targets of the WHO Global action plan on dementia. Work is also already underway for this year's World Alzheimer Report, which will focus on timely diagnosis - something that is denied in so many parts of the world and that is now needed more than ever. We are pleased to announce that we will be working alongside the McGill University, Montréal, one of the world's leading public research universities, to produce this vital piece of work.

This year we will also focus more on regional events, which highlights how much more we could do if we had Regional Directors to work with our members. We know this is a big thing to fund but we also know it could be transformative in getting national action plans done. Increasing the policy research work we are doing is making our work in the area of national plans more targeted, informed and inspired than ever.

With G20, G7 and a number of other big political gatherings on the horizon, and the political debate being dominated by COVID-19, we feel that advocacy on behalf of our constituency - a constituency that sadly continues to grow and that has been often overlooked in the pandemic - is needed now more than ever.

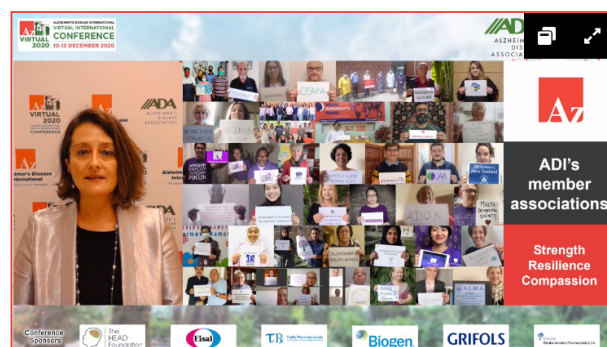
I look forward to working with you all in 2021. We are on the cusp of some really important advances in our field and never before have I had so much hope. Let us make it another year that matters.



**CEO Paola Barbarino**



**The virtual conference lobby of ADI 2020.**

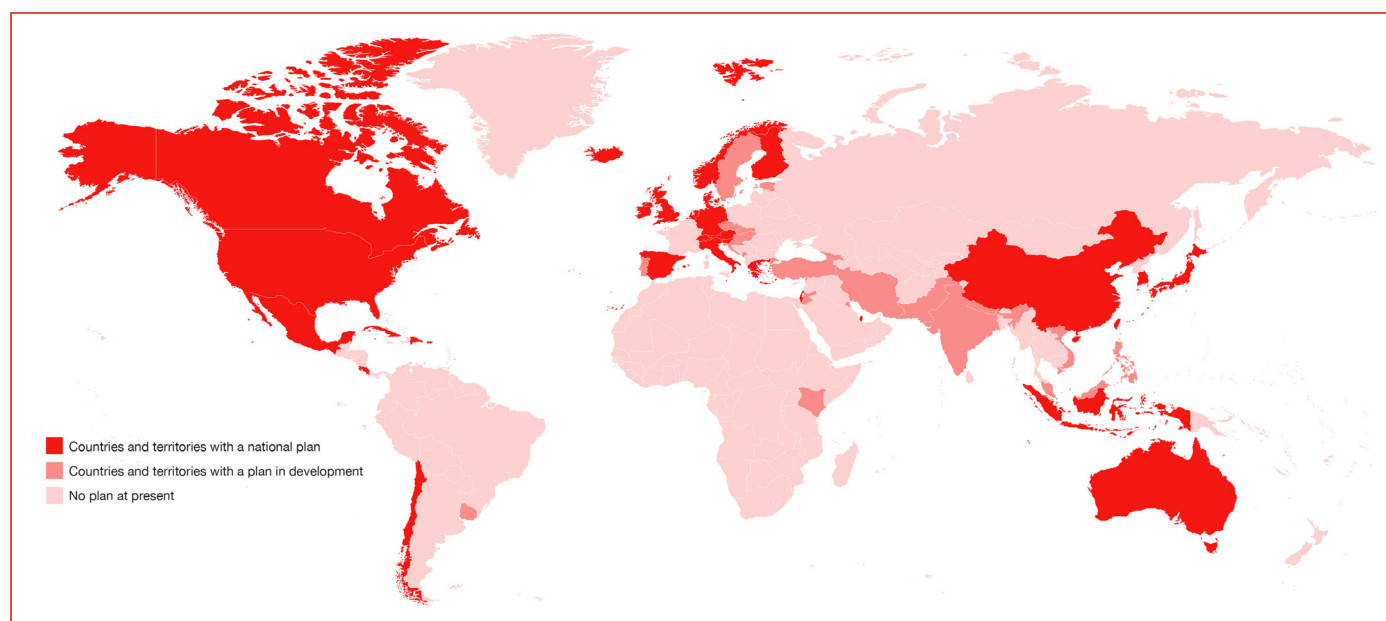


**Paola opens up ADI 2020, highlighting the work and resilience of Members over the last year.**



**The ADI 2020 conference ends with a sing-a-long to 'What a Wonderful World'.**

## National Dementia Plan Updates



Countries with plans on dementia or in development in 2021.

With many of 2020's headlines having been dominated by the COVID-19 pandemic, we've highlighted some of the national dementia plan announcements and updates that you may have missed in the last 12 months.

### Iceland



On 9 April, Iceland's Ministry of Health announced the publication of a national dementia strategy. The strategy, made up of 6 areas and covering 48 actions, lays out an action plan of support for people living with dementia over a 5-year period.

The strategy was developed with the consultation of people living with dementia and their carers, as well as with consideration to the **World Health Organization (WHO)'s Global action plan on dementia 2017-2025**

### Germany



On 1 July, the German government announced that a national dementia strategy would officially be implemented from 1 September following its development by the Federal Ministry for Family, Seniors, Women and Youth, the German Alzheimer Society or Deutsche Alzheimer Gesellschaft (DAzG) and the Federal Ministry of Health, along with other key stakeholders.

One of the key focuses of the plan is its commitment to diversity among people who are affected by or living with dementia, with specific provisions for those who are living alone with dementia, younger people living with dementia and those from migrant backgrounds.

### China



It was declared on 1 September that China had adopted a National Dementia Plan as part of China's Action Plan for Healthy China 2030. Complementing the dementia plan, the Action Plan for Healthy China 2030 also includes provisions for dementia and services to support older people's mental health.

Since its announcement, several provinces have started implementing the Action Plan for Healthy China 2030. Additionally, the national health commission has released the treatment guide for cognitive disorders, with the first chapter focusing on the diagnosis and treatment plan for common subtypes of dementia.

## National Dementia Plan Updates



Dr. Daisy Acosta (left) with the Dominican Republic's Ministry of Public Health.

### Dominican Republic



The month of July also saw a further commitment to national dementia plan implementation with the Dominican Republic's Ministry of Public Health announcing on 23 July that the country was launching a strategy. Titled 'Plan de la respuesta a las demencias en la República Dominicana, 2020-2025', the strategy is the 33rd to be adopted globally.

Following the announcement, Dr. Daisy Acosta, co-founder of Asociacion Dominicana de Alzheimer and Honorary Vice President of ADI, said: *"This is a fantastic development for the Dominican Republic, where there is still a great deal of stigma surrounding dementia. I hope it will encourage other governments in Latin America to adopt national plans."*

### Netherlands and Norway



At the beginning of December, the Norwegian Government announced that it had updated its national dementia plan to 2025 following a positive review of its previous plan. The updated plan will centre around the three key areas, including timely diagnosis, dementia-friendly societies and research.

The Dutch Government also announced in December that they had published a new National Dementia Strategy 2021-2030, which focuses on the key objectives of dementia research, reducing the stigma for people living with dementia and improving dementia-related services and support.

### Italy



Though Italy first adopted a national dementia plan in 2014, it was announced on 21 December that the plan would receive government funding for the first time in its history. An allocation of 15 million euros over a 3-year period will be given towards the plan following amendment approval by Italy's Budget Commission.

The approved amendment was inspired by a bill written by ADI member Alzheimer Italia and Senator Barbara Guidolin. An interview with Senator Guidolin can be found on **page 6**.

Mario Possenti, Secretary General of Alzheimer Italia said: *"The funding of the National Dementia Plan does not represent a point of arrival but the beginning of a path, both of recognizing the rights of people with dementia, and of creating a system that knows how to respond to all their therapeutic, care and health needs and that can also support the families."*



## Senator Guidolin on Italy's recent National Dementia Plan funding success

### What first inspired you to work with Alzheimer Italia?

I met the Alzheimer's Federation Italy at a conference in December 2019. Right from the start, I appreciated the great seriousness and pragmatism that distinguishes the work of the association, which has since allowed for excellent collaboration. Since then, I have also studied issues surrounding Alzheimer's and dementia in detail.

We both felt it necessary to put in place concrete actions in order to be able to help people with Alzheimer's and their families; primarily, fighting for the establishment of a fund aimed at implementing the National Dementia Plan.

### When you started working on the original bill that inspired the recently approved amendment, what message(s) did you find most important to convey to other government officials and the general public?

In September 2020, I filed Bill No. 1988, the main objective of which was to finance the National Dementia Plan. Though Italy adopted its plan in 2014, it had never been funded. I worked hard, as did the Federation itself, so that a fund aimed at the implementation of this plan would be included in the Budget Law for 2021. During this time, I tried to make the Italian Government and the public understand the importance of the establishment of this fund.

I addressed my colleagues and the Italian Government, reiterating the importance of giving concrete answers to the various problems that affect those living with dementia and their families, who often struggle to be heard. The numbers speak for themselves - in Italy there are more than a million people with dementia. Urgent action is needed.

The most important message that I think must be conveyed to governments and public opinion is that Alzheimer's disease and other types dementia are a global problem - they do not spare anyone. With an impact on the population that is projected to grow, it is essential that governments implement social policies aimed at people living with dementia, to support their families who care for them, to combat the isolation that these people often experience, and to implement programmes to overcome the social stigma linked to Alzheimer's and dementia.

**Pictured: Senator Barbara Guidolin with Paola Barbarino in Palazzo Chigi, December 2019.**



### Could you explain some of the positives, as well as the difficulties, that you've experienced during the process?

The greatest difficulty I encountered at the beginning of the journey was to make my colleagues understand the importance of considering dementia as a priority. Research is essential but so is social and health care, which must be provided by competent staff, as well as support for the families who are often caregivers.

The greatest satisfaction came with the establishment of a fund dedicated to Alzheimer's and dementia, which is expected to last at least 6 years.

### What would you like to see happen next following the budget approval?

With the Budget Law for 2021, the Legislator seems to be aware of the seriousness of the phenomenon and the need for resources for a real breakthrough. It is specified that the fund is intended to finance the action lines of the Dementia National Plan.

The fund will also be used for the purchase of healthcare equipment, aimed at enhancing early diagnosis, as well as the treatment and monitoring of patients with Alzheimer's disease.

What I would like now are two things. The first is the rapid enactment of the decree that will allocate resources among the regions to carry out the mentioned interventions. The second is the increase in the fund set up by budget law to allow more interventions for those living with dementia and those who care for them.

### Do you have any advice on how the general public, such as carers or people living with dementia, can do more to support countries in implementing National Dementia Plans?

The suggestion that I would like to give to people living with dementia is to not isolate themselves but to turn to the numerous associations present around the world who can offer support. For the general public, I would implore that they find compassion for those who are affected and begin to educate themselves on the different ways they can support those in their communities.

I also ask that people don't resign themselves and rather fight together for all those affected by dementia and their families, so that their needs are brought to the fore. Society must be made aware of the difficulties of people living with dementia and their families who care for them, but the institutions must also respond quickly.

## News

### World Alzheimer Report announcement

ADI is pleased to announce that we have commissioned McGill University, Montreal, Canada to deliver the next two editions of the World Alzheimer Report on the crucial and inter-related topics of Diagnosis (2021) and Post Diagnostic Support (2022).

An expert team led by Dr. Serge Gauthier, with Dr. Pedro Rosa-Neto, Dr. José A. Morais, Claire Webster, Dr. Tamara Ellen Carver, Diane Weidner, Carol Servaes, Zeina Zeinab Salameh, Leila Zahabi and Maria Vincelli are already working towards the 2021 report: Journey through the diagnosis of dementia. The report is scheduled for launch during World Alzheimer's Month 2021, alongside a global awareness raising campaign.

Dr. Gauthier said on behalf of the McGill team: *"We strongly believe that our combined experience and expertise in research, care, education and lived experience in dementia-related illnesses will provide a tangible, meaningful and inclusive report on diagnosis and the management of dementia to Alzheimer's Disease International."*

**The McGill University Research Centre in Studies in Aging**, the **McGill Division of Geriatric Medicine** and the **McGill Dementia Education Program**, supported by the Office of Education Technology and Online Learning at Steinberg Centre for Simulation and Interactive Learning, are leading complementary initiatives devoted to prevention, diagnostics, management, knowledge dissemination and support for care partners.

Chris Lynch said: *"We are delighted to be working with such a dynamic and experienced team at McGill. We are on the cusp of breakthroughs in both treatment and diagnostics, which will influence the next two World Alzheimer Reports, and the McGill team has the expertise to bring the clinical, care and innovation elements together and to capture the vital voice and lived experience of people with dementia and their carers."*

**More information around this year's World Alzheimer Report can be found [here](#).**

### From Plan to Impact IV

May 2021 marks the fourth anniversary of the launch of the WHO's Global action plan on dementia. To coincide with this important date, ADI will be producing our annual report 'From plan to impact' on the progress being made.

In 2020, we saw the impact COVID-19 was having on people living with dementia, their carers and loved ones, on service provision globally, and in causing disruption to diagnosis and research. We also witnessed incredible response, innovation and resilience. This year's report will continue to consider the ongoing impact of the pandemic as well as analysing progress, barriers and enablers in all 7 action areas of the Global plan, including an update on the primary goal of national dementia plan development, funding and deployment.

**Learn more about our previous 'From plan to impact' reports.**



### Staff changes

ADI's Communications and Policy Manager, **Annie Bliss**, will be leaving the ADI team at the beginning of February for an opportunity at the NHS Confederation. England. We wish Annie the best of luck in her new role.



Thanks to some dedicated funding, ADI welcomes **Dr. Karen Watchman** to the team as our new Senior Publications Manager. Karen has over 20 years of experience in research, teaching and publications, in the field of Alzheimer's and dementia and will work closely with Chris Lynch ADI's Deputy CEO and Director of Policy & Publications and she has already started work on the World Alzheimer Report 2021.



## News

### ADI partakes in C20 discussions

From 25-27 January, Chris Lynch, ADI's Deputy CEO and , participated in the Civil 20 (C20) kick off meetings, held virtually from Rome under the Italian Government's G20 presidency.

While G20 priority areas this year will be the pandemic response and climate change, Chris is working hard to ensure that healthy ageing and dementia are recognised and that we gain some continuity from the strong work and position achieved during the **G20 in 2019** led by Japan.

Older people and people with dementia have been disproportionately affected by COVID-19 and it is vital to ensure these two vulnerable groups are at the forefront of pandemic recovery plans and future pandemic protection. Chris will continue to coordinate with members in the next few months to advocate to relevant governments to emphasise the urgency and importance of inclusion.

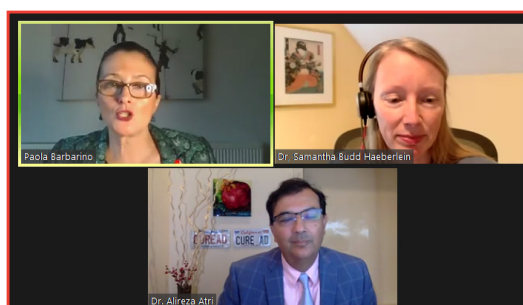
**Visit ADI's COVID-19 resources and support directory.**



**ADI Deputy CEO Chris Lynch poses a question to Minister Leonardo Bencini on the G20's response to the disproportionate impact of COVID-19 on older people and those living with dementia.**

### Webinars from ADI in 2021

Following the success of **last year's webinars around COVID-19** both for members and the general public, ADI will continue to deliver a series of webinars in the upcoming year.



**Paola Barbarino, Dr. Alireza Ali and Dr. Samantha Budd Haeberlein answer questions from the audience.**

On January 14, ADI hosted its first webinar of 2021 where Biogen's Head of Neurodegeneration, Dr. Samantha Budd Haeberlein, presented data from Biogen's Phase 3 clinical studies ENGAGE and EMERGE. If approved, ducanumab would be the first disease-modifying treatment for Alzheimer's disease.

During the webinar, Dr. Alireza Ali, Chair of ADI's Medical and Scientific Advisory Panel, made an important point in saying: *"The treatments we have currently – they're not nothing, they have value in meaningfulness but we need more effective treatments. This idea that we're going to find a magic bullet solution is not going to happen in the next few years."*

ADI's **next webinar** will take place on 24 February and will centre around the development and deployment of the COVID-19 vaccine globally and what this means for the dementia community.

**Sign up to our mailing list to receive more information around future webinars, as well as other important ADI updates.**

### New website

As you may have already seen, we updated our website just before the New Year. We are excited by the opportunities that our new website has allowed us, including but not limited to: our reports, resources and publications now organised in one collection and with a better search function, an expanded directory for our member associations, and in our membership development programme, as well as a change in domain name.

Formerly 'alz.co.uk', you can now find us at **'www.alzint.org'**, better reflecting our global status. For the time being, our old website address will redirect you to the new site, but we ask that you please update any links you maintain.

Our email addresses have also changed to reflect our website's new domain name, so you will now see ADI emails coming from **info@alzint.org**. Like our old website address, you can still contact us through our old email addresses of @alz.co.uk, but do ask that you please update your records so that we don't miss any correspondences from you.

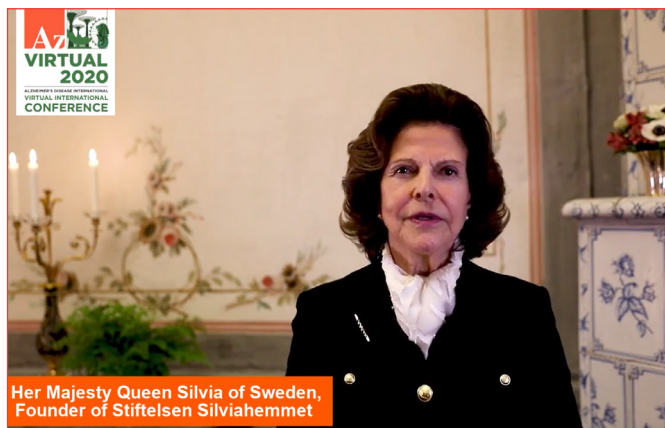
If you have yet to explore our new website, we encourage you to please have a look. We welcome any comments you may have about the website and its content, as we continue to work in further improving it.

**Visit the new ADI website.**



## ADI 2020 Conference

### ADI holds first virtual international conference



Two ADI royal ambassadors delivered video messages.

Throughout the conference, ADI heard from its ambassadors, Luis Guillermo Solís Rivera, the former President of Costa Rica; Their Majesties Queen Sofia of Spain and Queen Silvia of Sweden. The conference also received blessings from His Holiness Pope Francis, who wished for a “successful and inspiring virtual event”, as well as an Apostolic Blessing for all of those attending and are working for the wellbeing and support of those affected by dementia.

Because of the conference’s virtual format, ADI 2020 was able to host more sessions and poster presentations than ever before, including around the topics of COVID-19 and dementia-related design. There was also an addition of an ‘Art Stand’ where delegates could explore a ‘Book Stand’ and ‘Vintage Radio’.

The conference came to an end with a powerful message around the importance of maintaining hope for people living with dementia and their

caregivers, particularly during a year fraught with difficulties.

In closing remarks, Mohamed Said and Rohani Rahmat shared the story of their journey, and Mohamed’s diagnosis with vascular dementia. Talking about their experience of joining Alzheimer’s Disease Association (ADA)’s Voices for Hope programme, Rohani said: *“People living with dementia and their care partners not only need to be sympathised with but to be empathised with. Being acquainted with other participants brought joy in our lives as we are frank with our sharing – it brings smiling and laughter with each session. Each session is very inspiring and motivating... I realised I am not alone in struggling with my journey to cope in caregiving.”*

Before the conference was adjourned, Noriyo Washizu of Alzheimer’s Association Japan (AAJ) played the piano to Louis Armstrong’s ‘What a Wonderful World,’ where the ADI staff joined in a remote sing-a-long. Never has there been a more poignant moment for the global dementia community to come together in mutual support and solidarity.

ADI extends a special thanks to ADA for their support in organising the first virtual international conference of ADI, as well as all of the committee members, presenters and delegates for contributing to a great conference.



Mohamed Said shares a piece of art during the closing ceremony.



## ■ ADI 2020: Delegates on their experience

### Dr. Claire Burley, early career researcher & bursary recipient

Many thanks to ADI and the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) for the opportunity to attend ADI 2020 and present my research. Despite our world being turned upside-down by the pandemic, ADI hosted a spectacular event. I particularly enjoyed hearing from experts from a range of backgrounds extending beyond academic, research and clinical fields. One speaker shared an incredibly moving personal story about their mum who had dementia, the impact it had on their lives and how they shared their experience in a positive way to support and influence thousands of others. It was very inspiring and emphasizes the importance of us all coming together and collaborating in this way. I feel truly humbled to be a part of that.



**Dr Claire Burley  
presenting at ADI  
2020**

I am also very grateful for the opportunity to share my research at UNSW Sydney. I talked about cost effectiveness of person-centred care, a meta-analysis of nonpharmacological approaches for depression, a qualitative study exploring the views of people living dementia, and a special interest group and research network. I am very pleased with how it went and welcome anyone interested in finding out more to get in touch. It was great to hear other early career researchers working on interesting projects such as cognitive stimulation therapy, and fantastic that so much focus was on nonpharmacological approaches to improve quality of life for people living with dementia.

Thanks again to the ADI organisers and everyone involved. I recommend others interested in dementia care and research to find out more about ADI and attend their future conferences.

### Lily Liu, carer & bursary recipient

As a family caregiver for an almost 90-year-old mother with dementia, I was so excited to be able to attend the 34th international Alzheimer's Disease International (ADI) Conference. It was going to be a wonderful opportunity to not only learn about new research but also to share during my poster presentation the unique cultural and other issues I have identified related to family caregiving as an immigrant in America, as well as a member of the global Chinese diaspora.

Of course, none of us was surprised when the pandemic upended the plans of so many international conferences. The update that ADI 2020 would still take place on a virtual platform was welcome news for us all. Even more happy news for me was the e-mail from ADI informing me that I was awarded a generous bursary for full access to the virtual conference!

There were so many advantages to this virtual experience than if I were attending in person: the opportunity to sample more of the smorgasbord of offerings (plenary sessions, exhibitors' booths, poster sessions, symposia, workshops, networking events, etc.). And throughout the conference the warm hospitality of our gracious Singapore hosts could be felt even through my laptop screen.

As someone who loves languages, one thing that caught my attention was the many different pronunciations I heard of the word "Alzheimer's" because there were attendees from more than 100 countries, and yet how each and every one of us at this conference are all united to end this world health crisis and ensure that our loved ones live with dignity and that we carers are empowered with information, resources, and support.

### Dr. Hamad Al Sinawi, plenary speaker

I had the pleasure of presenting at the ADI 2020 virtual international conference during the plenary session 'The journey: Diagnostics, treatment care and support'. During my presentation, 'Social customs, expectations and religion in shaping the care provided', I spoke about how these elements are a vital part of dementia care and vary among different communities.

For many faiths, religion is considered an important source for comfort, helping the person with dementia and their caregiver accept the diagnosis and cope with the stressors that accompany the different stages of

dementia. It also enables caregivers to provide care regardless of the different challenges.

I was very excited to present on this topic yet very anxious that the internet connection would let me down that day. During my presentation, I gradually felt more relaxed but sadly 9 minutes on, I discovered my greatest worry happened and I lost internet connection!

When the internet was reconnected, I was thankfully able to complete my talk. Luckily, the organisers were very supportive and the audience were understanding and I had a good response during the panel discussion. Looking back, it was a good experience to manage such situations and not go in to meltdown mode.



## ■ Update from Dementia Alliance International (DAI)

### Is there a positive side to the pandemic for people living with dementia? From Kate Swaffer, Chair, CEO & co-founder

**We celebrated our 7th birthday in January and we were truly delighted to introduce Dementia Alliance International (DAI) member Alister Robertson as our new Chair.** Alister has been a member since 2016, and has recently stepped down as our Vice Chair, to take on the role of Chair, taking over from Kate Swaffer who continues as a board member, and the CEO.

Alister's new leadership role has been endorsed and welcomed by the Board of Directors and by our members and is recognition of the hard work Alister has done globally for our members, and in New Zealand where he is on the Board of Alzheimers New Zealand and a member of their Advisory Group.

He has a strong commitment to supporting people with dementia to have a voice, and to be included locally, nationally and globally.

Alister graduated from Lincoln University, Canterbury, New Zealand in 1978 with a Bachelor in Agricultural Commerce. He spent the following 30+ years in the rural finance sector, lending money to the primary sector.

In 2009, Alister and his wife, Charlene decided they would like to do something together, given their four sons had finished their schooling and were doing their own thing.

Alister and Charlene resigned from their respective jobs, sold their newly built home and purchased a Motel in Taupo, which they sold four years later.

They then moved to Napier, Hawkes Bay (2013) to be closer to their son and his family. They had a retail and café business until Alister's dementia diagnosis.

Alister's father had Alzheimer's and Alister was diagnosed with younger onset Alzheimer's in 2014, aged 60 years. He endeavours to follow the advice of trying to maintain a healthy brain by way of diet, remaining socially involved, good sleep, staying mentally active and exercise. Alister is a keen cyclist, which is his main mode of transport and this helps keeping him fit.

Alister participates in the various activities provided by DAI and would like to see more Kiwi's become active



**Alister Robertson, new Chair of DAI.**

members of DAI, as well as more people with dementia globally to join for peer-to-peer support, and to get involved in the global work done by DAI. He is committed to the values and mission of DAI, and the work that is needed to ensure our advocacy continues and our rights are upheld.

It continues to be imperative to change misperceptions about dementia, address stigmas associated with it, discourage the detrimental psychological and physical abuse of people with any type of disability including those experienced by people with dementia, and demand that the voices of people with dementia be included in decisions directly affecting us. The misguided under-estimations of our potential continue to create oppressive and humiliating barriers to our full engagement in society. Some of us have even been publicly accused of being imposters, on the grounds that supposedly no one with dementia could address an audience of professionals at an academic or medical conference.

DAI will therefore continue to advocate and educate, starting in our own local neighbourhoods, nationally and globally, at professional conferences, and in the vast online communities we have built. We are dedicated to helping all people live more positively with dementia – not just die from it.

DAI's vision is "A world where all people are valued and included".

We will all continue to advocate for our rights to equal and full inclusion in public spaces and activities; we educate the public on our human-ness in the face of cognitive disabilities, so that we are not reduced in legal or social status. We seek to live positively with a high quality of life (just as all people do – that's the point), to be valued for who we still are, and to be included as equal citizens.

**People with dementia can join DAI for free [here](#).**

**People interested in DAI can learn more [here](#).**

As the outgoing Chair, and a co-founder, I am proud to hand over the reins to Alister.

Stay safe and well, as we all face another year with the COVID-19 pandemic still affecting so many people around the world.



## Looking towards 2021



ADI members for the July 2020 Global Perspective.

Last July, we asked some of our **members** to let us know how they were adapting to the COVID-19 pandemic. For this Global Perspective, we wanted to know what some of our members were looking to achieve in 2021.

### Alzheimer's Association Japan (AAJ)

*"Continuing to advocate for people living with dementia and their families at the time of the pandemic."*

### Asociacion de Alzheimer de Puerto Rico

*"More preventive measures observed by the population."*

### Demensia Brunei

1. Drafting of the Brunei National Dementia Action Plan
2. ADI-ASEAN (The Association of Southeast Asian Nations) partnership in Health and Youth sectors presented in the ASEAN Summit Progress
3. Encouraging the growth of the YEP (Youth Engagement Programmes) in ADI associations."

### Fundación Alzheimer de Venezuela

*"For a government change and that a national plan for Alzheimer's and other dementias will be approved."*

### Alzheimer's Indonesia

*"Empowering and connecting with people with dementia and also their families."*

### Fundación TASE

*"Maintaining the synergy between member associations or foundations in terms of strategies and support to reach more people. In 2021, we want to find ways to support people not only digitally, but in some way address many resource-poor people who do not have the technologies to link up to a digital world. We have several projects this year; we turn 10 years old and one of our goals is to have talks, free activities, to develop our 'May Alzheimer's not stop us' magazine, as well as to join the great global campaign for Alzheimer's and other Dementias in the month of September!"*

### France Alzheimer

*"Recognition of dementia as a disability in France, among others."*



## Voices for Hope

**I am Emily Ong, a dementia advocate; co-facilitator of Alzheimer's Disease Association Singapore, Voices for Hope program; Focus Group member of the Global Dementia Observatory and Dementia Alliance International.** It is a privilege to have been given this opportunity to speak on behalf of my global friends living with dementia; it is an affirmation of "Nothing about us, without us."

My journey with dementia started with the French Toast incident. On a usual morning, French Toast is one yummy yet simple breakfast to prepare. However, I suddenly found myself struggling to remember what ingredients I need and how to make French Toast. All I knew was that I needed bread. I have no recollection or impression that I had made it before. It was like my brain had a blackout, there was nothing to retrieve at all. That was when my elder daughter saw an urgent need to make an appointment with a neurologist specialized in cognitive neurology.

I was diagnosed with cognitive impairment and young onset dementia at 51 years old. It was the worst nightmare I could have ever imagined. How I wished it was just a horrible dream. There were so many unanswered questions. How was it possible that I had dementia despite being young and healthy? Was I going to be useless and needing to depend on others for everything?

There was no post-diagnostic support system in place, to help me process the rawness and brutality of this diagnosis. There was no one to hold our hands and help us to grieve for the loss of the future we had planned. I felt so alone and terrified, and yet, I had to put up a brave front for my family that things will be okay. All I knew was that there is only one way in dementia, and that is a downward spiral, with no hope of cure and no way to maintain my independence. I was told of day-care services, where activities like colouring and playing mahjong were provided to stimulate cognition; memory cafes where people sang familiar songs to relive memories of yesteryear. None of this made me feel empowered, engaged, or enabled.

I was at the lowest point in my life when I found Dementia Alliance International (DAI) and also the "Voices for Hope" (VFH) program. For the first time since my diagnosis, I saw hope and the possibility of living a life with meaning and purpose again.

At DAI and VFH, we laugh, we discuss, we talk about



Emily Ong (bottom row, 3rd from the left) with other members of Voices for Hope.

how to care for ourselves, we inspire and support each other. In short, we are doing all the normal things in life. This is what I want to share and encourage others to do: live a normalized life. Yes, it will never be the same again. There will be changes, and you might need to adjust your expectations and make adaptations with whatever capacity you still have but never, never doubt your ability to live your life to the fullest potential. However, people living with dementia and their care partners need support from the wider community to have hope again.

### Allow me to share my acronym of HOPE with you:

- **H for Hear us out** - and then tell us what you think of our suggestions. Encourage and support us to have our voices heard. Even though people with dementia may change in the way they think, feel, behave, interact, and communicate, this does not mean they don't have feelings, preferences, opinions, or thoughts.
- **O for Offer support** - you must ask why offer and not provide? Because assistance is meant to enable us to help ourselves and maintain our functioning. The daily capacity to do things has a direct influence on the independence of people with dementia and their quality of life. So, let them decide what kind and level of support they need.
- **P for Partner with us** - let us guide you with our lived expertise in our conditions. Involve people with dementia in the planning of programs and activities. It not only empowers these individuals but also leads to more effective use of resources and better outcomes.
- **E for Enable us** - focus on our remaining capacity. Minimize and compensate for any functional changes resulting from the disability caused by dementia. People with dementia need neurological or physical rehabilitation programs, to help them regain the highest level of function and independence.

Please embrace the **HOPE** acronym so that you can shine hope into the lives of those living and affected by dementia. Thank you.



## Research and STRiDE Update

### STRiDE Update



They say that innovation often comes out of adversity – and this has never been more true than in the case of how STRiDE (Strengthening responses to dementia in developing countries) teams have responded to the challenges of the Covid-19

pandemic. Despite being forced to pause face-to-face research throughout most of 2020, STRiDE teams across all seven countries have found creative ways to move their research and stakeholder engagement to virtual platforms, developing methodology and protocols around how to run virtual interviews and focus groups effectively.

Across the whole STRiDE project, work package teams set about re-imagining project timelines and data collection methods that could engage stakeholders and enable them to participate in an ethical and safe manner. Country-specific field work continues, albeit virtually, with team members also taking time to analyse existing data and to begin publishing some emerging findings.

The ADI 2020 Virtual Conference provided a significant opportunity for the STRiDE team to share

some of the project findings, with eight early career researcher posters accepted. In addition, there were also two STRiDE-focused sessions during the conference; one highlighting work and emerging evidence from specific work packages in areas such as stigma and the impact on carers, while the other was a live Q&A event that enabled people worldwide to pose questions and promote discussion.



The virtual 2020 annual STRiDE all-team meeting.

And despite a challenging year, there are some silver linings. Opportunities to support policy change have emerged in countries like Kenya and Brazil. So as we enter 2021, the STRiDE team remains enthusiastic and tenacious in the face of continuing Covid challenges – ready to keep moving forward.

**Learn more about STRiDE.**



## WEBINAR

### COVID-19 vaccines: The global dementia movement & how you can help

**Wednesday 24 February**  
**1pm London | 8am New York**

