



# Annual Report 2020



Dementia Alliance International

Cover: WHO Director General Dr Tedros Adhanom Ghebreyesus and Unit Head, Sensory Functions, Disability and Rehabilitation Marcos Cleza celebrate Rehabilitation 2030 Forum. DAI has attended all WHO Rehabilitation 2030 Forums because dementia is a major cause of disability and rehabilitation is a human right.

A DAI WEBINAR

## “Staying engaged without driving”

**Dr Jacki Liddle**  
(OT, Research Fellow, PhD, BOT (Hons))

**Dr Theresa Scott**  
(NHMRC-ARC Dementia Research Development Fellow and a Psychologist)

April 23/24, 2019




THE UNIVERSITY OF QUEENSLAND AUSTRALIA

DEMENTIA ALLIANCE INTERNATIONAL  
The global voice of dementia

A DAI Meeting Of The Minds Webinar

## “Clowning and Dementia”

**Professor Lenisa Brandão**  
University of Rio Grande do Sul

February 26/27, 2020



DAI

A DAI Meeting Of The Minds Webinar

## “StepUp for Dementia Research”

**Yun-Hee Jeon, RN, PhD**

25/26 September, 2019



StepUp THE UNIVERSITY OF SYDNEY

DAI

5 YEARS 2014-2019

A DAI Meeting Of The Minds Webinar

## “Assistance Dogs for people with dementia”

**Keith McVilly PhD,**  
Professor of Disability & Inclusion, The University of Melbourne

**Phil Hazell,**  
Chair, Dementia Australia Dementia Advisory Committee

23/24 October, 2019



THE UNIVERSITY OF MELBOURNE

DAI

5 YEARS 2014-2019

A DAI Meeting Of The Minds Webinar

## Human Rights in Residential Aged Care

**Dr Linda Steele and Bobby Redman**

May 27/28, 2019



UTS UNIVERSITY OF TECHNOLOGY, SYDNEY

Dr Linda Steele

DEMENTIA ALLIANCE INTERNATIONAL  
The global voice of dementia



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## About Dementia Alliance International (DAI)

DAI was founded by eight people diagnosed with dementia, representing three countries (USA, Australia and Canada) and was officially launched on January 1, 2014. Our founding members are the late Dr Richard Taylor, the late Dena Dotson, Amy Shives, Kate Swaffer, John Sandblom, Steve Ponath, Janet Ford and Susan Stephens. The organisation is run by and for people with dementia, and members seek to represent, support, empower and educate others living with the disease, and the wider dementia community.

DAI is an organization that strives to provide a unified voice of strength, advocacy and support in the fight for individual autonomy and improved quality of life for people with dementia and our families supporting us. Our work on claiming the Human Rights for all people with dementia means we are legally entitled to be included, and not just consulted, or represented by others.

Thanks to the generosity of the late Dr Richard Taylor, Dementia Alliance International is a US Corporation with 501(c)(3) not for profit status, which means donations by US citizens are tax deductible. DAI is the peak organisation globally representing persons with dementia, and thus widely accepted as the global voice of dementia, now representing members from 49 countries. Membership of Dementia Alliance International is free and is open to anyone with a medical diagnosis of any type of dementia. We are very keen to represent ourselves in all matters concerning dementia, in the philosophy of “Nothing about us, without us.”



From left: DAI members Maggie Weidmark, Lynda Hogg, Selva Marasco (standing) with Co-founding members Kate Swaffer, Susan Stephen, Janet Ford (Pitts), and the late Dr Richard Taylor at the ADI2014 conference in Puerto Rico.

## Chair/CEO Report, 2020

It is with great pleasure I report on another successful year with DAI, in spite of the significant challenges we all faced due to the COVID-19 Pandemic. I'd like to thank the current board members for their support, friendship and hard work in 2020, and look forward to working with them in 2021 and beyond.

The year 2020 was one like no other in our shared history, and the COVID-19 pandemic almost stopped the world from spinning! Like all other organisations, we increased our services and support to members, and although DAI are early adopters of it and had been using zoom since 2013, were pleased it was a skill already embedded for most of our members. That the rest of the world has had to catch up with working in the virtual space, has been in some ways, of benefit to people with dementia, as it has made the world more inclusive.

I'd also like to thank all members who volunteer in any way to support the work we do for the direct and indirect benefit of our members, especially our peer-to-peer support group co-hosts and Cheryl Day who manages all of our support group and brain health master files and scheduled emails, members of our subcommittees. On behalf of everyone at DAI, I also thank our fabulous volunteers, Sarah Yeates, our Board Secretary, Tamara Claunch, our Finance Officer and a co-host of the brain health meetings, and Peter Watt who provides our graphics and logos, as well as formatting all of our documents and publications. It is also through him we have two printing companies who provide pro bono printed materials such as banners or brochures, if needed.

Board member James McKillop from Scotland celebrated 20 years of advocacy. DAI is honoured to have him on our board, and as an active member including as a co-host of the UK peer to peer support group. Congratulations James. Congratulations also to Graeme Atkins, the recipient of the prestigious Richard Taylor Advocates Award in 2020.

Finally, I wish to thank Alzheimer's Disease International (ADI) and Dementia Australia (DA) for continuing to partner with us, and for the funding provided as part of these strategic partnerships. DAI is the voice of people with dementia, DAI is the for people with dementia, and DA is the national peak body in Australia advocate for people with dementia and their care partners. We are delighted to work with them, and that they are willing to work with us and support our work in this way.

Stay safe and well,



Kate Swaffer  
Chair, CEO & Co founder

# 2020 Board of Directors



Chair/CEO & Co Founder  
Kate Swaffer - Australia



Vice Chair  
Alister Robertson - New Zealand



Treasurer & Co Founder  
John Sandblom - USA



Eillen Taylor - Australia



Wally Cox - USA



Bobby Redman - Australia



Bill Turner - Australia



Christine Thelker - Canada



James McKillop, Scotland



Diana Blackwelder - USA

# 2020 Richard Taylor Memorial Advocates Award

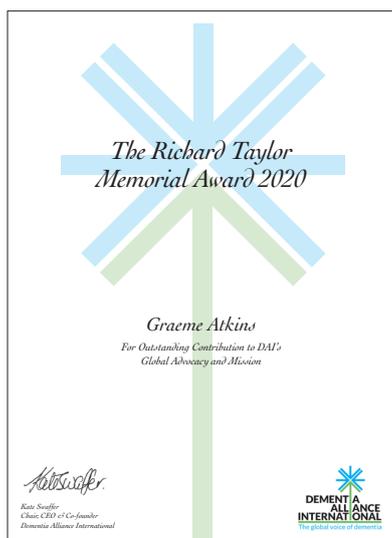
## Graeme Atkins wins the 2020 Richard Taylor Memorial Advocates Award

DAI is pleased to announce the recipient of the 2020 Richard Taylor Advocates Award, recognised on World Alzheimer's Day 21 September 2020. This year it goes to DAI member Graeme Atkins from Australia for his outstanding service to others living with dementia, and his commitment to DAI's mission and vision of a world where ALL people are valued and included.

Graeme was diagnosed with the younger onset Alzheimer's type of dementia in 2009. He has been an advocate for improving outcomes for people with dementia, in particular by composing and performing songs about being diagnosed or living with dementia.

Graeme says he can only do what he does, because of the love and support of his wife Susan, also lovingly known, as we now say in DAI thanks to our co-founder Kate Swaffer, as his Back Up Brain.

DAI is proud to call Graeme their 'Resident Rec. (or is that wreck?) Officer! Thanks for everything that you continue to do Graeme.



# World Alzheimer's Report 2020

## World Alzheimers Report 2020: Design, Dignity, Dementia: Dementia-Related Design and The Built Environment

On day 23 of World Alzheimer's Month/Dementia Awareness Month #DAM2020 we were pleased to share the Alzheimer's Disease International World Alzheimer Report launched on World Alzheimer's Day: Design, Dignity, Dementia: Dementia-related design and the built environment. Our daily series is varied and we hope, relevant, and that this topic is critical to the future of dementia care.

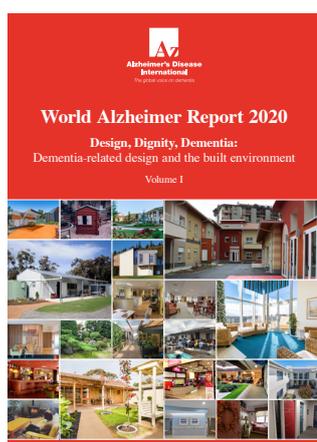
Increased awareness had been desperately needed of the potential of good design to improve equal access for people with dementia, and there has been increasing urgent global demand by people living with dementia to see this translated into practice.

The two volumes of the 2020 World Alzheimers Report have brought together the principles and practice and will be an important resource now and into the future.

The webinar hosted by ADI was extremely well attended, with more than 1100 who registered, and over 600 people from 77 countries who logged in and attended the live event.

An important theme running through the webinar was around dignity – or the lack of dignity accorded to people living with dementia by certain design methods.

Panellist Kevin Charras PhD showed a slide of different examples of this, stating: "It's quite appalling when design relies on stigma and stereotypes of dementia. It turns into furniture that is vintage, colours and contrasts that are exaggerated, and signage that is triple in size, and streets inside buildings, which becomes very confusing."



# Member Services

DAI members facilitate and provide online peer-to-peer support groups and social groups for people with dementia through Facebook and Zoom (online video conferencing), for our members, and which are free; you can join here. Online support groups are ideal for those who cannot drive to their local “in person” support group or who live in isolated areas with limited access to services.

Many of our members also like to join more than our DAI support groups, and may also belong to a number of other groups run by different organisations or individuals, either online or in person if they have them available in their local areas.

DAI has commenced a number of additional services or events for its members, including a weekly Living Alone Online Social Support Group held every Sunday at a time zone suitable to members in Europe, the UK, Scotland, the USA and Canada, hosted by Julie Hayden from the UK, and David Paulson in the USA. We also hold a weekly Living Alone Social Support group for members in Australia, New Zealand and Asia, hosted by Bobby Redman and Jo Browne. As membership increases, so does the demand for peer-to-peer support groups; hence we will also aim to be hosting more in different regions in 2021

Peer to Peer support groups continue to grow in numbers and time zones, and anyone with dementia can join for free, by becoming a member of DAI.

**01** | Join a DAI online peer-to-peer support group today. [www.join dai.org](http://www.join dai.org)

**02** | Facetime, Zoom, or Skype with family and friends.

**03** | Follow ADI's up to date advice and resource page. [www.alz.co.uk](http://www.alz.co.uk)

**04** | Follow the World Health Organisation daily updates. [www.who.int](http://www.who.int)

**05** | Join your peers, family and friends at DAI's monthly Café Lé Brain & Webinars.

**06** | Contact your national Alzheimer's organisation.

**07** | Exercise daily.

**08** | Maintain physical distancing and stay safe.

**DAI**  
**ALLIANCE**  
**INTERNATIONAL**

**FOR PEOPLE WITH DEMENTIA DURING THE COVID-19 PANDEMIC**

DAI has a 24/7 open access Zoom room available for members, family and friends.  
[www.infodai.org](http://www.infodai.org) | email: [info@infodai.org](mailto:info@infodai.org)

DAI Vision: A world where all people are valued and included

## Peer to peer support groups

### Weekly peer to peer support groups

Day	Time	Hosts	
Monday	10:00 AM ACST	Eileen Taylor & Kate Swaffer	AU/NZ/SG
	9:00 AM GMC	James McKillop & Dennis Frost	UK/EU/SA/AU
Wednesday	1:30 PM ACST	Bobby Redman and Kate Swaffer (Alister, Cheryl & Eileen are back up hosts)	AU/NZ/SG
Thursday	1:00 PM CDT	John Sandblom & Wally Cox	USA/CA
	3:00 PM CDT	Kate Swaffer, Sid Yidowitch, Dallas Dixon	USA/CA/AU
Friday	2:30 PM CDT	Christine Thelker & Kate Swaffer	USA/CA

### Living Alone Social Support Groups

Day	Time	Hosts	
Sunday	5 PM GMC	David Paulson & Julie Hayden	USA/CA/UK, weekly
	5 PM AEST	Bobby Redman & Jo Browne	AU/NZ, fortnightly

### Monthly Social Support group

Tuesdays, Japan, Scotland, Canada, USA & AU, as members are available



A few members of the Friday DAI peer to peer support group having a “ future’s so bright I gotta wear shades” moment.

## What is a Peer to peer support group?

A Dementia Alliance International (DAI) peer-to-peer support group consists of a small group of people with a diagnosis of a dementia, who meet regularly to discuss their experiences, problems and strategies for coping and living more positively with dementia. There are a number of different types of support groups, but the types DAI provides are weekly online peer-to-peer support groups, and one to one buddying and mentoring.

## How can someone join a DAI Support Group?

- Contact us at - [www.joindai.org](http://www.joindai.org)
- One of our members will then contact you to assist you find an appropriate group with a vacancy
- Please note, you must be a member of DAI to join, which is free - [www.joindai.org](http://www.joindai.org)

## What does a DAI support group provide and how do they work?

- The DAI support groups meet online, and the weekly group is restricted to 12 people with dementia and who attend regularly;
- Peer-to-peer support groups help to beat the isolation of dementia;
- Learn how supportive it is being part of a support group- with others also living with a diagnosis of dementia;
- There is no need to leave your home, if you have a way to connect to the Internet;
- Your family support person, or even a paid carer can assist you to attend, but participation is for people with dementia; and
- Learn how rewarding it also is to support and empower people newly diagnosed with dementia.

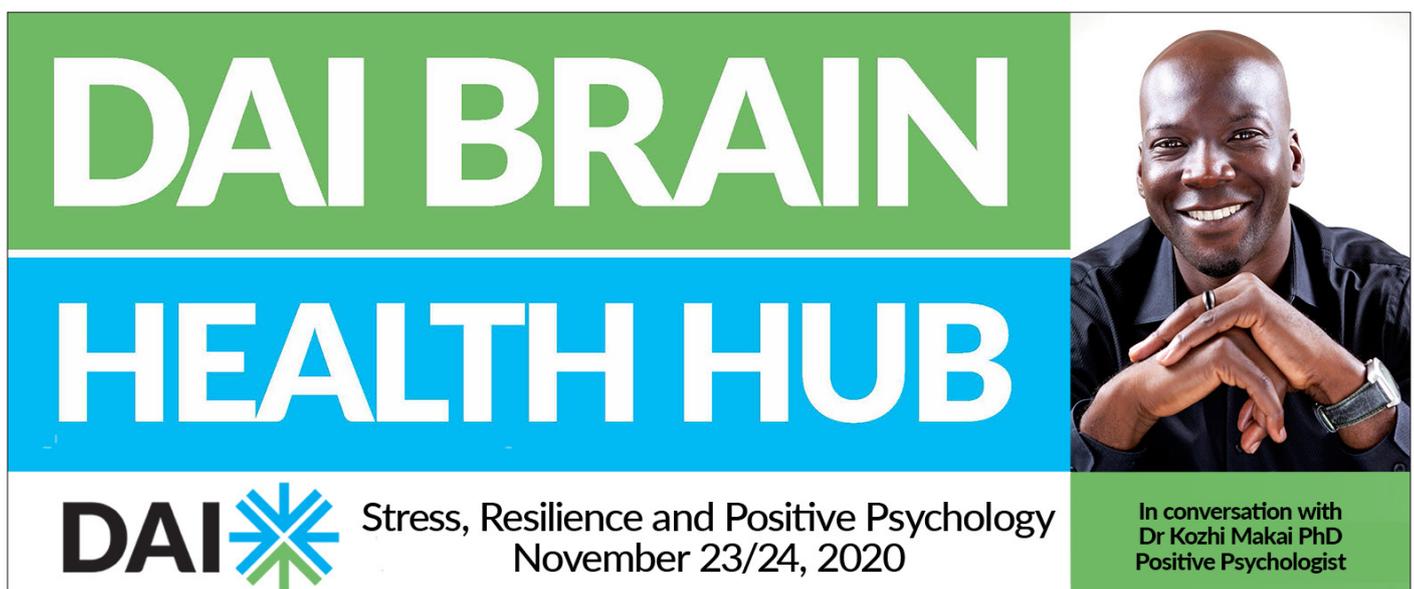
## The Brain Health Hub

The Brain Health Hub was set up to support members wanting to manage dementia (either themselves, or with the support of their own doctor) with a lifestyle approach to dementia such as the Bredesen Protocol.

These groups are not exclusive to DAI members, and anyone interested in brain health is welcome to join the meetings and the Facebook page.

Our Facebook Brain Health Hub page continues to grow, and we have modified our meeting to suit different time zones, hosting two per month for everyone.

Contact us at [info@infodai.org](mailto:info@infodai.org) for more information.



**DAI BRAIN**  
**HEALTH HUB**

**DAI**  Stress, Resilience and Positive Psychology  
November 23/24, 2020

In conversation with  
Dr Kozhi Makai PhD  
Positive Psychologist

The banner features a portrait of Dr. Kozhi Makai, a smiling Black man with his hands clasped, wearing a dark shirt and a watch. The text is arranged in a structured layout with green and blue background blocks.

# World Rocks Against Dementia

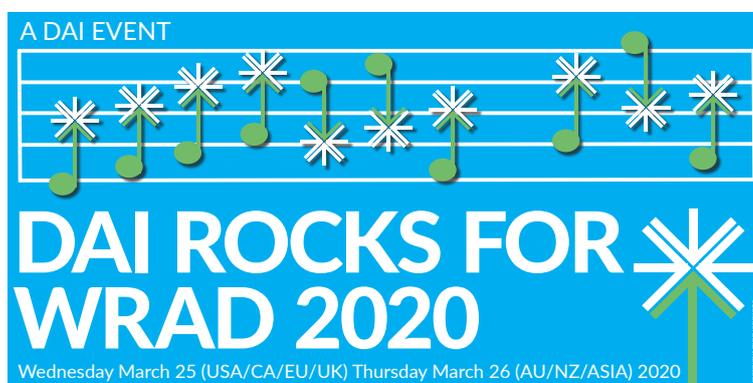
2020 WRAD was hosted by Wally Cox and Alister Robertson

DAI 's vision is that all people are valued and included, and we also have a strong philosophy that working together makes us all stronger. We believe by doing so, we will achieve more tangible change for all people with dementia and our families. This includes having fun together!

Through hosting the online WRAD event, we aim to bring the power of music to everyone, and support the global initiatives, the Rock Against Dementia, WRAD, and the Purple Angel. The event was, as always an great success. It was also a chance to destress for those feeling concerned about COVID-19. Due to the virus, most live events have been cancelled. Thankfully, DAI members are used to online events, so everyone is safe...

Our 2020 WRAD program included some new original performances, written and performed especially for the DAI. As it was combined it with our monthly Cafe Le Brain, there was also be an update about DAI, and lots of time to chat.

Opening and closing live performances are once again by the incredible Graeme Atkins, who supported by his wife, is a wonderful example of living positively, alongside the very real and daily challenges of a diagnosis of dementia. His songs are original, and DAI is grateful to have his friendship and support.



## International Advisory Group (IAG)

There is no update for 2020 as the group has not met. This group was set up to provide professional support, and as required, advice. Members review publication drafts of publication or other DAI documentation, get involved in research projects, or get involved with, or provide assistance or support with DAI projects.

Historically, national or local organizations advocating for people with dementia and/or their families invite people with dementia and care partners to join their advisory groups. DAI has upturned this concept for the purpose of ensuring we have a depth of expertise and knowledge to draw on, and we include people with and without dementia. We are very grateful to the members of this group, and understand they contribute as they are available to, or when they have an interest in a specific project or topic.

Non-DAI members:	DAI members:
Ian Kremer, EO, LEAD Coalition, USA	Cheryl Day, Australia
Daniella Greenwood, Dementia Consultant, Australia	Bonnie Erickson, USA
Bill Hillstrom, CPA, USA	Diana Blackwelder, USA
Chris Lynch, Deputy CEO, ADI, UK	Dr. James McKillop, Scotland
Sarah Yeates. CEO, Caladenia, Australia	Julie Hayden, UK
Denise Craig, Psychologist and PhD Candidate, Australia	Bobby Redman, Australia
Dr Kenny Chui, Hong Kong	Val Schache, Australia
Professor Lyn Phillipson, Australia	Alister Robertson, New Zealand
Professor Lee-Fay Low, Australia	Walter Cox, USA
Sonya Barsness, USA	Bill Turner, Australia
Susan Macauley, Canada	Julie Hayden, UK
Lisa Poole, Canada	Dennis Frost, Australia
Leah Bisiani, Dementia Consultant, Australia	Dr. David Paulson, USA
Al Power, MD, USA	Paul Lea, Canada
Teepa Snow, Dementia Consultant, USA	Agnes Houston, Scotland
Dr Ellen Skladzien, CEO, Downs Syndrome Australia, Australia	Jane Washburn, USA
Dr Daniel C. Potts, USA	Lynda Henderson, Australia
Dr Louise Heuzenroeder, Australia	Mary Beth Wighton, Canada
	Eileen Taylor, Australia
	Ian Gladstone, Australia
	Kate Swaffer, MSc, Australia

If you are also interested in becoming involved, please contact us at [info@infodai.org](mailto:info@infodai.org)

## Global Partners and Relationships

**United Nations:** DAI applied for ECOSOC Status with the UN, received full ECOSOC membership at the Executive Board meeting in 2020.

**World Health Organisation:** DAI continues to have many opportunities to work with the WHO, and although not in Official Relations with them, work directly with them, for example, providing members to join the Global Dementia Observatory Focus Group of Experts with Lived Experience.

**Conference of State Parties on the CRPD:** DAI still has DPO status with the CoSP

**International Disability Alliance:** We have retained Observer status membership of this organization, which was proposed to be reviewed formally in 2020.

**Global Rehabilitation Alliance:** Launched in May 2018, DAI is one of the Founding member organisations.

**StepUp 4 Dementia Research:** DAI was invited to become an Organizational Champion for this newly established research organisation in Australia. The aim is to partner researchers with people with dementia and care partners or families.

**World Dementia Council:** Two DAI members are full members of the WDC; members with dementia include Hilary Doxford from the UK, and Maryna Maritz, from South Africa.

**LEAD Coalition:** DAI continues to work with this organization in the USA; John Sandblom and Diana Blackwelder represent DAI at their monthly meetings

**NCD Alliance:** DAI continues to work with the NCD Alliance, alongside ADI towards a better representation of Dementia at the UN High-Level Meetings in New York, and other important events and meetings.



# Strategic Partner Summaries



# Alzheimer's Disease International

## 2020 Report for Dementia Alliance International

Early into 2020 Alzheimer's Disease International (ADI), was closely tracking developments in the Asia Pacific region, as the first signs of what was to become the global coronavirus pandemic were emerging. ADI's global conference was scheduled to take place in Singapore, to be co-hosted with our local member, Alzheimer's Disease Association. Anticipating the challenges of the growing pandemic we postponed the event until December 2020, delivering what became our 34th global conference and our 1st fully virtual gathering of the dementia community.

The conference, themed around the 7-action areas of the World Health Organization's (WHO) global plan, saw 1600 delegates join from 130 countries. Due to the rescheduling we were able to introduce additional sessions on the COVID-19 and dementia related design.

Design was also the focus of the 2020 World Alzheimer Report titled: 'Dignity, Design & Dementia', with DAI contributions from Kate Swaffer and Dennis Frost. ADI commissioned a team led Prof Richard Fleming, Australia, to create a report that reflected on 30 years of dementia related design research, highlighted the role pioneers and innovators, best practice and education, and positioned a set of values and principles that can be adapted globally.

Due to the pandemic the World Health Assembly (WHA) in May 2020 was suspended. ADI submitted a number of online statements, in particular around rights and access to treatment and care, at a poignant time, during a period when some countries were experiencing shortages of equipment, exceeding emergency hospital bed capacity, and so we called for absolutely clarity of policy and fairness in triage decision making.

ADI decided to delay the launch of the report 'From plan to impact; maintaining dementia as priority in unprecedented times', which usually coincides with WHA. Hosting a side event in June, we looked at progress and barriers towards global targets. ADI was joined by Kate Swaffer, Devora Kestel, Director of the WHO Mental Health team, plus government representatives from Germany and Iceland (both launching plans during the pandemic, as did China and Dominican Republic). Currently 34 countries have national plans, a significant gap to the target of 146 of 194 WHO Member States by 2025. An additional report during the year, of which Kate Swaffer took an advisory role, was the ADI, Global Coalition on Ageing and Lien Foundation Innovation Index of 30 Cities, looking at urban innovation preparedness. The report analysed five categories of strategy, early detection and diagnosis, access to care, community support and business environment.

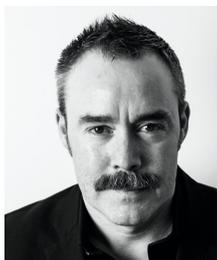
Our COVID-19 response focussed on advice, support and communication. ADI launched an online resource adding global content, and hosted a series of webinars throughout the year, sharing information, advice and first-hand experience of the pandemic. An early video by Prof Huali Wang, Alzheimer's Disease China, offering health and care advice during the crisis, was viewed over 13,000 times. In addition to the webinars, ADI also hosted a series of masterclasses to support associations through what was a tumultuous period. Several members of DAI contributed to the webinars and the online resources. ADI and DAI also co-hosted a global human rights webinar.

The World Alzheimer's Month 2020 campaign materials, toolkit and masterclasses were adapted to reflect the global pandemic. The theme was "Let's talk about dementia" and built on the insight from the World Alzheimer Report 2019 on attitudes to dementia and the stigma that still pervades. 94 countries took part and the accompanying social media campaign generated 20 million engagements.

ADI currently has 100 member associations and 19 associations on the development programme. ADI continued to support member activities, especially during these difficult times, which now includes showcasing progress in a dedicated area on the new ADI website and during the conference. From the research perspective ADI continued to develop the STRiDE project, with DAI and the London School of Economics, gathering association leads from the 7 countries in London, just prior to lockdown, at a point where country level situational analyses were reaching completion. Taking advantage of the gathering ADI, working with ITN Productions filmed updates from Brazil, India, Indonesia, Jamaica, Kenya and Mexico for the new documentary film "Hope in the age of dementia" which was launched in June and showcased at the Global conference in December.



Paola Barbarino  
CEO, Alzheimer's Disease International



Chris Lynch  
Deputy CEO & Director of Policy, Communications & Publications, Alzheimer's Disease International

### Dementia Australia Key Activities & Achievements

#### Responding to COVID-19

From the onset of the COVID-19 pandemic, we quickly pivoted around Australia to adapt our services and provide vital support and information for people living with dementia, their families, carers and the aged care workforce. We modified many of our services and activities to deliver them by telephone or online in a COVID-19 safe way. Our National Dementia Helpline operated as normal throughout the pandemic and we produced a series of COVID-19 Help Sheets offering tips for those living with dementia, families, friends and carers, residential care providers and home care providers.

We joined with other sector peak bodies to deliver a national Older Persons COVID-19 Support Line. Our partnership approach also included working with 13 aged care peak bodies and consumer advocacy organisations to develop the Industry Code for Visiting Residential Aged Care Homes during COVID-19. The code created a nationally consistent approach to allow residents to receive visitors while minimising the risk of spreading COVID-19.

We further supported the aged care sector by providing free online training for frontline aged care staff via our Centre for Dementia Learning. The courses aimed to increase participants' understanding of dementia and provided frameworks to help with problem solving.

Finally, we launched the Keep the World Open campaign to raise awareness and tackle discrimination. The campaign urged Australians to take a pledge to help keep the world open for people living with dementia, not just during the COVID-19 pandemic, but every day.

#### Dementia Action Week

The theme for Dementia Action Week 2020 was 'Dementia. A little support makes a lot of difference.' and focused on three people living with dementia who live full and active lives and receive support that enables them to keep doing the things they love. Each day of Dementia Action Week explored a new theme and provided practical tips, supportive tools and information for everyone to adopt and share.

Levels of engagement for the campaign far exceeded expectations considering it had to be held entirely online for the first time to ensure the safety of our community. The online advertising campaign delivered 552,881 impressions and the traditional media campaign resulted in audience reach of 7.2 million.

#### Royal Commission into Aged Care Quality and Safety

In 2020 we continued to contribute to the Royal Commission into Aged Care Quality and Safety through submissions, hearings, community consultations, research and more. Submissions related to areas including program design, the future of the aged care workforce, the needs of carers of people living with dementia and people living with younger onset dementia in the aged care system. We welcomed a special report on the COVID-19 pandemic in aged care from the Commission and Dementia Australia representatives presented at workshops held throughout the year. This was all in the lead up to the release of the Final Report expected in early 2021.

## **Quality Care Initiative**

The final event of the Quality Care Initiative, a Symposium, was due to be held in Sydney in March 2020 but was cancelled due to COVID-19. Dementia Australia reimaged the Symposium to deliver six keynote sessions across six weeks, free of charge and online. Aimed at the aged care workforce the program included presentations from Dementia Advocates, government representatives, Australian experts and international experts. Topics included quality care, dementia and leading cultural change.

The series was a great success with a total of 4,223 registrations and 1,301 attendees in the first live session, exceeding our target.

## **Dementia Advocates**

Dementia Australia works collaboratively with Dementia Advocates and external stakeholders to elevate the voices of people living with dementia, their families and carers. We coordinate and continue to grow the National Dementia Advocates Program which now has more than 400 active members; we link Dementia Advocates to places / platforms where decisions are being made, ensuring their experiences are heard and promoted to government, media, services, fundraising and policy; we work with Dementia Advocates to ensure they are supported, well informed and prepared for their involvement in advocacy opportunities; and we actively seek Dementia Advocates' feedback to continually improve the program and consumer engagement outcomes.



Maree McCabe  
CEO, Dementia Australia

# The LEAD Coalition

## 2020 Report for Dementia Alliance International

### Highlights

Thanks to advocacy from the LEAD Coalition community, other stakeholder organizations, grassroots activists across the country, and the courageous leadership from our congressional allies, vital work will be maintained and expanded by federal agencies to accelerate science and improve quality of life among people living with dementia and their carers. NIH's overall budget will be increased by another \$1.25 billion to \$42.93 billion and Alzheimer's/dementia research will be increased by \$300 million to an astonishing \$3.118 billion annually (NIH invested \$631 million in dementia research in FY 2015, so the FY 2020 level will be roughly 494% higher). Because all NIH institutes will receive an increase in their base funding apart from the \$300 million increase targeted to NIA for dementia research, NIA likely will have total resources above \$3.118 billion available for dementia research. FY 2021 funding for the BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies Initiative) will increase \$60 million to \$560 million. A wide variety of aging services and support programs also are slated to receive increase funding in FY 2021, including a number of programs particularly important to the dementia community including the Alzheimer's disease demonstration grants, respite care, home delivered and congregate meals. See the NCOA aging program funding chart (<https://www.ncoa.org/article/current-federal-budget-and-appropriations-for-aging-services-programs>) for a thorough breakdown of FY 2021 levels. The appropriations package also will increase CDC's resources its public health approach to brain health and dementia with \$15 million to continue implementation of the BOLD Infrastructure for Alzheimer's Act.

### Federal Agencies Advancing Dementia Priorities

Strong collaborative relationships between advocates and federal agencies continue to deliver transformative progress to improve quality of life for people facing dementia now while accelerating the science to prevent, slow and stop the underlying diseases.

- The U.S. Department of Health and Human Services (HHS) released the National Plan to Address Alzheimer's Disease: 2020 Update (<https://aspe.hhs.gov/report/national-plan-addressalzheimer-disease-2020-update>)
- HHS also launched Healthy People 2030 (<https://www.healthypeople.gov/>), the nation's 10-year plan for addressing the most critical public health priorities and challenges. Importantly, Healthy People 2030 continues to include two dementia objectives (begun in 2020) and has added a third dementia objective as recommended by the LEAD Coalition (<http://www.leadcoalition.org/2019/01/17/hp2030-php/>): Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider – DIA-03. Learn more about each of the dementia objectives (<https://health.gov/healthypeople/objectives-and-data/browse-objectives-dementias>)
- The National Institute on Aging convened the 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (<https://www.nia.nih.gov/2020-dementia-care-summit>), which results in a final report including 67 research recommendations (<https://www.nia.nih.gov/sites/default/files/2021-01/DementiaCareSummitReport.pdf>).
- The Centers for Disease Control and Prevention (CDC) established Public Health Centers of Excellence (PHCOE) to Address Alzheimer's Disease and Related Dementias focused on risk reduction, early detection and diagnosis, and caregiving.

- The U.S. Food and Drug Administration (FDA) approved Tauvid (flortaucipir F18) for intravenous injection, the first drug used to help image a distinctive characteristic of Alzheimer's disease in the brain called tau pathology (<https://investor.lilly.com/newsreleases/news-release-details/lilly-receives-us-fda-approval-tauvidtm-flortaucipir-f-18>).

## A World in Upheaval

Nothing prepares us as individuals for a pandemic. But our professional and deeply personal fight against Alzheimer's disease and other forms of dementia gives us extraordinary experience in applying unrelenting urgency, exceptional collaboration, remarkable creativity, and unswerving humanity to this moment.

We understand the dangers of pseudo-science and snake oils, denial and halfmeasures, penny-wise and short-sighted policy, and the amorality of suggesting that older or sicker people sacrifice themselves for the economic benefit of others. We also understand the power of embracing the value of all people, scientific partnerships, candid and accurate public health messages, leadership that erases silos and partisanship, and robust material support for those on the front lines including people with the disease, their families and health care providers. We understand -- and many of us have taken action to address -- the practical reality that generalized advice such as social distancing must be adapted to meet the needs faced by people living with dementia and their care partners.

As with the dementia pandemic, we knew the COVID-19 pandemic would get worse before it got better. We grieve the loss as we embrace the hope. We do not know the pace or the inflection point for dementia, but we do know that inflection point will come and it will come sooner if we maintain our resolve, redouble our efforts, invest the necessary resources, and work together.

In deepest gratitude,  
Ian



Ian N. Kremer, JD  
Executive Director  
Leaders Engaged on Alzheimer's Disease (LEAD Coalition)

# Dementia Advisory Committees/Dementia Working Groups



# Dementia Advocacy Canada

## 2020 Report for Dementia Alliance International

Dementia Advocacy Canada (DAC), formed in January 2019, is a grassroots group of people living with dementia and care partners from across Canada who want to have an active and respected role in decisions that impact their lives. DAC wants to influence policy, inform program development, improve access to supports and services across Canada for people impacted by dementia.

DAC aims to collaborate with existing groups to amplify the voice of lived experience and make a positive difference for people impacted by dementia. This includes social support organizations like the national and provincial Alzheimer Societies, advocacy groups, technology accelerators and international groups like Dementia Alliance International.

DAC's 2020 advocacy priorities were carried over from 2019 and remained:

- Rehabilitation for people living with dementia upon diagnosis
- A single point of contact to navigate the health and social support systems upon diagnosis and through to end-of-life
- Increasing capacity and national standards of excellence for the dementia healthcare workforce

Many DAC members are actively engaged as speakers at dementia-related events and conferences, and several are co-authors and investigators of Canada's top research organizations. In addition, many are members of other dementia-related organizations such as Dementia Alliance International.

Like elsewhere in the world, COVID-19 had a tremendous impact on people living with dementia. Recreational activities and most social supports were cancelled. Canada had the dubious honour of the highest long-term care infection and death rates among first world countries. Retirement home and long-term care residents were trapped in their rooms for months, subjected to isolation and separation from friends and family. Stories of neglect and abuse flooded the news.

In response, Dementia Advocacy Canada launched a series of letter writing campaigns to federal members of parliament requesting their urgent attention to address system deficiencies exposed by COVID-19 including the lack of quality care and social support and a failure to recognize family as essential members of the care team.

Representatives from DAC were invited to join the Alzheimer Society of Canada's COVID-19 and Dementia Task Force to help address the gaps in the health and social care system.

DAC's objectives for 2021 include capacity-building in new members and advocating to have Canada's National Dementia Strategy fully funded and fully implemented.

Submitted by Mary Beth Wighton and Lisa Poole



DAC members at a conference in Toronto

## Singapore Voices for Hope 2020

2020 Report for Dementia Alliance International



Hearty smiles during a virtual graduation for Voices for Hope (Cohort 4) participants!

Despite the COVID-19 pandemic, the Voices for Hope programme by Alzheimer's Disease Association (Singapore) continues to coach persons with dementia and care partners, giving them a boost in their confidence as they actively contribute to the community through their stories and sentiments.

Since 2019, some 50 participants have benefited from this programme, and they have been involved in more than 100 public sharing opportunities, including media interviews and community engagements. We are inspired by the great work from Dementia Alliance International (DAI), and will continue to seek new approaches to encourage more people to advocate for the dementia cause.

### Milestones

After graduating from the programme, two persons living with dementia, Emily Ong and Thomas Ong have further advanced to be co-facilitators for the Voices for Hope programme.

With their lived experiences, their involvement in content development has greatly benefited participants in their dementia knowledge and advocacy roles. Both are also members of the DAI, where they contribute ideas to raise awareness about the condition in a global coalition.



Emily Ong



Rohani Binte Rahmat

Under Emily's mentorship, we have seen remarkable strides by other participants including Muhammad Said, who is living with vascular dementia and his care partner Rohani Binte Rahmat. The couple delivered a closing speech at the Alzheimer's Disease International 2020 virtual conference, which was attended by more than 1,600 delegates across the globe. Emily was also a plenary speaker at the global conference where she gave a talk on 'Understanding and Acceptance of Dementia'.

### Making a Mark with DAI

In September 2020, the Voices for Hope programme received accreditation from Kate Swaffer, Chief Executive Officer & Co-founder of DAI. She acknowledged that the programme "has the potential to be of significant value globally for all advocacy organisations, as finding and keeping advocates are commonly difficult,". Kate also highlights the importance of building capacity for advocates, at the same time, to support them in some of their pursuits in personal advocacy goals that are achievable. We look forward to working with DAI to introduce integrative and innovative approaches to further our advocacy cause!

# Alzheimer's NZ Advisory Group

## 2020 Report for Dementia Alliance International

Alzheimer's NZ Advisory Group members relied heavily on Zoom to work on both national and international policy in 2020. They also received numerous requests for assistance hopefully reflecting a growing realisation that 'nothing about us without us' includes people living with dementia.

The year began with input and advice to the Dementia Alliance International paper on Valuing the advocacy of people with dementia and obtaining Alzheimer's New Zealand's endorsement.

Meanwhile, at home, group members were writing to the Ombudsman to ensure that planned audits of secure dementia facilities brought forward owing to Covid19 included the need for access to fresh air and exercise, meaningful, purposeful activity, social contact, access to quality medical / nursing care, and connection with family no matter what the situation. The group were invited to meet with Ombudsman's office staff and were later also consulted about the needs of people with disabilities during lockdown.

An election forum organised by Alzheimer's NZ provided an opportunity to put questions to politicians particularly around their commitment to implement the Dementia Action Plan. Letters were also written to candidates seeking commitment to support the implementation of the Dementia Action Plan. Alzheimer's NZ's webinar series on Dementia Rights as Human Rights included a powerful presentation from group member, and Board member Alister Robertson, on New Zealand's Dementia Declaration.

Some of the many other Advisory Group activities included:

- Alister Robertson's appointment to the Accreditation Committee which oversees the Dementia Friendly Recognition Programme
- Input into Alzheimer's NZ's project to develop shared data indicators around services and standards
- Participation in DAI webinars
- Letters to the Editor of regional newspapers
- Feedback on the Ministry of Health Aged Care Covid report around the need to include people living with dementia in both the design and delivery of surveys; workforce needs; and, improved knowledge about dementia generally.
- Creation of a short video in support of DAI
- Correspondence with and visits to Ministers and other officials around implementation of the Dementia Action Plan
- Feedback on planned World Alzheimer's Month activities
- Input into Alzheimer's NZ's Briefing to the Incoming Minister of Health
- Using our Dementia Declaration to frame an invited response to the Ombudsman on how the human rights of people in secure dementia care can be upheld in the event of a pandemic lockdown.

- Input into a plan for a NZ app to support carers of people with dementia based on the WHO manual iSupport.
- Participation in Alzheimer's Disease International (ADI)'s annual conference (including a presentation by Alister Robertson).
- The end of 2020 was marked with our first face to face meeting in nine months, and a celebratory Christmas lunch. Alzheimer's NZ is grateful for the group's generosity in sharing their knowledge and skills.



*Alzheimer's NZ is grateful for the group's generosity in sharing their knowledge and skills.*

# Dementia Australia Advisory Committee

## 2020 Report for Dementia Alliance International

The Dementia Australia Advisory Committee (the committee) is made up of people living with dementia. As a formal group, the committee provides strategic advice to Dementia Australia and other stakeholders on shaping dementia services, programs, policy development and advocacy goals.

The committee aims to be a catalyst of change, working towards an inclusive future, where people living with dementia are valued and respected.



DAAC meeting via Zoom

In 2020, despite the impact of COVID-19, DAAC met regularly via Zoom and were involved in a wide variety of projects. DAAC worked together with Dementia Australia staff across the organization and external agencies with a common purpose to support people to live well with dementia.

Key achievements and highlights for 2020 include:

- Generated the idea for the Australia Dementia Action Week campaign to challenge the often pre-conceived idea of what someone with dementia 'looks like' and to show that you can live well with dementia.
- Advocated for Dementia Australia to address consumer involvement in the decision making aspects of research and building capacity to achieve this. This work resulted in a dedicated position being created to focus on building capacity of researchers and people with lived experience being involved in research in a collaborative way.

- Advocated for the impact of COVID-19 and Australia 2019-2020 bushfire season on people living with dementia, carers and their families to be well understood and a priority to ensure people are supported. This included developing an accessible survey that addressed these topics and analysing the results. Members were also involved in a video sharing their experiences on the impact of COVID-19 and recommendations. The video was shown at the Federal Parliamentary Friends of Dementia event on 25 November 2020.
- Developed resources to support people to use Zoom, including a detailed guide and four tip sheets. There has been a fantastic response to these resources, and they are being used both within and external to Dementia Australia.
- In collaboration with the Dementia Australia Consumer Engagement team, prepared a project proposal paper to develop an engagement framework to ensure purposeful participation of people with lived experience of dementia within Dementia Australia. The title of this project is A Stronger Voice Together.

Committee members also actively individually contributed to many media opportunities and presentations across a wide range of topics.

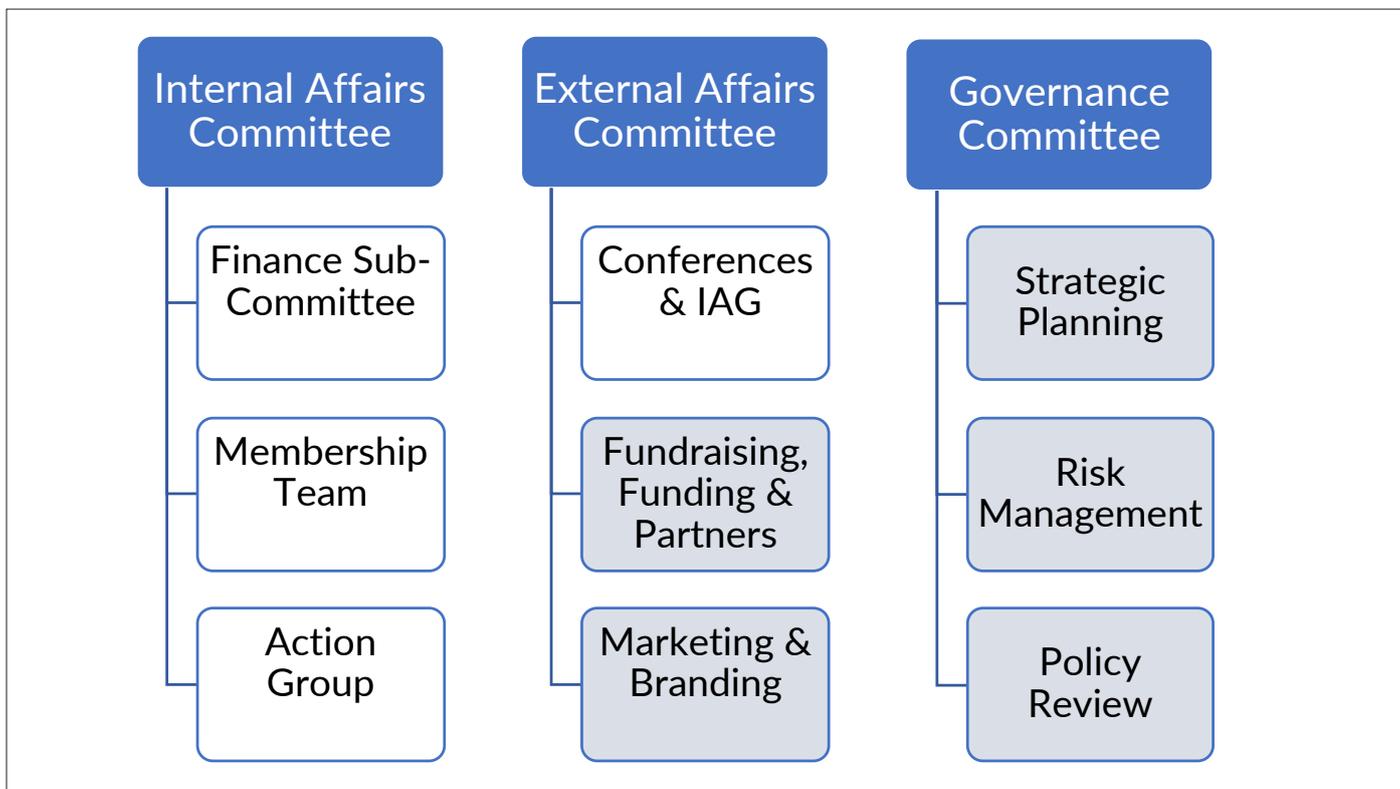
“There is great satisfaction in knowing we are helping Dementia Australia support people with dementia, their families and carers to live well” – Chair Phil Hazell

For more information about the committee, visit <https://www.dementia.org.au/aboutus/advisory-groups/dementia-advisory-committee> or please email [DAAC@dementia.org.au](mailto:DAAC@dementia.org.au)

# Governance and Operational matters

## Improved Operational Structure and Governance

In 2019 DAI commenced a major review of its services, and overall operational performance and governance. The following flowchart outlines our working structure.



Discussions were held, board and member surveys were completed, and reviews were completed early 2020. Many of the operational tasks continue to be completed by the board, and we worked towards our sub committees and volunteers taking over much of this work, and the board moving towards governance. We were also keen to hear from members, on matters like this, as well as member services, and actively engaging with members of the Action group and emerging sub committees to ensure members are being best served, and we are fully IRS compliant.

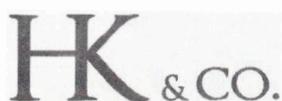
DAI has and will continue to review the By Laws and Strategic Plan, has developed a new travel policy, and reviewed other Governance documents in depth. This is a normal and required business practice. In 2019 we had two issues which required legal attention, and subsequently were advised to update the member criteria section to enable us to exclude membership to people who are, for example, convicted felons.

Two formal non-member (and non-voting) volunteer positions were considered and adopted, one as Secretariat, and the other as a Finance Officer, to support the Finance and Fundraising committee. Our Finance Committee has also been working with an online financial reporting programme called QuickBooks, to improve and ensure consistent and ongoing transparency of our finances. Like all new tasks or online platforms, it has been a complicated learning curve but has progressed well.

Members of our Action Groups, Membership Team and Finance Committee continue to provide sage advice which reflects good governance, organizational growth, and positive members experiences. We thank them for their hard work, commitment to DAI and to our members.

## Financial reporting

This year, we have again retained the services of Mr. Bill Kerr, from Hillstrom, Kerr and Company Incorporated in the US to complete our monthly financial reports,



Hillstrom, Kerr & Company, Inc.  
1029 Highway 6 North, Suite 650-248  
Houston, TX 77079  
(832) 436-4200  
www.hillkerr.com

April 11, 2021

To the Board of Directors  
Dementia Alliance International, Inc.  
Ankeny, Iowa

Management is responsible for the accompanying financial statements of Dementia Alliance International, Inc. (a Texas not-for-profit corporation) which comprise the statements of assets, liabilities and fund balance—tax basis for the year ended December 31, 2020, and the related statements of revenue and expenses—tax-basis, and changes to fund balance—tax-basis in accordance with the tax-basis of accounting for the year ended December 31, 2020, and for determining that the tax-basis of accounting is an acceptable financial reporting framework. We have performed compilation engagements in accordance with Statements on Standards for Accounting and Review Services promulgated by the Accounting and Review Services Committee of the AICPA. We did not audit or review the financial statements nor were we required to perform any procedures to verify the accuracy or completeness of the information provided by management. Accordingly, we do not express an opinion, a conclusion, nor provide any form of assurance on these financial statements.

The financial statements are prepared in accordance with the tax-basis of accounting, which is a basis of accounting other than accounting principles generally accepted in the United States of America.

The owners have elected to omit substantially all of the disclosures and the statement of cash flows ordinarily included in financial statements prepared in accordance with the tax-basis of accounting. If the omitted disclosures and statement of cash flows were included in the financial statements, they might influence the user's conclusions about the Company's financial position, results of operations, and cash flows. Accordingly, these financial statements are not designed for those who are not informed about such matters.

Sincerely,

Hillstrom, Kerr & Company, Inc.

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2020  
FOR THE YEAR ENDED DECEMBER 31, 2020

STATEMENT OF REVENUE AND EXPENSES

Through December 31, 2020

REVENUE

DONATIONS, GRANTS and REIMBURSEMENTS		\$ 84,313.12
DONATIONS	\$ 33,611.53	
GRANTS	\$ 40,765.50	
OTHER INCOME	\$ 6,938.09	

EXPENSES

COMMUNICATIONS	\$ 2,160.64	
SOFTWARE & OFFICE SUPPLIES	\$ 847.05	
WEBSITE	\$ 1,461.75	
BANK CHARGES (Wire fee)	\$ 671.87	
TRAVEL AND CONVENTION EXPENSE	\$ 5,056.88	
PROFESSIONAL FEES	\$ 2,990.00	
	<u>\$ 13,188.19</u>	
NET INCREASE IN ASSETS 010120 TO 123120		<u>\$ 71,124.93</u>

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
 COMPILATION REPORT 2020  
 FOR THE YEAR ENDED DECEMBER 31, 2020

STATEMENTS OF ASSETS AND LIABILITIES  
 AS OF DECEMBER 31, 2020

ASSETS	
BANK BALANCE WEST BANK	\$ 143,776.38
PAYPAL BALANCES	<u>\$ 2,822.94</u>
TOTAL ASSETS	\$ 146,599.32
LIABILITIES AND FUND BALANCE	
LIABILITIES	\$ -
FUND BALANCE	<u>\$ 146,599.32</u>
TOTAL LIABILITIES & FUND BALANCE	\$ 146,599.32

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
 COMPILATION REPORT 2020  
 FOR THE YEAR ENDED DECEMBER 31, 2020  
 DECEMBER 31, 2020

CHANGES IN FUND BALANCE

BEGINNING BALANCE JANUARY 1, 2020	\$ 75,474.39
DONATIONS	\$ 95,287.78
TRANSFERS	\$ (6,092.55)
EXPENSES	\$ 18,070.30
	<u>\$ 71,124.93</u>
ENDING BALANCE DECEMBER 31, 2020	\$ 146,599.32

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
 COMPILATION REPORT 2020  
 FOR THE YEAR ENDED DECEMBER 31, 2020

		<b>INDIVIDUALS</b>	<b>CORP SPONSORS</b>	<b>GRANTS</b>	<b>TOTALS</b>
January					
	WestBank	\$ -	\$ 6,025.91	\$ -	\$ 6,025.91
	PayPal	\$ 227.22	\$ 13.20		\$ 240.42
February					
	WestBank	\$ -	\$ 434.16	\$ -	\$ 434.16
	PayPal	\$ 209.49	\$ 151.00		\$ 360.49
March					
	WestBank	\$ 25.00	\$ 2,780.85	\$ 5,765.50	\$ 8,571.35
	PayPal	\$ 310.00	\$ -		\$ 310.00
April					
	WestBank	\$ 50.00	\$ 568.80		\$ 618.80
	PayPal	\$ 675.00	\$ 61.00		\$ 736.00
May					
	WestBank	\$ -	\$ 1,346.82	\$ -	\$ 1,346.82
	PayPal	\$ 465.65	\$ 4.08		\$ 469.73
June					
	WestBank	\$ 550.00	\$ 1,163.21	\$ -	\$ 1,713.21
	PayPal	\$ 625.00	\$ 9.58		\$ 634.58
July					
	WestBank	\$ -	\$ 74.07	\$ 3,315.50	\$ 3,389.57
	PayPal	\$ 783.00	\$ -		\$ 783.00
August					
	WestBank	\$ -	\$ 321.79	\$ 25,500.00	\$ 25,821.79
	PayPal	\$ 810.00	\$ 0.45		\$ 810.45
September					
	WestBank	\$ -	\$ 922.10	\$ -	\$ 922.10
	PayPal	\$ 265.00	\$ 8.38		\$ 273.38
October					
	WestBank	\$ 200.30	\$ 2,125.12	\$ -	\$ 2,325.42
	PayPal	\$ 190.00	\$ 1.00		\$ 191.00
November					
	WestBank	\$ 11,374.20	\$ 237.32	\$ -	\$ 11,611.52
	PayPal	\$ 190.00	\$ 1.00		\$ 191.00
December					
	WestBank	\$ -	\$ 1,341.42	\$ 15,000.00	\$ 16,341.42
	PayPal	\$ 190.00	\$ 1.00		\$ 191.00
		\$ 17,139.86	\$ 17,592.26	\$ 49,581.00	\$ 84,313.12

# Grants, Donors and Strategic partnerships update

## Fundraising

Fundraising continues to grow modestly, and DAI wish to officially and personally thank every single person who has donated to DAI. Whether is it \$5 or \$500, every amount helps. We have to make the small funds we have stretch a long way, and also must keep funds in reserve for our future.

**Alzheimer's Disease International:** Our Strategic partnership with ADI was signed off to continue for 2020, and we continue to work collaboratively with them. DAI Chair and cofounder, Kate Swaffer was re-elected as a board member, serving her second three-year term from July 2019.

**Boehringer Ingelheim International GmbH (BI):** The \$20,000 restricted funding received from BI was provided specifically for the following:

1. Attendance at the CoSP12, June 2019
2. A Capacity Building Program, held in LA in July 2019
3. Publication on Capacity building and engagement, in progress, to be launched at the ADI2020 conference in Singapore.

**Dementia Australia (DA):** DAI now has a strategic partnership with Dementia Australia, which included a small donation of unrestricted funding.

**Australian Community Hubs Grant:** DAI received a small, restricted Community Hubs Grant in Australia, for the period July 1, 2019 to June 30, 2020, which was used to fund the cost of peer to peer support group co-host training and zoom or website costs.

**Other:** A small number of research projects also support our time and expertise with funding; Graphic Print have continued to provide pro bono printing for DAI, for which we are extremely thankful; we also received a generous grant from an Individual Partner, Lisa Poole, allocated for use to support the funding of a new publication.

Never doubt that a small  
group of thoughtful  
committed citizens can  
change the world;  
indeed, it's the only thing  
that ever has.

*Margaret Mead*





email: [info@infodai.org](mailto:info@infodai.org)

web: [www.infodai.org](http://www.infodai.org)

join DAI: [www.joindai.org](http://www.joindai.org)



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



[@DementiaAllianceInternational](https://twitter.com/DementiaAllianceInternational)