



# Annual Report

**2019–2020**



**Alzheimer's Disease  
International**

*The global voice on dementia*

# Organisation structure

## Elected Board (As at June 2020)

Mr Glenn Rees	Australia, Chair
Mr Dale Goldhawk	Canada, Vice Chair
Mr John Grosvenor	UK, Treasurer
Dr Alireza Atri	USA, Chair of MSAP
Mr Paul Attea	USA
Ms Faraneh Farin	Iran
Ms Paola Maeso	Uruguay
Ms Birgitta Martensson	Switzerland
Ms Meera Pattabiraman	India
Ms Kate Swaffer	Australia
Dr Huali Wang	China

## Honorary President (As at June 2020)

Princess Yasmin Aga Khan	USA
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## Honorary Vice Presidents (As at June 2020)

Dr Daisy Acosta	Dominican Republic
Prof Henry Brodaty	Australia
Mrs Wendy Fleming	New Zealand
Dr Nori Graham	UK
Mr Brian Moss	Australia

## Staff (As at June 2020)

Martin Ayres	Finance Assistant
Paola Barbarino	CEO
Nikki Bayliss	Head of Development
Katie Bingham	Events and Office Coordinator
Annie Bliss	Communications and Policy Officer
Jane Cziborra	Head of Events
Laura Dabas	Membership Manager and Membership Development Programme Lead
Rosie Houghton	Corporate Partnerships Manager
Michael Lefevre	General Manager
Chris Lynch	Policy, Communications and Publications Director and Deputy CEO
Joost Martens	Regional Director for the Americas (until May 2020)
Taylor Paatalo	Communications and Administration Assistant
Irma Rachmatiah	Finance Officer, Asia Pacific Regional Office
DY Suharya	Regional Director, Asia Pacific
Wendy Weidner	Research and Policy Project Lead

# Thank you to our donors

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- International Federation of Pharmaceutical Manufacturers and Associations
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- MetLife Foundation
- MSD
- Novartis
- Nutricia
- Otsuka America Pharmaceutical, Inc.
- PhRMA
- UK Research and Innovation through the Global Challenges Research Fund
- Van Otterloo Family

*Front cover: The ADI Asia Pacific regional conference, hosted by Alzheimer's Disease Foundation Malaysia, took place in Kuala Lumpur, Malaysia in August 2019, welcoming over 670 participants from 22 countries.*

# Chair's report

It takes years to change the culture and to invest in the intellectual capital of an organisation.



This year we have seen important outcomes of the investment which has been made by the ADI Board and staff in respect of communications, policy work and governance in recent years.

In the first half of the year, it was business as usual with important work in respect of advocacy at the global level (G20 in Japan) and country-based work in Lithuania, Malaysia, New Zealand, and Vietnam, amongst others. There was yet another successful World Alzheimer's Month and a World Alzheimer Report on attitudes and stigma which showed, despite all the good work done this century by so many, that stigma is alive and well and that 62% of doctors still regard dementia as a natural part of ageing.

ADI staff have done a brilliant job in producing another 'From plan to impact' report on the implementation of the WHO's Global action plan on dementia – or lack of it – with interesting insights from experts on each of the seven key action areas.

The ADI Asia Pacific Conference in Kuala Lumpur was a valuable opportunity to meet with the Malaysian Government on the development, funding, and implementation of a dementia plan. The conference itself was full of life and inspiring, in part because for the first time it included the Youth Engagement Programme. It was moving to hear the stories of young people about their experiences in caring for people with dementia.

In the second half of the year the pandemic struck, and it could have been a case of one step forward and ten back. But far from it, this period demonstrated the importance of the ADI worldwide network. This was especially true of the contribution of Dr Huali Wang from Alzheimer's Disease Chinese showing how adversity can be turned into opportunity, and the strength of the ADI communications team in running webinars on COVID-19 and other issues. Because of investment in policy and communications ADI was able to make the world a smaller place in sharing experiences.

ADI is continuing to be overwhelmed by overtures for partnerships from Universities and other NGOs. It has been increasingly important to focus on those where ADI can contribute and is not simply adding its logo to many others. Despite increased fundraising efforts, we have struggled to maintain the regional officer in Latin America but continue to strive to achieve our ambitions in Africa and the Middle East.

Behind every good organisation is a strong CEO and Deputy to ensure the welfare of staff in delivering the impossible. The Board joins me in deep appreciation of the leadership of the CEO Paola Barbarino at a critical time.

As Chair, I have been greatly helped by an active and committed Board. I would like to acknowledge those Board members stepping down – Andrew Ketteringham who has done a great job as Treasurer, Gerry Sampson for his leadership on membership issues, and Dr Ang Peng Chye whose contribution I have valued greatly over many years in the Asia Pacific.

My best wishes to you all our members.

**Glenn Rees AM**

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“ Because of investment in policy and communications ADI was able to make the world a smaller place in sharing experiences. ”

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*Dementia-friendly experiential activity for World Alzheimer's Day, Hong Kong. See page 9.*



# CEO's report

It is great to be writing this in February 2021 and able to reflect on a time (July 2019 to June 2020) which now seems so far different and distant! Such is the profound effect that this year of emergencies has had on the work of ADI.



The year started on a great note with an impactful and profoundly successful World Alzheimer's Month campaign "Let's talk about dementia" which was adopted by millions of people around the world including Pope Francis who humbled us all by reminding the world about the importance of eliminating the stigma of dementia.

The companion World Alzheimer Report was one of the most important we have published in recent years. It responded to a question I have had since I joined ADI. If one of the measures of our success is the reduction of stigma and increase of awareness, how do we create a baseline to measure these? One year of work and 70,000 respondents later, the report became that baseline, uncovering extremely important facts such as that 62% of healthcare professionals the world over (that's doctors and nurses) still believe dementia is caused by normal ageing.

The end of 2019 saw some important meetings including our regional conference for the Middle East in Beirut where the Lebanese government committed to a national plan, not long before the terrible blast that tore through the capital. At the meeting of the Caribbean members in Jamaica we persuaded the Minister of Health to look at dementia in the context of his NCD plan, and at a meeting of cross party parliamentarians in Tokyo I pleaded with Japan to be more active and visible on the international scene about its dementia effort.

I also had a special meeting with Dr Tedros Adhanom Ghebreyesus, Director General of the WHO; Deputy Director General Dr Zsuzsanna Jakab; Dr Ren Minghui, Assistant Director General for Universal Health Coverage (UHC), Communicable and Noncommunicable Diseases; and Dr Devora Kestel, Director of Mental Health and Substance Abuse. All reassured us then that dementia was high on the list of their priorities – although this was October 2019. After one year of COVID-19, we are very concerned that priorities will change

and we know we will need to keep fighting for dementia to remain at the top of the agenda for world leaders.

In December 2019, I was fortunate to address a high level group of religious leaders of different faiths at the Vatican on the thorny issue of palliative and end of life care and finally, to address the Italian government on the importance of financing the Italian National Dementia Plan.

All of that of course was before COVID-19 changed our lives forever. After postponing our conference in Singapore, we dedicated ourselves to the important work of uniting our members globally in their effort to help people living with dementia, especially in long term care, whose lives were devastated by the pandemic. From learning how to deal with masks, to advocating that governments stop fining people with dementia for not observing social distancing, from finding new ways to hug our loved ones, to realising and denouncing the trampling of human rights of older people around the world, ours has been an incredibly busy year. We have learnt to add value by

creating a great series of webinars which have attracted audiences of thousands after we opened them up to a wider public.

Above all in 2019/20, the relevance and importance of ADI's global work has truly come to the fore. It has also been a year where we have been able to demonstrate the agility, nimbleness and extraordinary professionalism and expertise of our team. A team that I am delighted and honoured to lead together with our wonderful, committed, and wise Board.

I continue to dream, hope, and fight for a better life for people living with dementia and their families.

**Paola Barbarino**



*Paola Barbarino meeting with Dr Tedros Adhanom Ghebreyesus, Director General of the WHO; Deputy Director General Dr Zsuzsanna Jakab; Dr Ren Minghui, Assistant Director General for UHC, communicable and non-communicable diseases; and Dr Devora Kestel, Director of Mental Health and Substance Abuse.*



# Members *(As at June 2020)*

<b>Argentina</b>	Asociación de Lucha contra el Mal de Alzheimer (ALMA)
<b>Armenia</b>	Alzheimer's Disease Armenian Association
<b>Aruba</b>	Fundación Alzheimer Aruba (FAA)
<b>Australia</b>	Dementia Australia
<b>Austria</b>	Alzheimer Austria
<b>Barbados</b>	Barbados Alzheimer's Association
<b>Belgium</b>	Ligue Nationale Alzheimer Liga
<b>Bolivia</b>	Asociación Alzheimer Bolivia (AAB)
<b>Bonaire</b>	Fundashon Alzheimer Bonaire
<b>Bosnia Herzegovina</b>	Udruženje AiR/Association AiR – Sarajevo
<b>Brazil</b>	FEBRAZ – Federação Brasileira de Associações de Alzheimer
<b>British Virgin Islands</b>	Virgin Islands Alzheimer's Association
<b>Brunei</b>	Demensia Brunei
<b>Bulgaria</b>	Foundation Compassion Alzheimer Bulgaria
<b>Canada</b>	Alzheimer Society of Canada
<b>Cayman Islands</b>	Alzheimer's and Dementia Association of the Cayman Islands
<b>Chile</b>	Corporación Alzheimer Chile
<b>PR China</b>	Alzheimer's Disease Chinese
<b>Costa Rica</b>	Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA)
<b>Croatia</b>	Alzheimer Croatia
<b>Cuba</b>	Sección Cubana de la Enfermedad de Alzheimer
<b>Curaçao</b>	Stichting Alzheimer Curaçao
<b>Cyprus</b>	The Cyprus Alzheimer Association and Related Dementias, Forget-Me-Not
<b>Czech Republic</b>	Česká alzheimerovská společnost
<b>Denmark</b>	Alzheimerforeningen
<b>Dominican Republic</b>	Asociación Dominicana de Alzheimer
<b>Ecuador</b>	TASE Foundation (Transcend with Love, Service and Excellence)
<b>Egypt</b>	Egyptian Alzheimer Society
<b>El Salvador</b>	Asociación de Familiares Alzheimer de El Salvador
<b>England, Wales, NI</b>	Alzheimer's Society
<b>Finland</b>	Alzheimer Society of Finland/Muistiliitto
<b>France</b>	France Alzheimer et Maladies Apparentées

<b>Germany</b>	Deutsche Alzheimer Gesellschaft
<b>Ghana</b>	Alzheimer's and Related Disorders Association Ghana
<b>Gibraltar</b>	Gibraltar Alzheimer's & Dementia Society
<b>Greece</b>	Panhellenic Federation of Alzheimer's Disease and Related Disorders
<b>Guatemala</b>	Asociación ERMITA, Alzheimer de Guatemala
<b>Honduras</b>	Asociación Hondureña de Alzheimer
<b>Hong Kong SAR China</b>	Hong Kong Alzheimer's Disease Association
<b>India</b>	Alzheimer's and Related Disorders Society of India (ARDSI)
<b>Indonesia</b>	Alzheimer Indonesia
<b>Iran</b>	Iran Alzheimer's Association
<b>Ireland</b>	The Alzheimer Society of Ireland
<b>Israel</b>	Alzheimer's Association of Israel
<b>Italy</b>	Federazione Alzheimer Italia
<b>Jamaica</b>	Alzheimer's Jamaica
<b>Japan</b>	Alzheimer's Association Japan
<b>Kenya</b>	Alzheimer's & Dementia Organisation Kenya
<b>Lebanon</b>	Alzheimer's Association Lebanon
<b>Lesotho</b>	Dementia Lesotho
<b>Macau SAR China</b>	Macau Alzheimer's Disease Association
<b>Macedonia</b>	Association of Alzheimer Disease – Skopje Macedonia
<b>Madagascar</b>	ONG Madagascar Alzheimer
<b>Malaysia</b>	Alzheimer's Disease Foundation Malaysia
<b>Malta</b>	Malta Dementia Society
<b>Mauritius</b>	Alzheimer Association Mauritius
<b>Mexico</b>	Federación Mexicana de Alzheimer (FEDMA)
<b>Monaco</b>	Association Monégasque pour la recherche sur la maladie d'Alzheimer
<b>Myanmar</b>	Alzheimer's Association Myanmar
<b>Nepal</b>	Alzheimer and Related Dementia Society Nepal
<b>Netherlands</b>	Alzheimer Nederland
<b>New Zealand</b>	Alzheimers New Zealand
<b>Nicaragua</b>	Fundación Alzheimer de Nicaragua (FADEN)
<b>Nigeria</b>	Alzheimer's Disease Association of Nigeria
<b>Norway</b>	Nasjonalforeningen for folkehelsen
<b>Oman</b>	Oman Alzheimer's Society

<b>Pakistan</b>	Alzheimer's Pakistan
<b>Peru</b>	Asociación Peruana de Enfermedad de Alzheimer y Otras Demencias (APEAD)
<b>Philippines</b>	Alzheimer's Disease Association of the Philippines
<b>Poland</b>	Polish Alzheimer's Association
<b>Puerto Rico</b>	Asociación de Alzheimer de Puerto Rico
<b>Qatar</b>	Qatar Alzheimer's Society
<b>Republic of Korea</b>	KAD (Korean Association for Dementia)
<b>Romania</b>	Romanian Alzheimer Society
<b>Russia</b>	Foundation Alzrus
<b>Saudi Arabia</b>	Saudi Alzheimer's Disease Association
<b>Scotland</b>	Alzheimer Scotland
<b>Singapore</b>	Alzheimer's Disease Association Singapore
<b>Sint Maarten</b>	St. Maarten Alzheimer Foundation
<b>Slovak Republic</b>	Slovak Alzheimer's Association
<b>Slovenia</b>	Spominčica
<b>South Africa</b>	Alzheimer's South Africa
<b>Spain</b>	CEAFA
<b>Sri Lanka</b>	Lanka Alzheimer's Foundation
<b>St Kitts and Nevis</b>	Alzheimer's Association of St. Kitts and Nevis
<b>Suriname</b>	Stichting Alzheimer en Overige Dementieën Suriname
<b>Sweden</b>	Alzheimer Sverige
<b>Switzerland</b>	Alzheimer Switzerland
<b>Syria</b>	Syrian Alzheimer and Memory Diseases Society
<b>TADA Chinese Taipei</b>	TADA
<b>Thailand</b>	Alzheimer's and Related Disorders Association of Thailand
<b>Tonga</b>	Huelo Alzheimers Tonga
<b>Trinidad and Tobago</b>	Alzheimer's Association of Trinidad and Tobago
<b>Tunisia</b>	Association Alzheimer Tunisie
<b>Turkey</b>	Turkish Alzheimer Society and Foundation
<b>UAE</b>	4get-me-not Alzheimer's Organization
<b>Uruguay</b>	Asociación Uruguaya de Alzheimer y Similares (AUDAS)
<b>USA</b>	Alzheimer's Association
<b>Venezuela</b>	Fundación Alzheimer de Venezuela
<b>Zimbabwe</b>	Zimbabwe Alzheimer's and Related Disorders Association



# Dementia as a global health priority

**O**ur work continued with great momentum during the first half of the financial year and then took an urgent and vital shift in focus early in 2020, as the enormity of the impact of the global coronavirus pandemic on the dementia community became apparent.

In the latter half of 2019, ADI built on the strong groundwork achieved earlier that year, helping to secure a vital commitment from G20 Health Ministers at their Okayama Summit, identifying 6 commitments around dementia in the declaration, including a drive to support the development of national dementia plans. CEO Paola Barbarino and Noriyo Washizu, Alzheimer's Association Japan, met with the National Diet of Japan (Japanese Government) and conducted media interviews in Tokyo.



Paola Barbarino with Noriyo Washizu and members of the Japanese government.

In the last quarter of 2019, Paola Barbarino met with the Director-General of the World Health Organisation (WHO), Dr Tedros Adhanom Ghebreyesus, and senior colleagues to discuss options for ensuring dementia remains a global health priority, as well as the need for national level awareness, particularly in the African region.



Paola Barbarino with Archbishop Paglia, Pontifical Academy for Life and Bishop Noel Simard, member of the Academy at the Religion and Medical Ethics Symposium, Vatican City

Additionally, a set of meetings took place in Rome at the Vatican and with the Italian Senate.



Italian Senate event.

## Targets of the WHO global action plan on the public health response to dementia 2017–2025

- **Dementia as a public health priority.** 75% of Member States to develop national plans, frameworks or policies on dementia or to integrate dementia into other plans by 2025
- **Dementia awareness and friendliness.** All Member States to develop public awareness campaigns and at least one dementia friendly initiative by 2025
- **Dementia risk reduction.** Achievement of targets on physical activity, tobacco and alcohol use, blood pressure and cardiovascular disease in the Global plan on NCDs 2013–2020 by 2025
- **Dementia diagnosis, treatment, care and support.** Half of Member States to achieve at least 50% diagnosis rate for dementia by 2025
- **Support for dementia carers.** 75% of Member States to provide training for carers and families of people with dementia by 2025
- **Information systems for dementia.** 50% of countries to collect and report on a core set of dementia indicators through their national health and social information systems
- **Dementia research and innovation.** Global research output on dementia to double between 2017 and 2025.

Towards the end of 2019, ADI co-hosted the annual Lausanne Dialogues with our partners OECD, World Economic Forum, and the Global CEO Initiative, with a focus on healthcare system preparedness, treatment development and regulation.



Paola Barbarino at the Lausanne Dialogues.

In February 2020, with our partner Dementia Alliance International, we hosted a rights webinar: “Dementia & rights; from principles to practice”.

Business travel was inevitably curtailed, as global pandemic restrictions were introduced, impacting on the ability to meet directly with, and advocate to, governments.



Human Rights Webinar with Dementia Alliance International.

Focus shifted to online engagement, including a successful Lithuanian government meeting, which resulted in a commitment to develop a national plan. A final trip in February 2020, prior to lockdown, focused on partnership opportunities and priority sharing with the OECD Health Team and a chance to meet the senior team at Alzheimer France in Paris.

The agenda for World Health Assembly in May 2020 was dominated by the global pandemic. The usual 10-day global session was commenced and immediately suspended, as Governments globally responded to the crisis. ADI submitted a strong statement on the disproportionate impact of COVID-19 on people with dementia focusing on informed and rights-based decision making, particularly in triage situations with scarcity of resources, and on access to treatment and care.

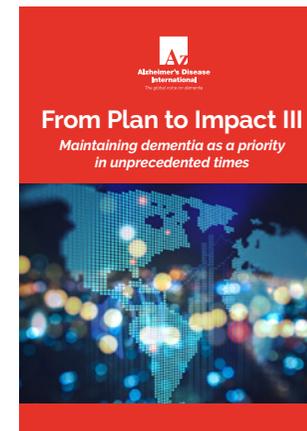
Usually, at the World Health Assembly, ADI would launch the annual review of progress towards the 7-action areas of the World Health Organization’s Global action plan on dementia. With global attention on pandemic crisis management, we delayed the report, titled ‘From plan to impact; maintaining dementia as a priority in unprecedented times’, until later in June 2020 and

Paola Barbarino, Chris Lynch and Laura Dabas with members of Alzheimer France.



held a virtual side event, with speakers including Dr Devora Kestel, WHO Director, Mental Health and Substance Abuse. We also had ministerial attendance from two of the four countries that were still able to launch a national dementia plan during very trying times, namely Germany and Iceland (the others being China and Dominican Republic). ADI’s advocacy call to action became even stronger; that national plans are the best tool available to governments in response to dementia, and even more so during healthcare crises like the coronavirus pandemic.

There are currently 34 national dementia plans in existence, and ADI’s ongoing attention, working with our partners, now focuses on advocacy with the remaining 160 governments that have signed up to the WHO Global dementia action plan, but who have yet to launch their plans.



# Dementia awareness

**A**wareness raising and challenging the stigma that surrounds dementia remains a key priority for ADI and our strategy for World Alzheimer's Month 2019 took a 3-stranded approach to this: delivering the World Alzheimer's Month campaign, a companion Pan American Health Organization (PAHO) region campaign, and the World Alzheimer Report.

For the World Alzheimer Report 2019, 'Attitudes to dementia', ADI commissioned London School of Economics and we jointly deployed a global dementia survey, translated into 32 languages and completed by 70,000 people. The findings were stark, including that 2 in 3 people still think that dementia is a normal part of ageing, including 62% of healthcare professionals, underlining the ongoing challenge and the absolute need for global awareness activity. The report has been downloaded more than 22,000 times.

The World Alzheimer's Month campaign ran throughout September with a theme of 'Let's talk about dementia', focusing on encouraging those

often difficult first conversations with a strong call to action to seek out information, advice, and support, including by directing people to their national Alzheimer's or dementia association. 94 country associations participated, with over 2 million social media impressions.

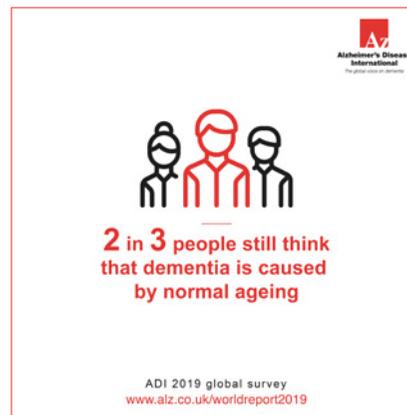
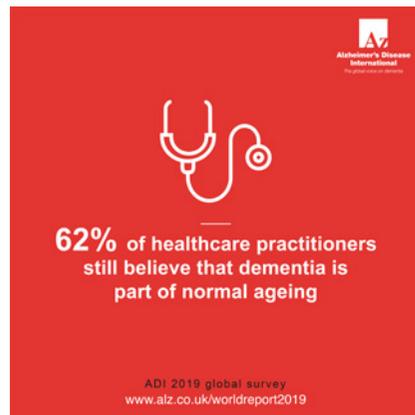
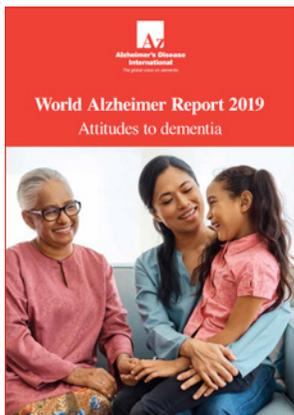
“ The World Alzheimer's Month campaign ran throughout September. 94 country associations participated, with over 2 million social media impressions. ”



Cristo Redentor, Brazil illuminated in purple for World Alzheimer's Day.



World Alzheimer's Month Basketball Challenge Match Pakistan.



Iran Dementia & Alzheimer's Association.

Through a strong partnership with the WHO regional office for the Americas (PAHO), ADI funded and deployed a regional campaign in 5 languages, specifically targeting Latin America and the Caribbean. The campaign built on the 'Let's talk about dementia' theme, included a focus on warning signs and risk reduction and saw strong collaboration between ADI member associations, PAHO country offices and ministries of health.

Momentum continued at an ADI Caribbean regional meeting with Dr Enrique Vega and Dr Claudina Cayetano from PAHO Headquarters joining the session to discuss amplifying and extending the reach of the campaign.

Media interest in the campaigns and the report was extensive, extending to over 500 pieces of coverage including global broadcast stations and print, such as BBC World Service, CBS News, Channel News Asia, Sky News, The Times of India, The Guardian, and particularly good radio reach with an interview with ADI's Deputy CEO Chris Lynch reaching 170 stations globally.

ADI closely monitored the coronavirus developments in early 2020, which was influential in the decision to delay our annual conference. Early in 2020, ADI anticipated the need to disseminate pandemic-related information and advice to our constituency, particularly our member associations. Information and resources were quickly developed, including the introduction of a series of both member and public webinars tackling vital subjects including healthcare capacity issues, triage protocols, and rights for people with dementia. We also shared the many innovative responses to support service provision and resilience from our global community.

Professor Huali Wang, Executive Vice President of ADI's member association in China, Alzheimer's Disease Chinese provided an early and incredibly valuable short video on caring for people living with dementia in the crisis, which has been watched over 13,000 times. The webinar series has been watched by thousands of people on the

ADI YouTube channel including supporting people with dementia during the pandemic, the hidden costs of the pandemic, innovating, palliative care, and future gazing.

In June 2020, ADI again joined forces with ITN Productions to produce a global documentary titled 'Hope in the age of dementia' showcasing scientific advances; artificial intelligence and technology advancements; pharmaceutical research; dementia strategy and national plans in low- and middle- income countries and integrating dementia into emergency response services.

“Media interest in the campaigns and the report was extensive, extending to over 500 pieces of coverage including global broadcast stations and print.”

ADI worked with ITN Productions to produce a global documentary "Hope in the age of dementia". Image shows Paola Barbarino (ADI) and Sharon Thomas (ITN).



PAHO campaign for World Alzheimer's Month.



## Collaboration with Dementia Alliance International

Dementia Alliance International (DAI) is proud to be in a strategic partnership with Alzheimer's Disease International and grateful for their support. DAI is the global voice of people with dementia; ADI is the global voice on dementia. The DAI 2019/20 board continued to be represented in 2019 by co-founders Kate Swaffer, John Sandblom, Eileen Taylor, Mike Belleville, Jerry Wylie, Agnes Houston, Bill Turner and Maria Turner, and then in 2020 as some stepped down, with James McKillop, Christine Thelker, Alister Robertson and Bobby Redman. DAI is also supported by volunteers, Sarah Yeates (Board Secretary) and Peter Watt (Marketing), and in 2020 Tamara Claunch joined our small but extremely important team of volunteers of people without a diagnosis of dementia.

James McKillop, MBE from Scotland, was awarded the 2019 Richard Taylor Memorial Advocates Award, on World Alzheimer's Day, September 21, 2019. James has been a pioneer dementia advocate, having been diagnosed himself with dementia in the last century, and DAI is honoured and privileged to work with, and walk beside him; our members find him a constant source of inspiration. James motivates many DAI members to keep going and is always a source of great wisdom and wonderful Scottish humour. Since joining DAI, James has continued his work locally and nationally as well as being a very active DAI member, on occasions



James and Maureen McKillop.

representing us internationally travelling with his wife, Maureen. James was elected as a DAI board member some years ago and continues to co-host the UK peer to peer support group.

The weekly peer to peer support groups have continued to support our increased membership. These support groups were increased in 2020, to provide additional support during the pandemic. Our co-host facilitator training was delivered again early in 2020, this time facilitated by Teepa Snow, We do this regularly to ensure our facilitators are trained and well supported. In 2019, DAI also ran a capacity building workshop for DAI leaders based in the US and Canada, held in Los Angeles.

DAI again ran a **#Hello my name** is blog series during World Alzheimer's Month in 2019, and many members were involved in conferences and events around the world. Members were very involved with events for DAI and ADI, or with their local or national Alzheimer's advocacy organisations. We also supported Alzheimer's Disease International, including for the launch of their 2019 World Alzheimer Report, Attitudes to dementia, which analysed the results of a global survey, supplemented by 40 expert essays and case studies. We continued to have representation at events such as the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, the World Health Assembly, the World Health Organization's mhGAP Forum, and Lausanne Dialogues VI, although this was virtual following the restrictions to travel placed on us by the pandemic.

A special online event was held to celebrate our 6th birthday in 2020, and our monthly webinars featured many speakers, including Dr Laura Booi, a Fellow at

Trinity College in Dublin from the World Young Leaders in Dementia, Jerry Wylie who hosted the World Rocks Against Dementia event, Drs Jacki Liddle & Theresa Scott, Dr Daniel Potts, Liz Smith and Alister Robertson, Christine Thelker, Dr Noelannah Neubauer, Professor Yun-hee Jeon, Professor Keith McVilly, Phil Hazel, Dr Al Power, and Professor Brandão who presented on clowning and humour.



Kate Swaffer.

People with dementia can **join DAI for free**, and anyone interested in dementia can **subscribe to our newsletters and blogs** or **donate** to DAI.

Finally, we thank everyone for their ongoing support, and work to improve the lives of all people living with dementia and our families.

### **Kate Swaffer**

Chair, CEO and Co-founder  
Dementia Alliance International

## Regional conferences, member meetings and Alzheimer University

- A 3-day Alzheimer University for emerging associations was held in London, UK in August 2019 with participants from Cameroon, Dominica, Estonia, France, Montenegro, Panama, and Vietnam.
- The ADI Asia Pacific regional conference, hosted by Alzheimer's Disease Foundation Malaysia, took place in Kuala Lumpur, Malaysia in August 2019, welcoming over 670 participants from 22 countries. The first ever Youth Engagement Programme brought together 300 participants, and 64 participants from 19 countries attended a regional members meeting (see cover image).
- DY Suharya, Laura Dabas and Board Member Birgitta Martensson attended the 29th Alzheimer Europe annual conference in The Hague, Netherlands in October 2019. The conference saw over 900 participants from 46 countries.
- The ADI Caribbean regional conference, hosted by Alzheimer's Jamaica, was held in Kingston, Jamaica in November 2019 with over 170 participants. 11 participants from 7 countries took part in a STRiDE orientation day, a regional member meeting and Alzheimer University prior to the conference.
- The Alzheimer Ibero-America congress was celebrated in Quito, Ecuador in November 2019 and was hosted by Fundacion TASE. Over 1,500 people attended the event and a regional ADI/PAHO meeting was organised with 20 participants from 15 countries.
- The first virtual Asia Pacific regional meeting took place in April 2020 with 39 participants.
- ADI held its second virtual council meeting in April 2020.



Members attending Alzheimer University, London

## Member webinars and online master classes

- A series of member webinars was held between March and July 2020 in response to COVID-19, on various topics such as: Maintaining services during a crisis:

How to continue supporting people with dementia and their carers; Mental health and wellbeing during self-isolation; Discrimination against elders; Positivity forum; a session in collaboration with United for Global Mental Health; Who decides what life is worth? Dementia and advocacy in a post COVID world. These webinars enabled member associations to feel more connected and share their experiences during the COVID-19 outbreak.

- An online masterclass on public speaking and media skills was delivered by Dale Goldhawk, Vice-Chair of ADI, in October 2019.
- COVID-19 response online masterclasses were circulated to members in July 2020. The themes were Corporate fundraising; Working with volunteers; Digital fundraising; and Virtual events and services, all related directly to the evolving COVID-19 situation.

Alzheimer Ibero-America Congress, Quito, Ecuador hosted by Fundacion TASE



## Facilitating research

Facilitating research is one of the pillars of ADI's overall vision and a priority underpinned by action area 7 of the WHO Global action plan, calling for a doubling of research output by 2025. Each year sees a growth in research activities at ADI, however the financial year 2019–2020 was unprecedented due to the challenges and unique opportunities brought about by the COVID-19 pandemic. Although the impact of COVID-19 did not begin until March 2020, it had a major impact on ADI's research endeavours, marking a point of disruption, recalibration, and renewed focus.

In July 2019, ADI took part in key discussions at WHO regarding the global burden of dementia and future data collection to determine prevalence, incidence, and cost with colleagues from King's College London, IHME (Institute for Health Metrics and Evaluation), London School of Economics, and Karolinska Institutet.

Into its second year of the project, STRiDE (Strengthening responses to dementia in developing countries) focus groups on stigma had begun in all seven countries. In January 2020, Alzheimer associations from six STRiDE countries gathered in London for a week-long workshop on knowledge exchange and impact as well as exploring what persuades policy makers to initiate policy change.

All STRiDE country teams entered 2020 full steam ahead. All were finalising their situational analyses, describing current dementia care, treatment, and support in their countries as well as identifying gaps and opportunities for promoting policy change. Field work focusing on the impact of informal care was ongoing in Jamaica and Mexico and was due to start in India. In Indonesia and South Africa, pre-testing and translation of the dementia prevalence and cost data toolkit had begun. Brazil and Kenya were preparing for phase 2 of their stigma

fieldwork, the development of a stigma intervention toolkit and assessment tool.

When the COVID-19 pandemic began, STRiDE had to pause all field work and the annual full STRiDE meeting was held virtually in March. All country teams continued with data analysis, desk reviews and research that could be done without face-to-face contact. Country teams continued collaboration with national advisory groups and explored use of technology whilst developing protocols around virtual interviews and focus groups.

As part of the COGNISANCE (CO-desiGning demeNtia dIagnoSis ANd post-diagnostic CaRE) project, the team based in Netherlands designed surveys and focus group questions to understand experiences, barriers and facilitators to dementia diagnosis and post-diagnostic support from the perspective of people living with dementia, their carers, and health care professionals. As with STRiDE, face to face research was paused and as the UK team began to develop toolkits supporting guideline development, much of this had to be done virtually.

As the COVID-19 pandemic spread globally, ADI took the lead in sharing reliable information and best practice at a global level through our COVID-19 webinars. We moved quickly to gather the best sources of information available at the time to ensure the advice we were



*STRiDE workshop, London, January 2020.*

providing was accurate and up to date. We reached out to key members of our medical and scientific advisory panel who helped us author position papers on advice around hospitalisation of older family members and resource allocation. We increased collaboration with the global research community, sharing emerging evidence and data, and contributed to 4 international publications about the impact of COVID-19, including in *The Lancet*.

## Treasurer's report

### John Grosvenor

I would like to thank Andrew Ketteringham for his six years as treasurer and his stewardship and sound control over the finances of ADI.



Andrew's timing was impeccable as I took over as Treasurer in March 2020 just as the pandemic tightened its grip around the world.

As a result of the efforts of Paola Barbarino and her team we were able to take actions in the second half of the financial year and I am pleased to report that for the year ended 30 June 2020 we were able to record a surplus of \$95,000 in unrestricted reserves. There is a need to build up our reserves and it is a major achievement that we have been able to do this at such an uncertain time.

In the year ended 30 June 2020 we were able to maintain our level of unrestricted income and this is vital if we are to continue the programmes which are needed more than ever to help people living with dementia. We have kept our costs firmly under control, particularly since March 2020, when we were faced with such uncertainty and unfortunately this meant we had to discontinue the regional office in Latin America. However, we have continued to invest in fundraising as it is vitally important to do this, so that we can raise funds to support an organisation that is dealing with a devastating pandemic experienced by millions of people around the world.

We took the decision to cancel the conference scheduled for Singapore in March 2020 resulting in a period of financial uncertainty. After initially thinking that we could defer, it became increasingly obvious that the global pandemic was not going to let this happen and the ADI immediately started planning for what became a fantastic virtual conference later in the year. Although this took us into the next financial year, I am pleased to note that the virtual conference will not be a drain on our reserves.

I would like to thank all those who have continued to support us. This includes all the member associations around the world who have pulled together in the past 12 months. However, our work would not be possible without the trusts, foundations, corporations and individuals that support us. Their support is recognition of the work we do and of the needs of the people living with dementia and carers. In particular we would like to thank those listed on page 2.

## Statement of financial position

### As at June 30, 2020

#### Assets

##### Current Assets

Cash	US\$ 486,389
Accounts receivable	475,302
Grants and contributions receivable – net of allowance for uncollectible accounts of \$10,000	617,377
Current portion of pledges receivable	50,000
Prepaid expenses and other	99,027
<b>Total current assets</b>	<b>1,728,095</b>

##### Property and Equipment

Furniture & equipment	75,253
Less accumulated depreciation	(26,921)
<b>Net property and equipment</b>	<b>48,332</b>

##### Other Assets

Rent security deposit	14,549
Deposit for website development	41,187
Pledge receivable, net of current portion	150,000
<b>Total other assets</b>	<b>205,736</b>
<b>Total assets</b>	<b>US\$ 1,982,163</b>

#### Liabilities and Net Assets

##### Current Liabilities

Accounts payable and accrued liabilities	US\$ 229,611
Deferred revenue	642,802
Current maturities of note payable	1,006
<b>Total current liabilities</b>	<b>873,419</b>

##### Long-term Liabilities

Note payable, less current maturities	2,695
<b>Total liabilities</b>	<b>876,114</b>

##### Net Assets

Without donor restrictions	226,946
With donor restrictions	879,103
<b>Total net assets</b>	<b>1,106,049</b>
<b>Total Liabilities and Net Assets</b>	<b>US\$ 1,982,163</b>

# Statement of activities and changes in net assets

## For the Year Ended, June 30, 2020

	Without Donor Restrictions	With Donor Restrictions	Total
<b>Support and Revenue</b>			
Dues	464,147	-	464,147
Contributions and grants	360,696	965,337	1,326,033
Conference revenue	-	-	-
Institutional funding	140,417	-	140,417
Interest and other	9,320	-	9,320
In-kind contributions	1,429	-	1,429
(Loss) on currency exchange transactions	(17,373)	-	(17,373)
Net assets released from restrictions	608,090	(608,090)	-
<b>Total support and revenue</b>	<b>1,566,726</b>	<b>357,247</b>	<b>1,923,973</b>
<b>Expenses</b>			
Programme	1,083,111	-	1,083,111
General and administration	238,138	-	238,138
Fundraising	150,248	-	150,248
<b>Total expenses</b>	<b>1,471,497</b>	<b>-</b>	<b>1,471,497</b>
<b>Change in net assets</b>	<b>95,229</b>	<b>357,247</b>	<b>452,476</b>
<b>Net assets, beginning of year</b>	<b>131,717</b>	<b>521,856</b>	<b>653,573</b>
<b>Net assets, end of year</b>	<b>226,946</b>	<b>879,103</b>	<b>1,106,049</b>

These figures are extracts from the financial statements which are available in full from [www.alzint.org/financials](http://www.alzint.org/financials)

## Income

ADI is a 503(c)(3) non-profit organisation, incorporated in the state of Illinois, USA. The figures in this report are for the 2019–20 year, which ended on 30 June 2020.

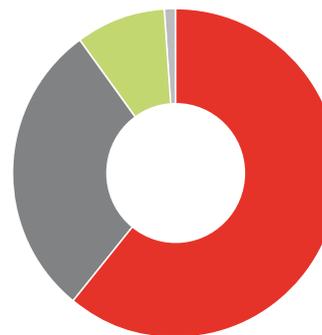
ADI member Alzheimer associations pay dues according to their own income. ADI also receives contributions and grants from corporations, foundations, trusts and individuals.

ADI also receives support from Friends of ADI, a UK-registered charity. Friends of ADI does not run any programmes of its own – it exists to support the work of ADI.

## Expenses

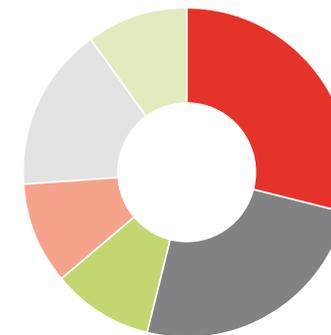
ADI's expenses are classified into six functions: the four main areas of programme work, management and administration, and fundraising.

'Member support and development' includes the Alzheimer University training programmes and other support and advice provided to Alzheimer associations. 'Promotion and awareness' includes World Alzheimer's Month, the Global Perspective newsletter and website, and ADI staff and Elected Board members also take part in other conferences and meetings to promote our work and our cause. It also includes ADI's public policy work, including the World Alzheimer Report. The spending on 'Research' is mainly ADI's role in the STRiDE project. There is a heading for the ADI International 'Conference' – in this year there was no conference because the pandemic resulted in a postponement, and conference revenue was deferred to next year.



## Income

- Contributions and grants 61%
- Dues 29%
- Institutional funding 9%
- Interest and other 1%



## Expenses

- Promotion and awareness 29%
- Member support and development 25%
- Conference 10%
- Research 10%
- General administration 16%
- Fundraising 10%



*We ended financial year 2019–20 working fully online with member associations adapting to the changing situation. Here Argentina's Asociación Lucha contra el Mal de Alzheimer (A.L.M.A.), hosting a live group video session for people living with dementia.*



**Alzheimer's Disease  
International**

*The global voice on dementia*

**Our vision is risk reduction, timely diagnosis, care and inclusion today, and cure tomorrow**

**Our mission** is to strengthen and support Alzheimer and dementia associations, to raise awareness and lower stigma about dementia worldwide, to make dementia a global health priority, to support and empower people living with dementia and their care partners, and to increase investment and innovation in dementia research.