2019 Annual Report

In 2018, 10 million, 512 thousand people were diagnosed with dementia.



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#Hello



Annual Report

AGM, November 20/21, 2018. Kate Swaffer

Welcome to everyone and thank you for making the time to attend our Annual General Meeting. I offer my sincere thanks to all members of the 2018 board for their hard work and commitment to DAI. Special thanks also to the outgoing 2018 board member, Phyllis Fehr from Canada, who will step down at the end of the year for personal reasons, and to the current board members who are continuing on.

As we come to the end of another very busy year of advocacy and activism by DAI members, and others, either collectively or individually, I would like to thank everyone for their energy and efforts for all people with dementia. Today we hold our 4th Annual General Meeting, and this year we have nine nominations for five vacancies. During the year, DAI has continued to grow and now has members in 48 countries. Our members continue to advocate for DAI, and many also work hard for their own national or local organisations. There have been literally dozens of events or conferences globally throughout the year, to raise awareness and improve outcomes for the 50 million people currently living with dementia. This continued growth and progress from our small start by our 8 founding members on January 1, 2014 is remarkable, and I'm proud of what we have all achieved, as a team, and of our past and current Board members and Action group members. Each year, our Board re-engages, strengthens its resolve, and empowers current and new members to live more positively, and to become self-advocates. I'm also looking forward to working with the incoming 2019 team next year.

Membership currently remains exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world, and we continue to seek to represent, support, empower and educate others living with the disease, and the wider dementia community, and are an organization that strives to provide a unified voice of strength, advocacy and support with a dream for individual autonomy and improved quality of life for people with dementia and our families supporting us. As the clinical and research community continue to 'revise' the guidelines between dementia and Mild Cognitive Impairment (MCI), one thing we may need to consider next year, and will get expert advice on, is whether MCI is considered early or pre-dementia; if it is considered dementia, this may mean we need to adjust our membership guidelines. On behalf of us all, my very special thanks must go to our very hard working and loyal volunteer. We could not have done it without you Sarah, and are indebted to you for this support. Sarah Yeates continues to support DAI by attending the board meetings and AGM and providing the Minutes, as well as other business and operational advice, and is also helping us with the Strategic Plan, and we are thrilled her health has returned.

The Richard Taylor Memorial Advocates Award

This year, it was a total surprise to me, as it was announced at the ADI Chicago conference that I was being awarded 2018 Richard Taylor Memorial Advocates Award. DAI also promoted it on the day this is usually announced, which is World Alzheimer's Day, September 21. Although the guidelines for this award were superseded by a majority board decision, made without my knowledge, I am proud and honoured to receive this award. Thank you.

World Alzheimer's Month 2018

This year, we were extremely busy, as we ran a daily blog series, and many members were involved in conferences and WAM events around the world. Our daily blog series of daily blogs was themed #Hello to present the uniqueness of our members and their personal experience of living with dementia, which was of great interest to members, families, and professionals. This series has resulted in many of them being used in a number of educational opportunities around the world. The series was so popular, we are continuing it, and started October with one from Professor Peter Mittler. Members all around the world were also involved with events for DAI or their local or national Alz organisations.

Conferences and other events

DAI members were well represented in Chicago at the ADI conference in July, and again at the Alzheimer's New Zealand -hosted another event during WAM in Brisbane. Many other events were hosted all around the world in our continued individual and collective efforts to raise awareness of dementia.

Many DAI members attended the recent Alzheimer's New Zealand conference, with board member Phyllis Fehr giving the opening keynote speech on Day 1 of the event, "Citizenship and Human Rights for people with dementia". Eileen Taylor, Alister Robertson, Bobby Redman, Valerie Schache and other

DAI members also gave presentations at this event. Board member Eileen (and her husband Dubghlas) Taylor, with the support of board members Alister and Phyllis, also co hosted a DAI Workshop at this conference, "Zooming in on Inclusion". There were many members in countries in Europe, the UK, USA and Canada attending and presenting at many conferences of other events, including in attending and presenting at events. A great number of advocates also attended the Alzheimer's Europe conference in Barcelona.

I was invited to present at a number of World Alzheimer's month events for DAI, and also to support ADI members, including in Taipei for a TADA conference on Human Rights and Dementia, and attending many meetings there to support their work there. I also met with the Vice President to discuss the importance of human rights and self advocacy, joined by a group of local self advocates and other official delegates. In Milan I spoke at the Alzheimer's Italia conference on World Alzheimer's Day, and supported their Call to Action in the form of a video petition Finanziare il Piano Nazionale Demenze: malati e famiglie non possono più aspettare.

DAI Webinars and other online events

DAI continues to host Webinars, with our November webinar next week is by Associate Professor Lee-Fay Low from Sydney University on Dementia and Rehabilitation: evidence and opportunities. This topic is of high important in light of DAI being a founding member of the newly established Global Rehabilitation Alliance at the World Health Assembly this year, and with the increasing demand for rehabilitation and other proactive support aligned to the Global Dementia Action Plan.

It is pleasing to see so many others starting to provide online education sessions using zoom or other platforms. For example, Alzheimer's Disease International is also hosting its first Webinar later today, Let's Talk About Dementia Research" as part of an ongoing educational series. Nigeria also hosted the first of its online educational Webinar series during WAM, with Chris and Jayne Roberts and Kate Swaffer as guest speakers.

Member News

Dr Jennifer Bute has just had the release of her first book, Dementia from the Inside: A doctor's personal journey of hope, available now. Congratulations Jennifer. Wendy Mitchells book, first published in the UK earlier this year Somebody I Used to Know continues to inspire, and has now also been published into Japanese and Spanish. Congratulations Wendy. Many others with dementia have published books on their own experiences of dementia, and many of these authors, and others living with dementia continue to write regular blogs.

Peter Berry and Lorayne Burgess from the UK (and perhaps other DAI members) have been involved in a BBC documentary, based on proving to the world people with dementia can still be employed; we congratulate them on this. Finally, we congratulate Mrs Helen Rochford-Brennan on her appointed as the Chair of the European Working Group of people With Dementia, and on receiving her Honorary Doctorate from the NUI Galway.

Human Rights Update

DAI continues to advocate at the WHO and UN for our access to the CPRD, and myself, and others have attended a number of high level events on rights. On 10-11 June 2018, I attended the Civil Society CRPD Forum: Day of General Discussions on Articles 4 (3) and 33 (3), an event preceding the 11th session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (CRPD), 12 to 14 June 2018, also in New York, USA. The 2018 theme was: "Leaving no one behind through the full implementation of the CRPD" With the following Sub-themes:

- National fiscal space, public-private partnerships and international cooperation for strengthening the implementation of the CRPD
- 2. Women and girls with disabilities which was our focus for any possible statements or contributions
- 3. Political participation and equal recognition before the law

In advance of both of these events, I submitted numerous applications to make formal statements, and although none were officially accepted, it was possible to create opportunities to do so whilst in attendance. I wish to thank the International Disability Alliance, who supported me to ensure I was on the agenda as part of the Civil Society delegation to make a brief formal statement on Day two of the Civil Society Forum.

Content for my statements were collated from information through DAI members, and from data and notes provided by Alzheimer's Disease International and the Global Alzheimer's & Dementia Action Alliance (GADAA). I was representing all three organisations, and our members, and included a quote from DAI member Professor Peter Mittler. Interestingly at these events, someone shortened the phrase, "Nothing about us, without us" to "Nothing without us", which was then



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TOGETHER WE ARE STRONGER



repeated regularly throughout both events. I made two formal statements, and a number of comments or informal statement at various side events.

Joint Statement 1:

Civil Society Forum Day 2, June 11, 2018 Joint Statement 2:

Round Table - Women and girls with disability COSP Day 2, June, 2018

To have a voice, it was therefore imperative to attend as many sessions as possible, and even to hold my hand up for sometimes long periods of time, to be able to make even a brief statement to bring dementia into to the discussions.

I managed to make three more formal joint statements, one in the discussion time at Round Table 1: National fiscal space, public-private partnerships and international cooperation for strengthening the implementation of the CRPD, another at Roundtable 3: Political participation and equal recognition before the law, and finally, one at one of the final Side events, Individual Social Responsibility to create inclusive world for Persons with Disabilities.

There were many Side Events I attended in order to ensure 'dementia' was represented, and where I was also able to make very short comments or statements. Some sessions were of such interest I went between rooms in the same time slot, based on who was speaking and what might be most relevant to DAI and people with dementia. When I wasn't in a Side event or at a Round Table Discussion, I was in the main Room, listening to the full COSP proceedings, or meeting with newly met colleagues to talk about the relevance of dementia to their work. These types of events are extremely busy, and curiously, not at all enabling for people with disabilities, except for wheelchairs, and sight or the hearing impaired. The sessions below provided opportunities for me to at least raise the issues people with dementia face, in the context of the topics.

- Transforming communities: Good Practices to Ensure the Rights of Persons with Psychosocial Disabilities
- Leaving no one behind through the full implementation of the CRPD via mutual global learning on the importance of inclusive labour markets -counting and documenting it all.
- Barriers to political participation for people with disabilities
- Leaving no one behind: Best practices for transitioning from institutions to community care
- LGBTI people with disability and implementation of the CRPD

- Including the most likely to be left behind: Women and Girls with Disabilities in rural and remote settings
- From Commonwealth Summit to Global Disability Summit: Economic empowerment of youth with disabilities for full participation in economic, social and political lives.
- Future research on disability and development: towards the implementation, monitoring and evaluation of the SDGs
- "Nothing about us without us" Accessibility and political participation of persons with disabilities
- Persons with Disabilities in Prison: Challenges & Good Practice
- Advancing the Rights of Persons with Disabilities through Social Dialogue
- Assistive Technologies: services enabling independent living and inclusion
- Financing the Implementation of the CRPD, Problems of instability and inconsistency: The Experience of Women and Refugees with Disabilities of the Global South
- Adolescence, disability and gender inequalities: understanding the policy implications of new research findings for LMICs
- Making Higher Education Accessible to Learners with Disabilities
- Specific needs of women and girls with disabilities
- Nothing about us without us General comment on meaningful participation
- Strengthening cooperation and partnerships in monitoring the rights of persons with disabilities. Experiences and way forward
- From Words to Action: Holding ourselves to account for Global Disability Summit Commitments
- Bridging the Gap (BtG): European commitment to data collection and use for the inclusion of women and girls with disabilities

DAI continues to make submissions to governments on our rights, on dementia plans, on access to the CRPD, and on other matters, as they come up. The LEAD Coalition also makes them often, and we co-sign many of theirs as an organization, to help strengthen their voice for change in the USA.

The Older Persons Convention is still under review, and we are also working towards ensuring it is aligned to the CRPD, and in which we hope the final draft will reflect this as well as include dementia. DAI is now a formal member of the The Global Alliance for the Rights of Older People, who works with agencies seeking to promote and strengthen the rights of older people.



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FIND YOUR VO CE



Services for members

DAI has commenced a number of additional services or events for its members, including a weekly Online Social Support Group held every Sunday at a time zone suitable to members in Europe, the UK, Scotland, the USA and Canada, and hosted by Julie Hayden from the UK, and David Paulson in the USA.

In December, we will again host an online non-denominational Faith service, and a non-religious Christmas celebration event. The dates are still to be advised. Families and friends are also welcome at these celebrations.

A Meeting Of The Minds Webinars

We have had an excellent year of events with many international speakers, and the program for 2019 is already in progress. Next week, we focus on Rehabilitation and Dementia, and in December, we will host two social events, one to celebrate Christmas, and the other, and online Faith service for those members who no longer wish to attend their local Church. If there are topics, or certain speakers you would like hear from next year, please let us know.

Fundraising

Fundraising has been modest this year, but I wish to officially and personally thank every single person who has donated to DAI. I also send a personal email thank you to every single donor. Whether is it \$5 or \$500, every amount counts, and what we can do with \$20, most other organisations would need more than \$20,000! We have to make the small funds we have stretch a long way, and also must keep funds in reserve for our future. Our fundraising team, also part of the Action Group are getting organised for campaign to get as many members to Chicago for the ADI conference in July next year as possible.

The most exciting of this section of this section of the report is the two partnerships we have almost finalised. After missing a full year of sponsorship, ADI have just agreed to a new Memorandum Of Understanding, for the amount of \$30,000 USD, for the current financial year.

Next week, we make another significant announcement of a new partnership, which currently is confidential. I can however, report here that it is a formal Strategic Partnership with Dementia Australia, and next week, I will co-sign a Memorandum of Understanding with their CEO Maree McCabe with them for a 12 month trial period, and we will receive \$20,000 AUD, and will have some joint targets and projects we work on together. DA is particularly interested in the contribution we can make to them o human rights, as they do not have the funds to get involved globally or attend the necessary meetings. Please do not share this information publicly until the Media Release late next week.

DAI is constantly working on building relationships with potential new partners, but also need members to help raise funds for DAI. For example, some of us use Christmas, birthdays and wedding anniversaries where we ask friend and family to donate to DAI, instead of buying gifts. This is also one way we override the challenge of not having charitable status in every country, as no birthday or Christmas gifts are tax deductible in any country!

Global representation of advocates

This year, I have represented DAI at a number of other international meetings, including the WHA in May, the COSP in June, and the mhGAP Forum in Geneva in October, where for the first time, the WHO hosted a parallel session on dementia. It has been a busy and exciting few months raising awareness and advocating for our rights.

Our advocacy in many countries continues to grow, and I personally have made many trips in the last couple of years to countries in SE Asia, initially as the ADI Ambassador, and now an ADI SE Asia Mentor, and have supported ADI members and their counties to empower and develop self-advocates. It is important we acknowledge and remember the Pioneers of advocates, of which DAI is truly honoured to have two on our current Board.

These advocates make is very clear, it is possible to live a positive, productive, and longer life than we are told to expect, after a diagnosis of dementia.

It is also important to note countries including Taiwan and Singapore will launch their own DWG's in 2019, and there is a continuing emergence of self-advocates in countries like this primarily due to the work of DAI and also ADI members who are now determined to empower and enable the inclusion of people with dementia in their own countries.

"In Singapore, the Alzheimer's Disease Association is highly inspired with the work done by Dementia Alliance (DAI) International. We are at the early stage of reaching out to families and persons with dementia to encourage them to share their inspiring stories through a new programme "Voices for Hope".

In 2018, during World Alzheimer's Month in Singapore, ADA invited DAI member Dennis Frost, his wife Tina and Nick Guggisberg, the Manager of Community Development



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MEETING OF THE MINDS



for the Kiama Municipal Council, to share their experiences and insights on creating a Dementia Friendly Kiama. Several Singaporeans also shared their personal stories – a first collaboration between international advocates, a local person with dementia and carer.

With more persons with dementia exchanging their personal stories and hopes, it may accelerate initiatives as Singapore steers towards a dementia inclusive society. We hope to continue working closely with DAI and share more good news in the months to come!" Thank you, Qian Ru

Alzheimer's New Zealand Advisory Group

"Support is the key to me leading as normal a life as possible. People knowing and treating me as the person I still am. Giving me room to live." (Advisory group member)

Alzheimers New Zealand's Advisory Group has been providing Alzheimers NZ with insight into the experience, needs and expectations of people living with dementia since 2014. Group contributions enable Alzheimers NZ to focus on areas and approaches which will make a real positive difference. The group is supported by a secretariat from Alzheimers NZ.

Group members comprising 4 people diagnosed with dementia, and 7 care partners, spent 2018 meeting with Government ministers and officials; providing advice on issues including difficult discussions in hospital; human rights; budgetary policy; mental health; and, end of life choices. Members also worked to reduce stigma and discrimination, and to foster the Dementia Friends programme. Some used media opportunities to improve public understanding around dementia.

Individual members led advocacy on respite care, individualised funding, and navigation. One of our group is an Alzheimers NZ Board member and he played a key role in organising the programme for our national conference where 30% of the 300 delegates were people living with dementia and/or care partners.

Other members are actively engaged advising on an Alzheimers NZ research project on the lived experience of dementia (Litmus Research). One member is a research participant.

Group members also worked to build capacity. Two members are part of Alzheimers NZ Education Advisory Group; some have written blogs; and three have appeared in videos about living well with dementia. Alzheimers NZ is extremely grateful to all the group members who donate their time, energy and commitment. The gratitude is even more heartfelt given the day to day injustices which accompany dementia.

'You look perfectly all right; you are bringing it on yourself by talking about it.' (Group member with dementia quoting comment from an associate)

Other Global Partners or Relationships

World Health Organisation:

We applied I July 2018 to be accepted into Official Relations with the WHO. Our application is pending, and will be voted on at the WHO Executive Board meeting in January 2019.

United Nations:

We have an application pending for ECOSOC Status with the UN.

Convention of the State Parties on the CRPD:

We have Disability Persons Organization (DPO) and Non Governmental Organization (NG) status since June 2017 with the Convention Of State Parties on the Convention on the Rights of Persons with Disabilities (CRPD).

Global rehabilitation Alliance:

Launched in May 2018, Dai is one of the Founding member organisations for this important new alliance. I have worked towards this, since attending the REHABILITATION: 2030 Forum at the WHO in February 2017, to ensure dementia and rehabilitation are a global focus.

World Dementia Council:

Two DAI members are full members of the WDC (Hilary Doxford and I)

LEAD Coalition:

DAI continues to work with this organisation in the USA, and two board members attend their monthly meetings.

GADAA:

DAI continues to work with this organisation as Steering Committee members.

NCD Alliance:

DAI has worked with the NCD Alliance, alongside ADI in particular this year, towards a better representation of Dementia at the High Level Meeting at the UN in September;



ALZHEIMER'S DISEASE ASSOCIATION





although dementia did not get a mention, we will continue to advocate for separate inclusion of people with dementia at all of these high level meetings and organizations.

International Disability Alliance:

We have retained Observer status membership of this organisation. Although they said they have reviewed their Constitution (they appear to discriminate against individuals living with dementia), we have not been offered full membership. And although IDA set up a committee to review and revise its Constitution, last year in order to enable an organisation such as DAI to become full members, without having to have national DAI organisations, when I asked for disability support after being invited to attend their recent AGM, I was no longer invited. This may be an area of advocacy that we need to focus on in 2019, and we welcome members input. Another example of this was the Global Disability Summit in London, co hosted by IDA and DfID, when it was almost impossible to receive an invitation for even one DAI member to represent the 50 million of us living with dementia. I would like to personally thank Howard Gordon for representing us at this event.

Website update

Unfortunately, the last 2 - 3 months, we have had continuing IT issues with our email system, still under review to be resolved. Our updated website, in our attempt to make it more accessible and enabling, has been well received with very positive feedback. Although we set up an online Discussion Board (similar to Talking Point in the UK), this has not been activated due to a lack of man/woman power to activate it for current and new members. We are currently getting a quote on the cost to add a 'live' Member calendar, which will advise you when your support group, or the next meeting is, in your time zone.

Brain health Hub

Our private Facebook Brain Health continues to grow, and we have modified our meeting to suit different time zones. 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, or healthy lifestyle interventions. Whilst this may not be a cure, but it does improve the quality of life for those of us who have made changes to diet and exercise, and also reduces our risk of other co morbidities.

DAI Printing

Graphic Print continues to provide all of our printing for DAI at a pro bono (free) rate. I am currently in discussion with two shipping companies to discuss a similar arrangement with them, so that we can send materials to members in any country, rather than have to find either the funds, or a printer who will do this for no fee.

Financial reporting update

This year, we have had the services of Mr. Bill Kerr, from Hillstrom, Kerr and Company Incorporated to complete our monthly financial reports, and we will publish our second Annual Report in January 2018.

Professional Advisory Group

This year, we have initiated setting up a Professional Advisory Group, to support our organisation and our work. Currently, acceptances to our invitations have been received from Teepa Snow, Dementia Educator; Bill Hillstrom, our Accountant; Chris Lynch, Deputy CEO of ADI; Daniela Greenwood, Dementia Consultant, and we are waiting to hear from others including Dr Al Power, and a member of the World Young Dementia Leaders, to provide us with a voice on the latest research about dementia.

Again, I thank you all for your continued support and work. We continue to welcome new members and are finding the growth of our peer to peer support groups is a unique free global service actively supporting and empowering our members to live with a better quality of life. My sincere thanks to everyone for their continuing dedication to improving the lives of people with dementia and our families, and I look forward to working with the new board in 2019.

We look forward to sharing our 5th birthday with your all in 2019!

atosucher.

Best wishes, Kate Swaffer, Chair, CEO & Co-founder



"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





2018 Board



Chair and CEO: Kate Swaffer, AU



Vice Chair: Jerry Wylie, USA



Treasurer: John Sandblom, USA



Secretary: Eileen Taylor, AU



Phyllis Fehr, Canada



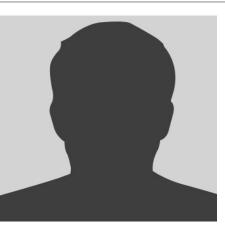
Maria Turner, USA



Agnes Houston MBE, Scotland



James McKillop, Scotland



Bill Turner, Australia



Alister Robertson, New Zealand



Carole Mullikan, USA



lan Gladstone, Australia (co-opted)

DAI Annual General Meeting

Tuesday 20th/Wednesday 21st November 2018

Minutes

Meeting opened at 8:10am (Melbourne time)

 Welcome. Kate Welcomed all to the 2018 Annual General Meeting

2. In Attendance:

Jennifer Bute
Nina Baláčková
Bobby Redman
Kris McElroy
Willard Colebank
Jane Washburn
Amy Shives
Ann Ferguson
Graeme Edwards
Jo Browne
Howard Gordon
Val Scache
Julie Hayden
Agnes Houston
Bob Savage
Hilary Doxford

Apologies:

Bill Taylor	Peter Jones
Cheryl Stephenson	Paul Lee
Helen Rochford-Brennan	

 Confirmation of Minutes of the Dementia Alliance International (DAI) Annual General Meeting For 2017 (Eileen Taylor)

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Motion: That the minutes of the Dementia Alliance
International Annual General Meeting held November
2017 are accepted as a true and accurate record
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Moved Eileen Taylor	Seconded Phyllis Fehr
Car	ried

4. Presentation Of Annual Reports For 2018

- Kate Swaffer presented the Chairperson's Report. Please find the full report attached. Special thanks were extended to Phyllis Fehr who steps down this year.
- John Sandblom presented the Treasurer's Report and Financial Statements.

DAI continues to do a large amount of work with very

little funds. Please find financials attached.

• Jerry Wylie presented the Action Group Report. Thank you to jerry and the other members of the action group for their hard work over the last year. Please find the Action Group Report attached.

Motion: That the Annual Rep	ports for the 2017-2018 year
be accepted as tabled.	
Moved Val Scache	Seconded Maria Turner
Car	ried

 Announcement Of DAI Member Recognition Awards.
 Congratulations to Michael Belleville who has contributed so much to DAI over the last 12 months, particularly in the area of IT and media.

An Award Certificate was presented to Michael.

7. Election Of Board Members:

We have five board member vacancies, and nine candidates:

Agnes Houston, Scotland
James McKillop, Scotland
Maria Turner, USA
Michael Belleville, USA
Ian Gladstone, Australia
Bobby Redman, Australia
Howard Gordon, England
Julie Hayden, England
Christine Thelker, Canada

An election was held via private message to Sarah Yeates (volunteer).

Congratulations to incoming Board Members Maria Turner, Christine Thelker, Michael Belleville, Howard Gordon and James McKillop.

Thank you to outgoing Board members Phyllis Fehr and Agnes Houston for their contribution to the Board.

Chair, Vice Chair, Treasurer and Secretary positions remain for another 12 months.

8. Meeting Closed at 9:30am (Melbourne Time)

2018 Action Group Report

Leaders of the DAI Action Group:

DAI Board members Jerry Wylie, Maria Turner and John Sandblom

The 2018 Action Group Members included: Jerry Wylie, Maria Turner, John Sandblom, Kate Swaffer, Alister Robertson, Eileen Taylor, Christine Thelker, Carole Mulliken, Michael Belleville, Kris McDougall, Roger Marple, Paul Lea and Dallas Dixon. Not all members are still involved.

The Action Group met weekly for much of the year; however we now meet once monthly on the 3rd Friday (USA/CA) – Saturday (AU/NZ) if you'd like to join us.

The group worked on projects including finding details of Helplines, and Crisis/Suicide intervention details for a number of countries, currently to being collated add to our website.

We also worked on updating our fundraising, governance and policy documents, and developed a number of new ones. Our draft Strategic Plan 2019-2021 is to be tabled at the first Board in 2019, following review by the incumbent and incoming board members.

Funding for DAI continues to be a concern, and is an ongoing challenge; hence we also devoted some time on thinking outside of the box to ensure we have ongoing monies to continue to support all DAI members, free of charge or membership fees. Our goal is also to support as many people with dementia to attend and present at conferences.

We therefore also focused on fundraising for the ADI Conference in Chicago to provide as many Bursaries as possible.

During March through to July, many DAI members were actively doing other fundraising events, selling self produced art, or holding smaller fundraising events to help raise funds for ADI Chicago in July.

A very Special thank you and Recognition to Christine Thelker who raised the most funds of all, ensuring her personal requirements for funding from DAI was minimal. We also thank Ian Kremer and the LEAD Coalition, for providing small bursaries for members and some care partners, without which we could not have sent as many members to attend the conference. Collectively, we helped make it possible for 8 of our members and their care partners to attend the Chicago Conference.

Action group members initiated some new recreational and fundraising webinars/events, hosting its first two online webinars. These will be regular DAI quarterly online fundraising events:

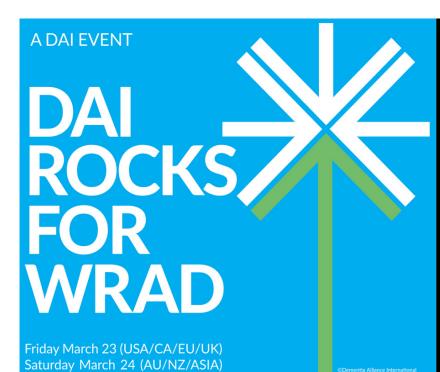
WRAD 2018 March 2018

DAI's #WRAD2018 was a fun, emotional and revealing event, and one that raised just over \$800 that went directly to supporting members to go to the ADI Conference in Chicago, and was hosted by Jerry Wylie.

A special thanks to ALL the performers:

- Kate Swaffer started the event with a short digital story thatincludedmusicandimagery,writtenandproducedin 2008 by Kate called "Dementia: My Story".
- Graeme Atkins performed and sang for us via zoom, singing a song he wrote especially for DAI, called, "wWe are Dementia Alliance International."
- 3. Lorne Pearson provided a song; "The Simple Things in Life" by The Glen Pearson Band
- 4. Luke Johanson performed his song "The Waltz"
- John Wood produced a video & song called "A Hidden World" about dementia John himself wad diagnosed with dementia shortly after producing this video.
- 6. Al Power's song "If You Don't Mind"
- Danielle Greenwood an original song she wrote & produced "Only One"
- 8. The Selwyn Foundation Singers performed "What A Beautiful World"
- 9. Candice Pugh daughter of one of our board members sang "The Rose"
- 10. Rhonda Nay performed "Dementia doesn't stop me wanting you"
- 11. Veda Meneghetti DAI Member wrote & recorded "Caught a glimpse"
- 12. Mark Shephard recording "Together we can change the world"
- 13. BaySamba group with Dubghlas Taylor performed "Old King Cole"
- 14. Graeme Atkins closed with "Al's Song" as in Alzheimer's

Another special thanks to Mike Belleville for the incredible IT production work which really brought it all together. Also to every one who helped promote it, attended and, donated to it.



world rock against dementia days #WRAD 18 IN MEMORY OF GLEN CAMPBELL DAVID CASSIDY MALCOLM YOUNG AC/DC

MARCH 23 - 25, 2018

September 26/27th Online Art Exhibition

DAI held its first Online Art Exhibition Webinar, also our second regular quarterly fundraiser and was hosted by Mike Belleville.

As part of DAI's World Alzheimer's Month / Dementia Awareness Month, with many original artworks from people with dementia, we hosted a spectacular online Art Exhibition event. We aimed for 50 attendees, and about 20 people attended, although 37 people registered. This event was also a fundraiser for DAI; we had a target of \$500 and reached \$461.00 USD. Thank you to all who donated.

Finally, we invite YOU to join this incredible team; together, we can make 2019 even better.



In 2018 ADI continued with a key focus of supporting members to encourage their governments to develop funded national dementia plans. ADI believes that national plans are the best tool available to comprehensively tackle this challenge. Progress towards the national plans target of the Global action plan on the public health response to dementia 2017-2025 has been slow, with only 3 being adopted in 2018. Qatar was the 29th country to adopt a National Plan, and 30 countries are in the process of developing plans (many, encouragingly, in low- and middle- income counties). At the World Health Assembly in May 2018, on the first anniversary of the Global plan, ADI hosted a panel of government experts to discuss progress; a panel including Kate Swaffer representing DAI. In 2019 we will follow this up and also launch the second edition of the 'From plan to impact' report, monitoring progress.

The 33rd International Conference of ADI took place in Chicago, USA, with 770 participants, including a strong contingent from DAI. For the first time the conference included a focus on innovation, technology and entrepreneurship. It reflected the need for innovation across all sectors, including industry, and included a presentation IKEA on a new range of furniture designed with dementia in mind. Also well-received was a workshop by DAI on the Global action plan. Each day the Conference opened with a speech by a person with dementia.

World Alzheimer's Month 2018 was marked by activities in over 80 countries – the biggest campaign so far. The month began with the launch of a news and current affairs-style programme, made in collaboration with ITN Productions, which explores the risks, growth and future response to dementia. Several new materials were launched, including the World Alzheimer Report 2018. This report took an innovative approach, reaching beyond academic and policy audiences, appealing to anyone with an interest in the hopes and frustrations of dementia research. It included interviews from 20 researchers from nine countries and an excellent contribution from DAI member Jennifer Bute. ADI also published a report with the Karolinska Institutet and Professor Anders Wimo on 'Global estimates of informal care'. ADI contributed to the launch of two other reports: the OECD's 'Care Needed' report and the Global Coalition of Aging's second 'Innovation Index' and an update to the G7 Index.

Throughout the year, four ADI Alzheimer Universities were held in London, Guatemala and Sri Lanka, accompanied by the sharing of knowledge and resources at ADI regional meetings in Asia Pacific, Latin America, the Middle East and Europe. ADI welcomed six new members in 2018, with 13 associations on our Membership Development Programme.

ADI continued with its ambassador programme, realising the value of awareness raising through globally recognised figures and leaders. Joining the former Costa Rican President, Luis Guillermo Solís Rivera, ADI was delighted to announce Their Majesties Queen Sofia of Spain and Queen Silvia of Sweden.

ADI looks forward to a busy 2019, with many new projects and new partnerships. In particular, ADI is working in collaboration with the Pan-American Health Organization on an awareness-raising campaign for the region. There will be a big focus on stigma for the World Alzheimer Report and also the World Alzheimer's Month campaign, and we aim to support this with a stigma focussed documentary.

From the research perspective we will continue to develop the STRiDE project, with DAI and the London School of Economics and Political Science (LSE); and the COGNISANCE project with DAI. A global webinar series on dementia research and trials will continue into 2019, having received positive reception in 2018.

ADI is working closely with Alzheimer's Disease Association Singapore for the next ADI International Conference in March 2020. We are also finalising a programme of regional meetings which should include South Africa, Malaysia, Ecuador and Jamaica, as well as in the Middle East and Europe in 2019.

Paola Barbarino, Chief Executive Officer Alzheimer's Disease International



In 2018, the NCD Alliance (NCDA) continued its core functions of global advocacy, accountability, capacity development, and knowledge exchange. The third United Nations High-Level Meeting (HLM) on Noncommunicable Diseases in September 2018 was a milestone in the global NCD response, and the first time NCDs were reviewed in the Sustainable Development Goal era.

NCDA led NCD civil society engagement throughout the process, ensuring comprehensive inputs to the outcome document that presented a balanced approach to prevention, treatment and care and addressed risk factors for NCDs. This effort resulted in civil society and people living with NCDs being recognised in the final outcome document as key partners in the NCD response.

To reinforce HLM advocacy, and tapping into collective frustrations with apathy and inaction, NCDA launched its first thematic campaign, ENOUGH. The NCD movement was mobilised with a digital campaign and the first Global Week for Action on NCDs reaching millions of people worldwide. People living with NCDs, high level champions and hundreds of advocates from NCDA's network of supporters, members and over 55 national and regional alliances demanded "our health, our right, right now." The campaign also witnessed the launch of a resource on integrating mental health into policy, processes and actions to prevent and control NCDs. The voices and perspectives of people living with NCDs have grown in prominence since the establishment of the Our Views, Our Voices initiative with a number of countries building national advocacy agendas of people living with NCDs with contextualized inputs from people living with NCDs. NCDA's new report on "Meaningfully Involving People Living with NCDs: What is being done and why it matters", which lays out some definitions of key concepts and explores what meaningful involvement of people living with NCDs currently looks like within Civil Society, Government, and Health Care Delivery was launched alongside the Global Conference on Primary Health Care in October 2018. The year also saw the launch of the WHO GCM Community of Practice on Meaningful Involvement of People living with NCDs facilitated by NCDA in consultation with a Steering Group of global experts, which includes Kate Swaffer representing DAI and ADI. The Community of Practice looks to unravel the concept of meaningful involvement of people living with NCDs, its need and benefits in strengthening the NCD response at all levels.

Finally, NCDA's membership structure opened, and the Alliance has continued to expand and grow its network of partners and members since it became a standalone NGO in May 2017.

Katie Dain, Chief Executive Officer NCD Alliance World Dementia Council Leading the Global Action Against Dementia

The World Dementia Council is pleased to update the DAI on our work over the past year. The WDC was established by the G8 at the 2013 London summit and our role is to challenge and support the international community to deliver on the 2025 commitments. The council is the only international organization whose members are drawn from every part of the dementia movement. There are 24 full members including scientists working to find a cure, academics, representatives of civil society, and individuals working in care, industry and finance. Importantly, two of these full members are people living with dementia, whose experience is a great benefit to our organization. Alongside our 24 full members, the council has associate members: individuals representing national governments or international institutions like the WHO and OECD. Through international advocacy, international leadership and building global networks, we help keep dementia on the international agenda.

2018 marked five years since the London dementia summit - the original summit hosted by then Prime Minister David Cameron as part of the UK's G8 presidency. To reflect on what had been achieved, and to accelerate international collaboration, we hosted a major summit in London in December 2018. Key government leaders included former UK Prime Minister David Cameron, UK Secretary of State for Health and Social Care Matt Hancock MP, Dutch Deputy Prime Minister Hugo de Jonge, OECD Deputy Secretary General Ulrik Vestergaard Knudsen, and Japanese Assistant Minister for Health and Welfare Kenji Suwazono. Speakers also included DIAN study participant and person affected by dementia Marty Reiswig, National Institute of Aging Director Richard Hodes, US journalist and Alzheimer's advocate Maria Shriver, and European Union Head of Neuroscience Stéphane Hogan, amongst many others. Topics addressed included data sharing, research funding and incentives, clinical trial participation, the role of technology, better care models, and risk reduction strategies for improved brain health. Presentations and summaries from the day can be found on the summit page on our website.

Alongside the conference the council published a new report, Defeating dementia: the road to 2025. The report identifies 14 actions which international decision makers can take to help accelerate progress towards the 2025 goals. We recognize what has been achieved since the 2013 summit – there are many things to celebrate from significant increases in government funding to more people than ever living in dementia friendly communities. But much more needs to be done if we are to defeat dementia.

Finally, we are also pleased to have translated the WDC's Global Care Statement into other languages including Chinese, Dutch, French, German, Icelandic, Italian, Japanese, Portuguese, Romanian, Spanish and Swedish. As we continue our global leadership engagements, we hope that governments, governing bodies, health and social care systems, care providers and communities in all parts of the world will adopt these urgent priorities, to ensure that those living with dementia and their families are given the highest quality care and support possible to meet their needs.

As we advance the dementia cause in this new year, we will be making announcements with partners about how we can address some of the public policy challenges that hold back progress. We will continue to ensure that the voice of people living with dementia helps to shape our work, and we congratulate you on what the DAI has achieved over the last year. We look forward to continuing our work with friends and organizations from across the international dementia community and wish you all a successful 2019.

Harry Johns, Chair Lenny Shallcross, Executive Director World Dementia Council



Year In Review

Thanks to all of you, 2018 has been a remarkably productive year in dementia policy and practice. Private sectors organizations made tremendous contributions to the field with projects in biomedical science and social science along with clinical practice and social service, across forms of dementia and stage of disease, for — and increasingly in partnership with — people living with dementia (undiagnosed, diagnosed, or as carers). We have highlighted many of these projects during LEAD Coalition teleconferences, through our newsletter and social media platforms, and in outreach to bring new partners forward to support your leadership.

Also thanks to you, countless grassroots advocates, and friends across Congress and the federal agencies, 2018 delivered breathtaking policy advances including:

- two federal appropriations packages, which raised NIH funding for dementia research from \$1.423 billion (FY 2017) to \$2.34 billion (FY 2019)
- the FDA's updated draft guidance "Early Alzheimer's Disease: Developing Drugs for Treatment Guidance for Industry"
- 58 prioritized research recommendations, from the first ever national research summit on dementia care and services, which NIH has begun funding
- NIH commitment to include the care and services research summit in its rotation of AD and ADRD research summits, with the next care and services research summit scheduled for March 24-25, 2020
- NIH and the Agency for Healthcare Research and Quality (AHRQ) work to develop a systematic review of evidence on effective care-related interventions for people with dementia and their caregivers to inform decision making about which care/non-pharmacologic interventions are ready for dissemination and implementation
- NIH's National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research
- CDC's 2018-2022 Healthy Brain Aging Road Map, which included new action steps focused on dementia detection and diagnosis and on disaster preparedness
- CMS made permanent the code for assessment and care planning services for people with cognitive impairment and expanded telehealth services

 Congress passed and sent to the President the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, and earlier in the year both the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act were signed into law.

Again thanks to you, 2018 was another year of growth and expanded influence for our coalition:

- The LEAD Coalition community has 100 formal member organizations and over 100 more informally allied organizations supporting and participating in our policy positions and activities
- Our monthly teleconference averages over 90 participants and reaches over 500 influencers and decision makers
- We have more than 26,000 social media followers and our Twitter messages made almost 20 million impressions
 I am honored to serve and represent our community in a variety of roles including:
- Dementia Friendly America executive committee
- Public Policy & Aging Report editorial board, a quarterly journal of the Gerontological Society of America
- UCLA Dementia Care Study advisory committee
- AD-PACE executive steering committee
- Family Caregiver's Role in Patient-Focused Drug Development steering committee, joint project between the National Alliance for Caregiving and LEAD

Looking Ahead

In 2019, there will be no shortage of important issues for our community to address including congressional appropriations and federal agency actions, reauthorization of the Older Americans Act and PCORI, reintroduction of the Concentrating on High-Value Alzheimer's Needs to Get to an End (CHANGE) Act and the Palliative Care and Hospice Education and Training Act (PCHETA), development of the 2019 NAPA Plan Update and the 2020 NIH Bypass Budget, and support for ongoing implementation of projects such as Dementia Friendly America, the CDC Roadmap and AD-PACE. That list is long but surely not comprehensive.

lan N. Kremer, Executive Director

Leaders Engaged on Alzheimer's Disease (LEAD Coalition)



This has been a fruitful year of collaboration between DAI and the Worldwide Hospice Palliative Care Alliance to advocate for, and support greater recognition of, the need for improved access to palliative care for people living with dementia worldwide. Palliative care is a crucial component of Universal Health Coverage as defined by the WHO yet access to palliative care for people with dementia worldwide is woefully inadequate.

With aligned goals to ensure that the people who are directly affected by conditions are heard, the partnership between the WHPCA and DAI is a powerful and fruitful one. Our activities together have included:

- Kate Swaffer attended the World Health Assembly in May 2018, giving interventions onbehalf of the WHPCA, bringing her knowledge and experience as a person living with dementia, as well as a trained nurse, to the delegates. She gave an impassioned, yet evidence based, case for access to palliative care for people worldwide, including those living with dementia.
- Later in the year, Kate participated in a review of grant applications from low and middle income countries for projects to enhance and build th voice of those directly affected in palliative care advocacy. The review was completely undertaken by people directly affected by palliative care or conditions that may require it. The reviewers included older people, people affected by cancer, people with palliative care needs and international patient group partners. The impact of the four grants awarded in India, Rwanda, Zimbabwe and Romania will be reported in 2019.
- In addition, Kate Swaffer participated in a project to raise the voice of women directly affected by palliative care to decision makers in a report for World Hospice and Palliative Care Day entitled 'Because I matter. In this report, Kate wrote a public letter to the Australian Assistant Minister for International Development requesting that the issue of palliative care, including for people with dementia, was considered in Australia's work on development.

Finally, in line with our shared desire to see greater collaboration between palliative care orgs and people living with dementia networks particularly in low and middle income countries, we were delighted to see greater joint working in Kenya with the Kenyan Hospices and Palliative Care Association and the engagement of Dr Zipporah Ali, a WHPCA board member National level partnerships will be crucial to making a difference to the lives of people on the ground. She has also been selected to be on the National Advisory Group (NAG) for the project on: Strengthening Responses to Dementia in Developing Countries (STRiDE) in Kenya.

Increasingly the crucial importance of palliative care as part of comprehensive health services is being recognised. It is vital that people with dementia are not left behind and WHPCA and DAI look forward to increased collaboration to increase access to palliative care for all and ensuring the voice of people living with dementia is heard.

"Dementia Alliance International is a vital organisation bringing the voice of people with dementia to the fore. The WHPCA values our collaboration with DAI and looks forward to working together to meet our shared goals of ensuring the voice of people living with dementia is heard and that people with dementia get the palliative care that they need and want, wherever they are in the world."

Stephen Connor, Executive Director Worldwide Hospice & Pallative Care Alliance

Financials

DEMENTIA ALLIANCE INTERNATIONAL, INC. COMPILATION REPORT 2018 FOR THE YEAR ENDED DECEMBER 31, 2018

STATEMENT OF REVENUE AND EXPENSES

REVENUE

	DONATIONS, GRANTS and REIMBURSEMENT	S		\$ 66,906.18
EXPENSES				
	SOFTWARE EXPENSES	\$	2,680.15	
	BANK CHARGES	\$	182.00	
	POSTAGE	\$	502.55	
	LODGING			
	EQUIPMENT PURCHASE	\$	143.88	
	SALES TAX	\$	10.20	
	ADVERTISING	\$	-	
	PAYPAL FEES	\$	107.76	
	PROFESSIONAL FEES	\$	300.00	
	TRANSFER	\$	-	
	REIMBURSED EXPENSES	\$	-	
	MISCELLANEOUS EXPENSES			
	TRAVEL AND CONVENTION EXPENSES	\$	20,021.43	
		\$	23,947.97	
				\$ 23,947.97

\$ 42,958.21

DEMENTIA ALLIANCE INTERNATIONAL, INC. COMPILATION REPORT 2018 FOR THE YEAR ENDED DECEMBER 31, 2018 DECEMBER 31, 2018

CHANGES IN FUND BALANCE

BEGINNING BALANCE JANUARY 1, 20	018		\$	32,684.84
	\$	66,906.18		
TRANSFERS EXPENSES	\$	23,947.97		
			\$	42,958.21
ENDING BALANCE DECEMBER 31, 20	18		\$	75,643.05
STATEMENTS OF ASSETS AND LIABIL AS OF DECEMBER 31, 2018	ITIES			
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BANK BALANCE WEST BAN	ĸ	\$ 73,2	41.4	29
PAYPAL BALANCES		\$ 2,4	01.7	76
TOTAL ASSETS		\$ 75,6	43.(05
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LIABILITIES AND FUND BALANCE LIABILITIES	-	\$	-	
FUND BALANCE		\$ 75,6	43.(05
TOTAL LIABILITIES & FUND BALA	ANCE	\$ 75,6	43.(05

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DEMENTIA ALLIANCE INTERNATIONAL, INC.

COMPILATION REPORT 2018

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	20,000.00	\$ 24,575.00
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MISCELLANEOUS EXPENSES	TRAVEL AND CONVENTION EXPENSES	TOTAL EXPENSES

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August										3			
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DEMENTIA ALLIANCE INTERNATIONAL, INC.

DEMENTIA ALLIANCE INTERNATIONAL, INC. COMPILATION REPORT 2018 FOR THE YEAR ENDED DECEMBER 31, 2018

STATEMENT OF REVENUE AND EXPENSES CHECKING ACCOUNT WEST BANK **BEGINNING BALANCE DECEMBER 1, 2018**

\$ 27,663.36

REVENUE	Eventbrite, Inc.	\$ 793.09
	Wire Transfer	\$ 30,000.00
	Wire Transfer	\$ 13,594.00
	Network for Good Payment	\$ 252.61
	Eventbrite, Inc.	\$ 5.00
	Eventbrite, Inc.	\$ 20.00
	Wire Transfer	\$ 315.15
	Wire Transfer	\$ 3,187.07

EXPENSES

\$ 48,166.92

ADVERTISING	\$ -
CHECK PRINTING	
EQUIPMENT PURCHASE	\$ 11.99
WEBSITE	\$ 125.67
DEBIT CARD FEE	
PROFESSIONAL FEES	
POSTAGE	\$ 30.00
TRAVEL REIMBURSEMENT	\$ 2,336.53
CONVENTION EXPENSE	
WIRE TRANSFER FEE	\$ 80.00
SALES TAX	\$ 4.80
ACCOUNTING SOFTWARE FEE	\$ -
	\$ 2,588.99

ENDING BALANCE DECEMBER 31, 2018

\$ 73,241.29

Every 3 seconds someone's life is thrown in the bin.



24 hours a day, 365 days a year, DAI works hard to help pick up the pieces. But, we need your help.

Every 3 seconds, that's 20 times every minute, 1200 times an hour or 28,800 times a day, a person somewhere in the world is diagnosed with dementia. There is no cure and our members are commonly told to get their end of life affairs in order and get acquainted with aged care. They are given no hope.

Their future and pre-diagnosis life is taken away from them. Stigma and discrimination is still endemic

Dementia Alliance International is a not for profit 501c3 charity run by and for people living with dementia. Dementia Alliance International offers people diagnosed with dementia hope, to keep living and to reclaim their pre-diagnosis life. Dementia Alliance International needs your help today.



Donate or partner with us today: https://www.dementiaallianceinternational.org/donate-or-partner/

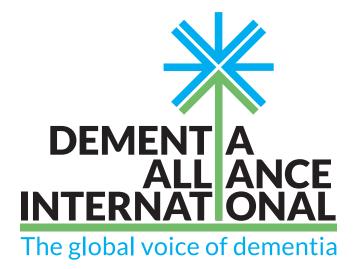


email: info@infodai.org 🙀 website: www.infodai.org



www.facebook.com/DementiaAllianceInternational









The work of Dementia Alliance International is supported by many individual donors, and these major sponsors

email: info@infodai.org

web: www.infodai.org



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