

DEMENTIA  
ALLIANCE INTERNATIONAL  
ANNUAL REPORT  
2016

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## SHORT HISTORY OF DEMENTIA ALLIANCE INTERNATIONAL

Dementia Alliance International (DAI) was set up by eight people diagnosed with dementia, representing three countries (USA, Australia and Canada). Our founding members are the late Richard Taylor PhD, the late Dena Dotson, Amy Shives, Kate Swaffer, John Sandblom, Steve Ponath, Janet Ford and Susan Stephens. We also remain grateful and wish to acknowledge DAI had a significant amount of voluntary support from Laura Bowley, before and after DAI was launched on January 1, 2014. Membership to DAI is exclusively for people with a medically confirmed diagnosis of any type of a dementia from all around the world. We 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 in the fight for individual autonomy and improved quality of life for people with dementia and our families supporting us.

Thanks to the generosity of the late Dr. Richard Taylor, Dementia Alliance International is a US Corporation with 501(c)(3) not for profit status, which means donations by US citizens are tax deductible, and we will continue with our efforts to gain this status globally. DAI is the peak organisation globally representing persons with dementia, and thus widely accepted as the global voice of dementia, now representing members from 38 countries. Membership of Dementia Alliance International is free, and is open and exclusive to anyone with a medical diagnosis of any type of dementia. We are very keen to represent ourselves in all matters concerning dementia, in the philosophy of “Nothing about us, without us.” Many persons with dementia are very capable of representing themselves, or speaking up for those who are no longer able to do so.

Our work on claiming the Human Rights for all people with dementia means we are legally entitled to be included, and not just consulted, or represented by others. We are also entitled to the appropriate disability support that any other persons or groups of disabled people are afforded. DAI works as an independent self-advocacy organization of people with dementia which is in mutual association with Alzheimer’s Disease International (ADI), and where collaboration is also possible with all national Alzheimer’s organisations and national or local Dementia Working Groups. We work actively with the Dementia Working/Advisory Groups and other local or national groups, as requested by them, or as is necessary to support our global work.

DAI would also like to highlight the partnership we have with ADI, who are also our major sponsor. Although we work in close collaboration, we work autonomously. ADI's Global Charter, 'We can live well with dementia', is slowly becoming a reality, in part due to their vision for inclusion of people with dementia, and their commitment to ensure it is not just rhetoric. They have done this with financial support, and by working with us, and as we work together in true collaboration the human rights and access to the CRPD of all people with disabilities, including people with dementia will become the norm. ADI Chair Glenn Rees has always been supportive of full and equal inclusion of people with dementia, and working with Glenn, ADI's CEO Marc Wortmann, the ADI team and the DAI and ADI global family, together, we are so much stronger.

*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)*

## 2017 BOARD

On November 15/16, 2016 we held our Annual General Meeting, including voting in a new board for 2017. In this, our first Annual Report, we welcome them and introduce you to our new members and thank them for being willing to join the Board of Directors. We feel proud and honoured the 2017 Board are members who have continued on, or have joined as new Board members. This was the first year we have more nominations than vacancies.

### Kate Swaffer Co-founder, CEO and Chair



Kate is the current Chair and Chief Executive Officer, and a co founding member of DAI. She is also a member of the World Dementia Council, a board member of Alzheimer's Disease International, and the outgoing inaugural Chair of the Alzheimer's Australia Dementia Advisory Committee. She is a Humanitarian, advocate and activist for people with dementia, a widely published academic, author and a poet. Her first book on dementia, *What The Hell Happened to My Brain?: Living Beyond Dementia*, was released in 2016, and her second book, *Diagnosed with Alzheimer's or another dementia*, co-authored with Associate Professor Lee-Fay Low was released in September in time for World Alzheimer's Month 2016. Her first two poetry books were released in 2012 and 2016, and her third one is currently [In Press]. Kate also writes a blog, currently with more than 60,000 subscribers, which was archived in the PANDORA Collection of the State (SA) and National Library of Australia in 2012.

Kate Swaffer has made a human rights based approach to dementia, hoping to reduce stigma, and improve the quality of life for the almost 50 million people already diagnosed with dementia; her focus over the last few years and is changing the way the world views dementia and empowering others they can live with dementia, not only die from it. Kate is living beyond a diagnosis of rare form of younger onset dementia, having been diagnosed at the age of 49 in 2008, when she was a married working mother of two teenage sons, also studying a double degree at the University of South Australia. She has a Masters of Science (Dementia Care, 2014), BPsych, BA, former Chef, Graduate Diploma in Grief counseling, and is a retired nurse. Kate is married to Peter Watt, who does a lot of pro bono work for DAI, and they have two adult sons.

### Mick Carmody, Vice Chair and Global Support Group Manager



Mick Carmody, 61 years old, lives in Brisbane Queensland. He was diagnosed with Fronto Temporal Dementia in 2013, and has since been diagnosed with Primary Progressive Aphasia (PPA). After going through all of the usual reactions when first diagnosed, after meeting Kate Swaffer was introduced to Dementia Alliance International ([www.infodai.org](http://www.infodai.org)). As this organisation is run entirely by people with Dementia, which is exclusively an advocacy and support group, of, by and for people with dementia, Mick was keen to join, and since has learnt to live as well as possible with dementia. Mick's journey so

far has been, sad, happy, exciting, mad, funny and many other things, which he often shares in the support groups or as a public speaker.

He is now an extraordinary global advocate for people living with dementia, and works towards ensuring their human rights, and he is very passionate about a DAI program called “Weekly online support groups”. Mick says, “Too many people fall through the cracks and are not advised on where to get help, or, who can help them”. These support groups fill in the cracks. The support groups empower people to live with dementia, not only to die from it, and they change outlooks and lives.

Prior to his own diagnosis of younger onset dementia, he had had a number of careers, including in the hospitality industry, sales and truck driving. His passion now is supporting others also diagnosed with dementia globally, and empowering them to live with dementia, not only to die from it. This is what get Mick out of bed each day, and why he has chosen to work hard to live positively. He has been married to his beautiful wife Sue for 38 years and they have lived in Brisbane for the last 14 years. They have two adult children, a son in law and a wonderful grandson. He enjoys photography and spending time with his family, and his advocacy work for Dementia Alliance International. His biggest joy being a part of DAI is empowering other people with dementia to also strive to live beyond dementia.

## **John Sandblom, Co-founder and Treasurer**



John Sandblom has lived in central Iowa, USA all of his life except for college which was eastern Iowa at the University of Iowa. He spent the majority of his working life in business-to-business sales, first print advertising followed by television advertising and then telecommunications sales. He was diagnosed with Younger Onset Atypical Alzheimer’s Disease at the age of 48 in 2007, by a gerontologist that specialized in dementia. He was the same physician that diagnosed his father with Alzheimer’s disease in his early 70’s. He went back through the diagnosis process from scratch at Mayo Clinic in 2009, where he was told it was medically undeniable that he had dementia but they could not tell him what type.

His local neurologist labeled John atypical FTD until November of 2011 when quite by surprise he received the complete research autopsy done on his father’s brain. It showed he died of Alzheimer’s Disease and since it has been believed that he has the same type of dementia that he died from, his diagnosis was changed to atypical Alzheimer’s Disease. John works at the local, regional, state and international levels now to advocate for people with dementia. His work founding support groups comprised solely of people living with dementia is the achievement he is most proud. John is currently the Treasurer, for his second year.

## Eileen Taylor, Secretary



Eileen Taylor was diagnosed with a Genetic younger onset Alzheimer's Disease in 2008 aged 58 and has been involved in medical trials for Alzheimer's Disease ever since. She lives in Brisbane, Australia with her husband, Doug and one toy poodle puppy. She is also a mother and grandmother. Eileen has a background in disability, rehabilitation, and counselling. She worked as a counsellor / social worker with adults and children in a community based service for nearly twenty (20) years before retiring in July of 2015. She recently completed University of Tasmania's MOOC on line course and has enrolled in their Bachelor of Dementia Care for 2016.

She likes to keep abreast on the latest news in the dementia world including any new research projects through Twitter and Facebook. Her hobbies include reading and patchwork and quilting. She is involved with the online support group in Australia co hosted with Mick Carmody, which she attends regularly, and "enjoys the camaraderie of the group." She continues to enjoy the challenge of being the DAI secretary and being more involved with the DAI's goals and its members.

## Phyllis Fehr

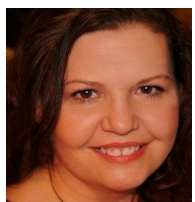


Phyllis Fehr, M.L.A., R.N., S.A.N.E.; Board member, Dementia Alliance International, 2017; Advocate; Ontario Dementia Advisory Group, Board member and Vice Chair. Phyllis Fehr was given a working diagnosis of early-onset Alzheimer's along with Lewy Body dementia; she was 53 years of age at the time. Phyllis was working full time in the intensive care unit as a registered nurse. On her days off she worked on call as a sexual assault and domestic assault nurse examiner. She is also a mother and grandmother. Phyllis promotes the abilities of people living with dementia by advocating for people living with this disease both locally and nationally.

She advocates change for persons with dementia as an Ontario Dementia Advisory board co-chair with a focus on government policy. Phyllis is on a number of boards and steering committees, including membership on the Advisory Group for the Ontario Dementia strategy and the Early Stage Working Group. She is an active board member for the Dementia LHIN board for HHNB; the Canadian Dementia Priority steering committee and numerous others. She is also a valued volunteer at her local Alzheimer Society for program planning and implementation. Phyllis is a popular guest speaker at a variety of events from a lived experience perspective, educating about stigma of dementia. We are delighted to have Phyllis join the board with her experience and wisdom.



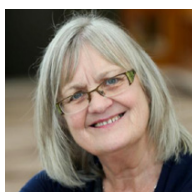
## Maria Turner



Maria Turner RN (retired), BSN; Board member, Dementia Alliance International. Maria lives in Greenville, SC, but is originally from Wales UK. She was diagnosed with the PPA or a non-behavioural variant of Fronto Temporal Dementia on April 1, 2016 and MND/ALS at Duke University Medical Hospital shortly after. She was then 48 years old. After many rounds of tests and misdiagnoses, she was told that she could not return to her beloved nursing career, but should go home, live every day, and get her affairs in order. After the initial shock, denial, and anger, she began to research and find out about this disease and how to live with it, but not be defined by it. Six weeks after diagnosis, Maria attended the AFTD Education Conference in Minnesota. This was a life changing experience for her. She was introduced to many amazing new friends. She laughed, cried, got lost, and met a whole new group of friends, allies, and family. She then got the confidence to message Kate Swaffer who, to Maria's surprise, messaged back and introduced her to Dementia Alliance International and Mick Carmody. Finding and attending online support meetings helped her see that suffering from and living with FTD are two very different things.

Maria wants to use her 30 years of nursing experience to help people who may not have as many resources as we who are currently reading this. Her passion is to see a stronger, more inclusive community through outreach to those newly diagnosed. Despite all the challenges she is now navigating through herself, she knows that there are many reasons to plan for and be excited about one's future even after diagnosis. "If I can walk alongside just one person and prevent them from having to go it alone, I will know that I had a part in breaking down barriers and helping end the stigma of dementia." DAI is thrilled she has joined the board, and will be taking on an active role supporting new members.

## Agnes Houston, MBE



Agnes Houston MBE was diagnosed with younger onset Alzheimer disease 2006 at the age of 57. She is a current board member of Dementia Alliance International, an exchange fellow of Edinburgh University, an active member of the DEEP network, a current committee member of the SDWG and a Director of Dementia friendly communities in the rural Highlands of Scotland.

She has campaigned for best practice in Dementia care and improving lives of People with Dementia especially on sensory issues, resulting in a booklet and DVD on Dementia and Sensory Challenges in 2015. She received a lifetime achievement award from Alzheimer Scotland in 2013, was awarded an MBE in 2015 and a Churchill Fellowship in 2016.

## Amy Shives



Amy Shives is a Board member and founding member of DAI, and holds a master's degree in education from Western Washington University in Bellingham Washington. Prior to diagnosis, Amy had a career as a counselling faculty member at Spokane community college. After 25 years in her position, Amy noticed she was having difficulty performing her varied professional duties. After a difficult and lengthy process of diagnosis, she was eventually diagnosed with younger onset Alzheimer's disease at the university of California San Francisco memory and aging center where she is enrolled in lifelong research studies for people with dementia. Amy grew up with her mother having had the disease. She currently works to increase awareness about the stigma surrounding dementia. Amy currently is on the National Alzheimer's Association Early Stage Advisory board where she is a national speaker speaking for people with dementia. Amy has a husband of more than 30 years and two successful happy daughters.

## David Paulson



David L. Paulson is a new DAI Board Member, and holds a PhD in Linguistics, MS.Ed. in Foundations of Education, and a BA in Spanish Business & Translation. David holds an Advanced Certificate in Second Language Acquisition / Teacher Education, is a member of several academic honor societies, has co-published several textbooks, speaks a number of languages and was a classical pianist before his illness. Paulson currently teaches in Spanish and is the French/Spanish Translator/Interpreter and Hispanic Student Retention Specialist at his institution.

David noticed emerging symptoms of cognitive impairment in his mid 40s, and by in his 50s, he retired early with a misdiagnosis of mental illness. Two years later, re-diagnosed with Dementia, likely of the Alzheimer variety, he has resumed his academic duties at a community college and remains professionally active in the promotion of multilingualism, English as a Second Language, The Teaching and Learning of Hispanic Cultures and their associated Indigenous Languages and Cultures, as well as Professional Spanish Translation and Interpretation. Paulson also invests much of his time in Advocacy for Persons with Dementia in the Americas. Paulson holds a PhD in Linguistics, MS.Ed. in Foundations of Education, and a BA in Spanish Business & Translation. He holds an Advanced Certificate in Second Language Acquisition / Teacher Education, is a member of several academic honor societies, has co-published several textbooks, speaks a number of languages and was a classical pianist before his illness. Paulson currently teaches in Spanish and is the French/Spanish Translator/Interpreter and Hispanic Student Retention Specialist at his institution. We are thrilled to welcome David onto the board.

*"My immediate future vision for DAI is to bring the Zoom support system to the Hispanic World (20+ counties) in General American (Guatemalan) Spanish Dialect, comprehensible to the vast majority of world speakers of Spanish. This will bring needed support and vital information to persons with dementia PWD as well as their caregivers. A broader vision will be to record and catalogue videos of*

*PWD from the Hispanic world as well as other languages and cultures throughout the world who step forward to talk about the experience of dementia in their own communities, countries and cultures. These voices can then be used to form a document of anecdotal evidence to inform the WHO of the reality of dementia in the world.”*

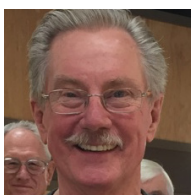
## **Brian Le Blanc**



Brian Le Blanc, National Public Speaker, Advocate, DAI Board member. Brian is a new Board member and a Retired Public Relations / Marketing Executive from Pensacola, Florida who has been living with Early (younger)-Onset Alzheimer's Disease since 2014. He volunteers his time speaking throughout the United State, as well as in his local area, about all things Alzheimer's and Dementia Related. In the State of Florida, he is Representing Individuals Living with Alzheimer's or other Dementia-Related Illnesses in the Dementia Care and Cure Initiative (DCCI) State-wide Taskforce – Tallahassee, FL.

Brian is a Public Speaker, Advocate and on the Leadership Board of the Covenant Care, Corp – Pensacola, FL. Brian is also a Public Speaker, Advocate, and a member of the Advisory Council with the Dementia Action Alliance – Falls Church, VA. He is a Public Speaker, Advocate and on the National Early-Stage Advisory Group for the National Alzheimer's Association – Chicago, IL, and a member of the National Early-Stage Advisory Group Alumni, as well as a Public Speaker, Advocate and on the Executive Committee for the Alzheimer's Association AL/FL Panhandle Chapter. His certifications include: Alzheimer's Association, 1) Know the 10 Signs: Early Detection Matters and 2) The Basics: Memory Loss, Dementia and Alzheimer's Disease. Brian's was educated at the Archbishop Rummel High School, Delgado Community College, and the University of New Orleans. We are thrilled to welcome him onto the board.

## **Chuck Frichot**



Chuck Frichot, a new Board member, is aged 76 and lives in Omaha, Nebraska. He was a Medical Doctor (Dermatologist) for the past 50 years, and retired in 2012 after memory problems developed and undergoing tests at the Geriatric center, with the diagnosis of dementia being made. His mother died of Alzheimer's and therefore he was very tuned into memory problems and Alzheimer's. Chuck had been on Aricept for 2 years and due to severe side effects, changed to Exelon, which he is tolerating. With his lovely wife they are very proactive and do everything possible such as exercise with trainer 2x/week, eating right, 8-10 hours sleep, socialization, hobbies (woodturning) and reading. Chuck has also been sober in a 12 step program for the past 35 years and has worked with many people. He scours the Internet medical literature daily for any and everything about Alzheimer's and possible etiological factors and treatment possibilities. He has also been in DAI with John Sandblom the past year or so in the weekly support meetings, which he now co-hosts. We are thrilled to welcome him onto the board.

## James McKillop



James McKillop was born in Wishaw Lanarkshire, Scotland in 1940. He leads a normal life, attended primary school, secondary school and had a job in the civil service until 1973. He is married and his first of four children, followed in 1977. James and his wife had normal family life on a low income, and spent all their spare time bringing up the children, taking them out whenever possible. After their first child they had to give up a car and did not have one for another twenty years.

In the mid 1990's, he started to have severe difficulties at work and in the home. Family life was badly disrupted as his behaviour had changed, for the worse. James eventually had to give up work as he could no longer cope. Then he was diagnosed with multi infarct dementia; he was devastated as had met it in my working life in huge mental health hospitals. Initially he went into a deep depression and stayed at home, but after some harrowing years and with excellent support he got his life back on track.

James was inspired to start the Scottish Dementia Working Group, a group for people with dementia and led by people with dementia. Professionals and carers had their own groups; this was ours. He has since been very active in the dementia field, giving presentations and writing articles. James's membership of DAI has brought him into contact with others across the world, and he looks forward to future chats and to participating on the board. DAI feels very lucky to have such a long time pioneering and successful advocate join our board.

## Human Rights Advisor



Professor Peter Mittler, CBE, MA, MEd, PhD, C.Psychol, FIASSID, Hon. Research Fellow, Emeritus Professor and former Dean of Faculty of Education, University of Manchester; former President Inclusion International; UN consultant in intellectual disability; diagnosed with Alzheimer's Disease 2006, living well with dementia. Peter is a global expert in the field of disability and human rights, and currently holds the position of Human Rights Advisor to DAI, although he is not board member. We remain indebted to the work he does for DAI, and for many other groups supporting people with dementia in the United Kingdom and Europe.

# CHAIR'S REPORT

Chair's Report  
November 2016  
Kate Swaffer

## Welcome

Welcome to everyone, and my sincere thanks to members of the board for 2016 for their hard work and commitment to DAI. Special thanks to outgoing board members, Susan Stephen, Leo White, Jeanne Lee, Helga Rohra, and co-opted board member Mary Radnofsky, and also to Professor Peter Mittler, our Human Rights Advisor who lives in Manchester in the UK.

As with all people with dementia, we occasionally get time zones mixed up, forget to set up our meetings or host our cafes, and it has happened this year as well. I would therefore also like to thank a DAI member, Laurie Scherrer who last year kindly offered to send us reminders each month, using her iPad. It has been extremely helpful and I truly appreciate her 'behind the scenes' support. Thank you Laurie.

On behalf of us all, my very special thanks must go to our very hard working and loyal DAI volunteer, Sarah Yeates, who also took on the job of the weekly emails to all members of all support groups. We could not have done it without you Sarah, and are indebted to you for this support, and your other support with Minutes and professional advice. Sarah wishes to step down from the support group work, and I hope to be able to announce a new volunteer for that job in the next few days. Our other volunteer, Nick Jenkins has been unable to be a more active volunteer due to his own private and professional commitments, but has been supporting us by working on a publication on Empowering and engaging consumers, for release in 2017. Thanks also to Nick.

## World Alzheimer's Month 2016

We postponed releasing our World Dementia Report, *Dementia Friendly Communities: Perspectives of people with dementia* until 2017, due to needing more time to ensure our survey results are accurately represented and all up to date information is included. However, we ran a daily blog series, highlighting member's stories, and other important information about dementia for the whole of the month.

As usual, Alzheimer's Disease International produced an excellent report released on World Alzheimer's Day, World Alzheimer's Report: Improving healthcare for people living with dementia. It was also felt, for this reason, it was sensible to release our first world report at a different time, so that it is given the attention it deserves.

## Conferences

DAI members were well represented in Budapest at the ADI conference in April, and again at the ADI Regional meeting held in conjunction with Alzheimer's NZ's biennial conference, Dementia Today: Diverse Communities Collective Action. We hope to have strong representation at the ADI conference in Kyoto in April 2017, and have supported a number of members who have never attended to submit abstracts. Mick Carmody was the invited plenary speaker in New Zealand, opening the conference and represented us brilliantly. Other members also gave excellent presentations, as in Budapest and Perth the year before, where there was a large contingent of people with dementia and their care partners.

## Women and Dementia

Earlier in the year an article published in Health Care for Women International by Rosie Erol, Dawn Brooker & Elizabeth Peel was released titled The impact of dementia on women internationally: An integrative review and it highlights that "women are disproportionately affected by dementia, both in terms of developing dementia and becoming caregivers. They conducted an integrative review of English language literature of the issues affecting women in relation to dementia from an international perspective." and "The effects of caregiving on health, wellbeing and finances are greater for women; issues facing women, particularly in low and middle-income countries need to be better understood. I am delighted we have secured a speaker for our monthly "A Meeting Of The minds" series for 2017 to speak to us about women and dementia.

## Human Rights Update

Professor Peter Mittler, Mary Radnofsky and I have been busy with the continued pursuit of a human rights based approach to dementia. At the ADI Members meeting in April, there was a 100% acceptance for all ADI members to move forward with a human rights based approach, and whilst 167 countries have ratified the CRPD, the work has really just begun to ensure it is implemented fully for the rights of people with dementia. Canada has just released its first National Dementia Strategy, and we hope to encourage more countries globally to be more active in this space. We have all attended various WHO meetings or other forums in Geneva, and Peter was an invited speaker at an event during the AAIC conference in Toronto. His presentation was titled: Living Well With Dementia: A Fundamental Human Right. DAI has also been able to actively support the Ontario Dementia Advisory Group in Canada with their work on human rights.

Peter Mittler and I also worked with ADI to co-produce a small booklet, as a supplement to a Side Event at the World Health Organisation concerning human rights and dementia, held in Geneva on 25 August. Mary Radnofsky [represented DAI](#) at the annual United Nations Conference of States Parties (COSP) to the Convention on the Rights of Persons with Disabilities (CRPD) June 13-17, 2016, and Mary and Peter Mittler represented us again in Geneva at the 2016 Social Forum in October, and Mary represented us at the CRPD event in New York earlier in the year, the first person with dementia to be at an event like this. Thank you to both Mary and Peter for their hard work for us all. You can read about the work we are doing on our [Human Rights webpage](#), and more about these meetings if you simply search 'Human Rights' through [our blogs](#).

## Publications

Earlier in the year, we produced a formal *Peer to Peer Support Group Information and Guidelines*, and our *Code of Conduct Protocols for Board members, volunteers and staff for our members*. These have also been downloaded or referred to by other organisations, and will become more formal global publications, and are currently being formatted in line with our other documents.

Then in May 2016, DAI produced its first official global publication, released during Dementia Awareness Week in the UK in May, *The Human Rights of People With Dementia: From Rhetoric to Reality*. This is now on our Resources page, under Publications, and has already been translated into Spanish, Italian and Arabic, and is currently being translated into Portuguese, Indonesian, Japanese, French, Polish and Russian. It is one way we can support all DAI and ADI members, and especially in the Lower and Middle Income Countries (LMIC's). We also released in October our Supporting and Accommodating People with Dementia at Conferences and Other Events publication to assist event organisers to better support us to attend.

Peter Mittler and I also worked hard to ensure representation at the 2nd CBR World Congress Event in Kuala Lumpur in September, by producing a flyer that went into 1500 conference delegates' bags and video for the event, which saved anyone needing to attend. The theme for this World Congress "CBR: Empowering and Enabling, was to provide a setting for diverse communities of practice, policy, education, research and social development to engage in a dialogue to promote the well-being of persons with disability around the world. It is important dementia is being represented in as many events like this as possible.

In 2017, we plan to release the following DAI publications:

1. DAI Report on Dementia Friendly Communities
2. Empowering and engaging people with dementia
3. Dementia Language Standards

## International Disability Alliance

We applied in 2016 for membership of this organisation, as it will give us a much better grounding in our human rights and disability focus, and have been accepted with Observer status. Membership of this organisation ensures we are fully informed of all disability rights information and activities globally, and will ultimately also provide access to funding to support fuller participation. We are working towards full membership of IDA in 2017.

## A Meeting of The Minds Webinars

Presenting at our next two events, we have excellent international speakers, and the program for 2017 is currently in progress. The December webinar is being held earlier than usual, as we felt December would be too busy for everyone later in the month. If there are topics, or certain speakers you would like hear from, please let us know. The 2017 calendar of speakers is already filling up. We remain concerned that professionals continue to register for these events as people with dementia, and our honour system is not respected. These events are our only source of 'income'.

Our very sincere thanks go to all of our speakers, who offer their time and expertise at no cost to us, and often, at a very unfriendly time of day for them, and as this is our first official Annual Report, we have gone back further than 2016 to ensure we formally thank everyone who has donated their expertise and time. Many DAI members have also contributed significantly to these events, as well as Laura Bowley, who volunteered for DAI until mid 2015, and we thank everyone for their contribution and attendance. We hope to have a full program this year, and will publish our program as it is confirmed. Many of our webinars are online on our [YouTube Channel](#).

## Thank you to the DAI "A Meeting Of The Minds" Webinar presenters

As this is our first Annual Report, I have included all speakers from 2014-2016

Associate Professor Lee-Fay Low,  
"Dementia, celebrations and Christmas", December 2016

Professor Myrra Vernooij-Dassen,  
"Selfcare and social health in dementia", November 2016

Ms Anne Kavanagh, Speech Pathologist,  
"Dementia: What is the role of the Speech Pathologist?", October 2016

Matthew Baumgart,  
"Moving the needle: How advocates can change government policy", September 2016

Associate Professor James McLoughlin,  
"Rehabilitation and dementia: A Hard sell!", August 2016



Mr Nick Guggisberg and Mr Dennis Frost,  
“The Kiama Dementia Friendly Community”, July 2016

Associate Professor Victoria Traynor,  
“Driving and dementia”, May 2016

Ms Teepa Snow,  
“Communication Challenges – Being Curious, Cautious, and Courageous”, April 2016

Ms Denise Craig, Clinical Psychologist,  
“Dementia Enablement Guide: A new post-diagnostic pathway”, March 2016

Emeritus Professor Rhonda Nay,  
“Sexuality and dementia: Right, Risks and responsibilities”, February

Associate Professor, Dr Allan Power,  
“Living with Dementia: new perspectives”, January 2016

Ms Nicole Batsch,  
“Dementia Friendly Communities Defined - Key Components for a Successful Start”, December 2015

Professor Steven Sabat,  
“Understanding the Selfhood of People with a Dementia: Context is Key”, October 2015

Mr Glenn Rees,  
“Global Perspectives of Dementia: what are the priorities?”, September 2015

Open event, “Memorial Tribute to Richard Taylor PhD”

Dr. Al Power,  
“Dementia Beyond Disease: Enhancing Well-Being”, June 2015

Ms Cathie Borrie,  
“Introducing The Long Hello”, March 2015

DAI members and supporters, “Words about words”, June 2014

*We also wish to share an annual overview received from the various organisations we work with, either in close but autonomous partnership or in mutual collaboration with each other.*

## **ADI Overview 2016**

ADI's new Strategic Plan was launched at the ADI Council meeting in April 2016, highlighting key strategic objectives including making dementia a global health priority; reducing stigma; strengthening membership; facilitating research; and generating sufficient income and using modern technology and communications to achieve ADI's objectives. The Council meeting was held on the first day of the 31st International Conference in Budapest, Hungary, which was attended by more than 900 delegates, and featured plenary sessions by global experts alongside the launch of new reports on Dementia Friendly Communities.

At this meeting, ADI adopted a rights-based approach in future advocacy efforts and this commitment has seen us working more closely with Dementia Alliance International (DAI). In March, we launched a joint policy paper, 'Access to the CRPD and SDGs by Persons with Dementia', <http://www.alz.co.uk/sites/default/files/pdfs/harnessing-crpd-dementia.pdf> and this was followed by a joint statement at an official side event to the 16th Session of the Convention on the Rights of Persons with Disabilities Committee meeting in August 2016.

In May 2016, the World Health Organization's Executive Board unanimously voted in favour of developing a Global Action Plan on Dementia following the involvement of ADI and 12 countries at a successful side event on dementia during the 69th World Health Assembly (WHA). This Action Plan will urge a greater commitment by governments worldwide to develop and improve National Dementia Plans, care and support for people with dementia, including the involvement of people with dementia and Alzheimer associations globally.

National Plans were launched this year in Greece, Indonesia, Slovenia, Macau SAR and Argentina, and plans were also introduced in Austria and Norway. The plan for Indonesia marked the first within South East Asia and there is hope that a plan will soon be launched in Chile, bringing the global total to 29.

World Alzheimer's Month 2016 was marked by campaigns in over 70 countries worldwide, including the launch of the World Alzheimer Report 2016; Improving healthcare for people living with dementia. The report calls for an increased focus on primary healthcare in dementia care that must be clearly defined, coordinated and collaborative.

Throughout the year, carer training and ADI Alzheimer University training for associations was held in Greece, London, Malaysia and New Zealand, and this was accompanied by the sharing of knowledge and resources at ADI Regional meetings in Sub Saharan Africa, Asia Pacific, Latin America and Non-Latin Caribbean.

## Global Alzheimer's & Dementia Action Alliance (GADAA) 2016

The Global Alzheimer's & Dementia Action Alliance (GADAA) is an international network of civil society organisations seeking to champion global action on dementia and support NGOs in responding to the challenge. Dementia Alliance International (DAI) is a member and sits on the [GADAA Steering Committee](#) alongside the [Alzheimer's Society](#), [Alzheimer's Disease International](#), [Age International](#) to provide overall strategic direction of GADAA.

The GADAA network aims to connect a broad spectrum of international civil society organisations (iNGOs) including international development organisations, health-focused NGOs, disability rights champions, human rights organisations, faith based groups and women's organisations. Alzheimer's Society, ADI and Age International join DAI on the GADAA Steering Committee. The UK Department of Health and the World Health Organisation are GADAA observers.

With the appointment of a dedicated Executive Lead for GADAA (Amy Little) in 2016, work has been underway to formalise the network and expand membership. The draft WHO-led Global Dementia Action Plan recognises the need for broad spectrum of civil society to partner in the implementation of the plan, and GADAA will continue to mobilise wider civil society in the crucial period ahead. Through GADAA, we can strengthen global efforts to tackle the stigma against dementia and raise awareness of the disease where it is needed most, particularly in lower and middle income countries. We can also encourage capacity building by matching larger NGOs with national Alzheimer's associations, and encourage iNGOs to support the delivery and dissemination of dementia tools and interventions. DAI is proud to be strategic partners with Global Alzheimer's & Dementia Action Alliance (GADAA) [www.gadaalliance.org](http://www.gadaalliance.org)

## The LEAD Coalition 2016

*Please note that results for 2016 are incomplete since the U.S. Congress and federal agencies have not finished their work for the year at the time this document was written.*

The [LEAD Coalition](#) is a unifying force for the U.S. dementia community with 94 formal member organizations and more than 80 additional participating organizations.

The LEAD Coalition works with Congress, a dozen federal agencies, and all its non-governmental organization partners to accelerate transformational progress in (1) care and support to enrich the quality of life of those with dementia and their caregivers, (2) detection and diagnosis, and (3) research leading to prevention, effective treatment and eventual cure.

The LEAD Coalition has been at the forefront of obtaining federal commitment and partnership to conduct the U.S.'s first-ever "[National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers](#)," which will be held at the National Institutes of Health (NIH) in October 2017. The LEAD Coalition also has advocated successfully for the

Centers for Medicare and Medicaid Services (CMS) to issue a [final rule for the 2017 Physician Fee Schedule](#) that will compensate designated medical professionals who provide cognitive and functional assessments and care planning services to people with cognitive impairments including Alzheimer's disease and other forms of dementia.

The LEAD Coalition has been advocating for congressional legislation to address caregiving generally and dementia caregiving in particular, including: the [Recognize, Assist, Include, Support, and Engage Family Caregivers Act \(RAISE Family Caregivers Act\)](#), the [Palliative Care and Hospice Education and Training Act](#), the [Alzheimer's Beneficiary and Caregiver Support Act](#), and the [Alzheimer's Caregiver Support Act](#). The LEAD Coalition worked with congressional appropriators to include a proposed \$350-400 million increase in dementia-specific research funding for FY 2017 (it appears likely that final legislation will be delayed until March 2017). The LEAD Coalition successfully advocated for the NIH's [FY 2018 Bypass Budget for Alzheimer's Disease and Related Dementias](#), which requests \$414 million in FY 2018 above its FY 2017 estimated base budget to continue momentum in pursuing the national goal of preventing and treating Alzheimer's disease and related dementias by 2025. The Bypass Budget includes research [milestones](#) and highlights recent NIH-supported basic, translational, and clinical research. The 2018 Bypass would devote roughly three times as much new funding to care and caregiver support research as does the 2017 Bypass.

The LEAD Coalition has worked with congressional and federal agency staff to inform development of the [21st Century Cures Act](#) and the [Prescription Drug User Fee Act \(PDUFA\) VI reauthorization plan](#) on a variety of issues. For example, the LEAD Coalition has pressed for inclusion of systematic approaches to collect and utilize robust and meaningful input from people living with dementia and carers that can more consistently inform drug development and, as appropriate, regulatory decision making. The LEAD Coalition also has helped residential care and biopharmaceutical industry partners shape their consumer preferences work.

For more information please contact Ian Kremer at [ikremer@leadcoalition.org](mailto:ikremer@leadcoalition.org).

## World Dementia Council 2016

The World Dementia Council, established as part of the G8/G7 focus on dementia, consists of 24 senior leaders, from academia, across industry and the NGO sector alongside leaders living with or affected by dementia. Our role is to lead the global fight against dementia, working in close partnership with colleagues such as the World Health Organisation

We have expanded during the year, driven by the desire to ensure that the World Dementia Council is well placed to continue to motivate, support and drive the changes that are needed across its five priority areas: finance, research, integrated development, care and risk reduction. Council members are determined to build on the Council's legacy of achievement, such as the creation of the \$100 million Dementia Discovery Fund to support dementia research, and the work led by Raj Long to bring together regulators to consider how to accelerate progress towards a disease modifying drug for dementia.

We have now set out an ambitious agenda for the next 18 months to two years and we are already well underway with work to achieve its goals – for example, by linking up with the Global Brain Health Institute to support a pilot of a tool for understanding the potential for reducing the risk of dementia in lower and middle income countries; and by encouraging the EU's Joint Programme in Neurodegenerative Diseases (JPND) – which has already led to promising discussions with research institutes in the US and India.

We also continue to work to identify new ways to raise awareness and break down stigma around dementia, for example by linking up with the World Federation of Science Journalists to consider how we can better support journalists, particularly in low and middle income countries, to write more effectively about Alzheimer's disease and other dementias.

Alongside this work the World Dementia Council continues to work alongside the World Health Organisation, feeding into their work to develop a global dementia action plan and to create a Global Dementia Observatory.

The World Dementia Council is proud of its record of achievement to date and ambitious for the future, but it is also mindful of the wide range of other bodies and organisations alongside which it works in this global effort. We are determined to be good colleagues to these organisations, supporting, enabling and catalysing their work, as well as driving forward our own agenda. We look forward to continue to work as part of this global community in the year ahead.

## FUNDRAISING

Our major sponsor is Alzheimer's Disease International, and we thank them for their continued support, both financial, and of ensuring an authentic voice of people with dementia globally. Our partnership with them continues to be positive and to grow. Whilst we retain a completely autonomous working relationship, supporting each others work is invaluable.

Professor Peter Mittler donated his speakers Honorarium to DAI from Axovant following his address in Toronto to DAI, and I have done a number of presentations this year where I have asked for the speaker's fee to be donated to DAI, which has raised significant funds from organisations for DAI. It is one way we can all help DAI with fundraising, as I guarantee apart from ADI, many conference conveners pay other speakers, and \$500 is a very reasonable fee. Axovant is also donating a larger sum to us to assist members to attend events in the human rights or disability space, and other related work (donations listed in Financial Reporting). Special thanks to Susan Suchan who is involved with a group who specifically raise money for organisations chosen by members each month, and which was donated to us earlier this year.

We held one Crowdrise fundraising campaign, raising very little, but we hope to hold one again soon, with the focus on raising funds to support members to attend Kyoto in April 2017. I also wish to officially and personally thank every single person who has donated to DAI. 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.

## FINANCIAL REPORTING

We have so far, not had a Finance Committee, which our By Laws state are required. The aim is that we will have enough new board members and other active members to find people willing to support John Sandblom on this committee. To date, he has had to manage this position alone, with little support, and I accept that as Chair I have taken final responsibility that the financial monthly reporting has been inadequate. I am pleased to announce we now have that matter rectified. Our Certified Practicing Accountant, Mr William Hillstrom, of Hillstrom, Kerr & Co., has been providing some services pro bono such as lodging our tax form to the IRS, and this year has provided a formal report for the AGM, at a very reduced rate.

ADI have requested that we provide them with formal report for future funding, and for us to apply for larger funding grants, we also need our financial records Audited, so we are working to find a firm in the USA who will do this pro bono, as we simply cannot afford the \$USA15-20,000 dollars required for it. As a registered Charity, this is also a legal obligation, which we will ensure is attended to in the coming year.

Generous donations or specified sponsorship was made by the following organisations:

### Major sponsors

Received from Alzheimer's Disease International (ADI), our partnership sponsor \$25,000

Received from Axovant, via ADI, specifically to support our human rights work \$10,000

### Other major donations

Received from Axovant, an Honorarium fee for a symposium at AAIC2017 Toronto, donated by Peter Mittler \$2,500

Received from the Lost Marbles Club via DAI member Susan Suchan \$1,000

Received from Teepa Snow \$500

Received from Kate Swaffer and Peter Watt \$528.49

Received from Tony Ramshaw \$200

Generous donations have also been made via our Webinars, in our Crowdrise campaign, or through purchases using SmileAmazon.com, and range from individual amounts between \$4.98 up to \$199.00. There are too many to list individually, but we wish to sincerely thank each and every one of you.

## In kind donations:

The Arabic translation of our Human Rights publication, was generously funded by Professor Lynn Chenoweth.

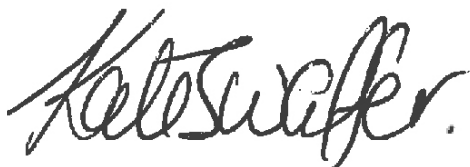
The Spanish translation of our Human Rights publication was provided by a number of DAI supporters; Dr Omer Silva-Villena, Developmental Psycholinguist from Valdivia-Chile, Lilia Mendoza and Federico Ortiz-Moreno, and DAI board member David Paulson.

Professor Richard Fleming, Dr Lyn Phillipson, Dr Nicholas Jenkins, Professor Jan Dewing, Dr Shibley Rahman and others have also provided in kind support for our blogs, publications and some other materials.

(Post AGM addendum: Our Certified Practicing Accountant, Mr William Hillstrom, of Hillstrom, Kerr & Co. has agreed to complete a monthly statement and an annual financial report, for an annual fee of approximately \$600 US)

## Thanks to you all

My sincere thanks to everyone for the continuing dedication to DAI and I look forward to working with a new board in 2017.



Kate Swaffer  
Chair, CEO and proud co-founder





# Financial Reports 2016



Hillstrom, Kerr & Company, Inc.  
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Katy, TX 77494  
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January 23, 2017

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

Management is responsible for the accompanying financial statements of Dementia Alliance International, Inc. (a Texas not-for-profit corporation) which comprise the statements of assets, liabilities and fund balance—tax basis for the year ended December 31, 2016, and the related statements of revenue and expenses—tax-basis, and changes to fund balance—tax-basis in accordance with the tax-basis of accounting, and for determining that the tax-basis of accounting is an acceptable financial reporting framework. We have performed compilation engagements in accordance with Statements on Standards for Accounting and Review Services promulgated by the Accounting and Review Services Committee of the AICPA. We did not audit or review the financial statements nor were we required to perform any procedures to verify the accuracy or completeness of the information provided by management. Accordingly, we do not express an opinion, a conclusion, nor provide any form of assurance on these financial statements.

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

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

Sincerely,

A handwritten signature in blue ink that reads "Hillstrom, Kerr &amp; Company, Inc." in a cursive script.

Hillstrom, Kerr & Company, Inc.

# Financial Reports 2016

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2016  
FOR THE YEAR ENDED DECEMBER 31, 2016

## STATEMENT OF REVENUE AND EXPENSES

### REVENUE

DONATIONS	\$ 47,455.47
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### EXPENSES

SOFTWARE EXPENSES	\$ 1,993.40
BANK CHARGES	\$ 449.76
POSTAGE	\$ 62.54
LODGING	\$ 318.00
EQUIPMENT PURCHASE	\$ 83.93
SALES TAX	\$ 25.02
ADVERTISING	\$ 10.00
PAYPAL FEES	\$ 69.03
PROFESSIONAL FEES	\$ 618.75

REIMBURSED EXPENSES	\$ 957.01
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MISCELLANEOUS EXPENSES	\$ -
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TRAVEL AND CONVENTION EXPENSES	\$ 30,487.00
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	\$ 35,074.44	\$ 35,074.44
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	\$ 12,381.03
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# Financial Reports 2016

DEMENTIA ALLIANCE INTERNATIONAL, INC.  
COMPILATION REPORT 2016  
FOR THE YEAR ENDED DECEMBER 31, 2016

## STATEMENTS OF ASSETS AND LIABILITIES

ASSETS	
BANK BALANCE WEST BANK	\$ 20,961.97
PAYPAL BALANCES	\$ 1,416.54
TOTAL ASSETS	\$ 22,378.51
LIABILITIES AND FUND BALANCE	
LIABILITIES	\$ -
FUND BALANCE	\$ 22,378.21
	\$ 22,378.21

## The Inaugural Richard Taylor Memorial Advocates Award

On World Alzheimer's Day, September 21, 2016, we announced the winner of the Inaugural Richard Taylor Memorial Advocates Award. Mick Carmody, our Global Support Group Manager and board member from Brisbane, also a very active advocate, was the winner of this prestigious inaugural award, and we congratulate him. There were a number of members nominated for this award, and Mick received the most nominations. He was unanimously voted the winner, in particular for his tireless commitment to all of our members, and his incredible work managing the support groups and providing a lot of peer to peer support to individual members. Thank you Mick for your dedication and hard work to all people with dementia. Thanks also to your lovely wife Sue and family who support and enable you to work so hard. We now have 8 regular support groups, and a monthly one for people with any type of Aphasia, and more to come in the near future.



Left: Kate Swaffer current Chair and Chief Executive Officer of DAI with the Inaugural Richard Taylor Memorial Advocates Award winner Mick Carmody, our Global Support Group Manager and board member from Brisbane.

**SEE THE PERSON**  
**NOT THE DEMENTIA**

© DEMENTIA ALLIANCE INTERNATIONAL



**Alzheimer's Disease  
International**

DAI wishes to thank Alzheimer's Disease International as our partner sponsor and Axovant for their donation to support our human rights work in 2017.



**AXOVANT**  
Dementia Solutions™

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