



Annual Report 2015–2016



**Alzheimer's Disease
International**
The global voice on dementia

Chairman's report



Glenn Rees

At the end of the year 2015-16 I can say with even greater confidence that dementia is on the global stage among the major health issues.

The WHO Ministerial Conference on Global Action on Dementia in March 2016 demonstrated the strong commitment that exists in many countries to tackling dementia. Over 80 countries were represented. The WHO Executive followed up the Minister's meeting with a decision to develop an action plan on dementia for adoption at the 2017 World Health Assembly. The agenda articulated by ADI in the *World Alzheimer Report 2015* provides the evidence and the basis for an action plan.

Equally encouraging was the first WHO Regional Dementia Plan adopted by the Pan American Health Organisation.

The Strategic Plan 2016-19 adopted by Council in Budapest provides the basis for building the support many members require to advocate to their respective governments for action on dementia. The Asia Pacific Regional Office has shown that an ADI local resource responding to local priorities can produce results.

ADI and Dementia Alliance International adopted a Memorandum of Understanding during the year that promises much in terms of being more inclusive of people with dementia. The prospect of monitoring the rights of people with dementia under the Convention on the Rights of Persons with Disabilities and the work on dementia friendly communities provides the legal and practical means to enable people with dementia to take their place in the community.

My thanks to my Board who not only work hard but cooperatively. And, it never ceases to surprise me how much the Executive Director and staff achieve with limited resources.

Executive Director's report



Marc Wortmann

ADI's Strategic Plan highlights the five key strategic objectives that guided our work from July 2013 to June 2016. The following report summarises the work undertaken to achieve these objectives during the year July 2015 to June 2016.

Objective 1: Making dementia a global health priority. ADI will lead global advocacy efforts and support the national advocacy of member associations to make dementia a public health priority.

In May 2016, the World Health Organization's 194 member countries unanimously voted in favour of a Global Action Plan on Dementia. This followed the involvement of ADI and 12 countries at a successful side event on dementia during the 69th World Health Assembly (WHA). ADI has been instrumental in calling for a resolution on dementia and a proposal to develop a global plan on dementia received critical support from the governments of Switzerland and Dominican Republic, with support from all of the member countries represented at the WHA. Once developed, 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 key stakeholders such as people with dementia and Alzheimer associations globally.

National plans were launched this year in Greece and Indonesia with the support of the national Alzheimer associations and ADI, and plans were also introduced in Austria and Norway. In March 2016, Indonesia became the first country in South East Asia, and the 24th in the world, to launch a Dementia National Plan. During the 67th Session

of the Regional Committee of the WHO for the Americas, held in September 2015 in Washington D.C., Pan American Health Organization (PAHO) country representatives voted unanimously in favour of a Regional Plan of Action on Dementia. The Plan of Action, which was developed with the support of ADI and its member associations in the region, obliges countries to develop national dementia plans.

At the ADI Council meeting in April 2016, member associations voted for ADI to adopt a rights-based approach in future advocacy efforts. Since its inception, Dementia Alliance International (DAI) - a self-advocacy organisation of people living with dementia - has called for recognition of the rights of people living with dementia and this commitment will see us working more closely with DAI. In March, ahead of the meeting, we launched a joint policy paper, *Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia*.

As well as our growing partnership with DAI, we continued to collaborate with a number of organisations to work towards our shared advocacy objectives, including Alzheimer Europe, the Global NCD Alliance and the World Dementia Council. A new relationship with World Young Leaders in Dementia was also formed.

Objective 2: Reducing stigma. ADI will lead global advocacy efforts and support the national advocacy of member associations to make dementia a public health priority.

Held in Budapest, Hungary, the 31st International Conference of ADI welcomed nearly 900 delegates from 70 countries. Hosted in partnership with the Hungarian Alzheimer's Society, the multi-disciplinary event attracted people with dementia, along with professional and family carers, researchers, clinicians, and staff and volunteers of Alzheimer associations. Plenary and parallel sessions alongside a popular exhibition and poster area highlighted

activities, research and experience from around the world. Two NCD Dialogue sessions encouraged discussion of common elements across non-communicable diseases including prevention, early diagnosis and end of life care. The conference marked the perfect opportunity to present the 2016 ADI-Home Instead Carer of the Year Award to Vassiliki Terkenli from Greece who received her award at the conference opening ceremony.

In September 2015 we coordinated the third global World Alzheimer's Month, which culminated on World Alzheimer's Day, marked each year on 21st September. World Alzheimer's Month supports Alzheimer associations worldwide to raise awareness of dementia and, as a result, reduce stigma. The theme, chosen by ADI, was *Remember Me*, and a new website dedicated to World Alzheimer's Month was launched. On Twitter, #WorldAlzheimersDay and #DíaMundialAlzheimer were two of the most popular hashtags on 21 September.

New publications on dementia friendly communities were launched this year. The first, detailing the principles of a dementia friendly community, contained a breakdown of the various aspects and considerations when developing such an initiative. The second, supported by a new section on the ADI website, listed examples of dementia friendly projects that have been developed around the world to date.

Objective 3: Strengthening membership. ADI will meet the needs of emerging and established associations and provide programmes that will enable members to best support people affected by dementia and their care partners.

In April 2016, the Alzheimer's and Related Disorders Association of Ghana and the Alzheimer's and Dementia Association of The Cayman Islands were accepted as members of ADI. The welcoming of these new associations increased the total number of Alzheimer associations which are part of ADI to 85.

In September 2015, ADI welcomed Alzheimer associations from Puerto Rico, St Kitts and Nevis, Pakistan, Norway, South Africa and Indonesia to the annual Alzheimer University training programme in London, a series of workshops to help strengthen and develop Alzheimer associations. The aim of the Alzheimer University is to give participants the tools to identify their association's aims, provide information, raise money and awareness, effectively govern their association and influence public policy. During the year, ADI continued monitoring those associations who attended the 2013 and 2014 programmes and their progress towards achieving their action plans set at the Alzheimer University. An additional half-day programme was held for ADI member associations in the Latin America region during their 8th regional conference in October 2015. The session, attended by 21 representatives from 10 countries, aimed to engage associations in developing an actionable 30-day plan to use the PAHO Strategy and Plan of Action to advance national plans in their countries. A further workshop took place with ADI's Caribbean member associations in February 2016. This session, while also featuring discussion over the PAHO Plan of Action, was primarily focussed on strengthening associations and increasing collaboration across the regional network.

ADI's Asia Pacific Regional Office continued to facilitate the sharing of knowledge and resources between associations.

The region launched the ADI Master Trainer programme in Dementia Care Skills in 2016, adapted from training developed by Alzheimer's Australia. Aimed at developing countries with a long-term objective of building self-reliance in dementia care training. ADA Singapore's Stephen Chan, Koh Hwan Jing and Mazni Kaswani facilitated 5-day workshops in Bangladesh and Indonesia. Bringing their experiences and knowledge to these associations has enabled them to continue to train carers based on what they learned. As a result, a total of 50 trainers from Bangladesh, Indonesia and Malaysia were trained and these trainers have conducted more than 20 training sessions in 3 countries and 20 cities in the Asia Pacific region reaching out to approximately 500-1000 family care partners and care-workers in a year.

In addition, 1000 carers were trained through a *Train the Trainers* programme in Greece. The trial project, called *Positive care in dementia*, was led by Alzheimer Hellas with the objective of supporting carers and professionals affected by dementia. The project trained 14 'Master Trainers', who then supported a further 1000 carers and 600 dementia professionals through training events across the country between December 2015 and March 2016. The course focussed on interactive ways to engage professionals and individuals supporting people with dementia. ADI also carried out a training programme in Bermuda.

At the 18th ADI Asia Pacific Regional meeting held in Manila, Philippines in November 2015, delegates from 13 member countries came together to co-create a framework for a *Strong ADI Member Association*. The key elements were grouped into five dimensions: Leadership & Governance; Financial Sustainability; Programmes & Services; Awareness & Advocacy and Organisational Development. ADA Singapore and ARDS India were the first to complete a self-assessment based on the framework and shared their findings at the ADI Conference in Budapest in April 2016.

As well as the 18th Asia Pacific Regional Conference, ADI staff and Board members were also present at: the 25th Alzheimer Europe Conference in Ljubljana, Slovenia in September 2015; the 8th Iberoamerican Congress on Alzheimer's Disease in Rio de Janeiro, Brazil; and the 3rd Regional Caribbean Conference on Alzheimer's and Dementia in Barbados in February 2016.

Throughout the year, ADI Board members and staff continued to provide support to member associations remotely, as well as at conferences and where possible through visits.

Objective 4: Facilitating research. ADI will facilitate and encourage research into care and prevention, epidemiology, and finding effective treatments.

In August 2015, ADI launched the *World Alzheimer Report 2015: The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. The report updates ADI's data on dementia's global prevalence, incidence and cost, highlighting the increasing impact on low and middle income countries. Promotion of the new report included a live online roundtable discussion. The discussion featured our Executive Director Marc Wortmann, Prof Martin Prince from King's College London and Prof Graham Stokes from Bupa, as well as an opening message from Kate Swaffer from Dementia Alliance International. *The World Alzheimer Report* was a core product of the ongoing collaboration between ADI

and the Global Observatory on Ageing and Dementia, which operates out of King's College London.

ADI also supports King's College London to facilitate the work of the 10/66 Dementia Research Group. This year the 10/66 Group's methodology was used by researchers for studies in Malaysia and Vietnam.

ADI's Medical and Scientific Advisory Panel (MSAP) provide international dementia expertise and represent ADI around the world. This year the MSAP met during both the Alzheimer's Association International Conference (AAIC) in July 2015 and the ADI Conference in April 2016. MSAP members continue to support ADI staff and member associations with enquiries, as well as working with ADI to publicly respond to new research findings.

Objective 5: Enabling ADI to achieve its objectives. *ADI will generate sufficient income and use technology and modern communications to execute the Strategic Plan.* See Treasurer's report.

Dementia Alliance International



In 2014, eight people with dementia founded Dementia Alliance International (DAI), which is a support and advocacy group of, by and for people with any type of dementia. Since then this NGO has grown and now provides weekly support for its members. DAI has become very active globally for human rights, access to the UN Convention on the Rights of Persons with Disabilities (CRPD) and improving services and support for people with dementia and their families and care partners. DAI is registered as a US Corporation with 501(c)(3) status which means donations by US citizens are tax deductible, and it is now the global voice of people with dementia, working in close but autonomous partnership with Alzheimer's Disease International.

In 2015, DAI's co-founder, and current Chair and CEO, Kate Swaffer demanded full access to the CRPD at the WHO's First Ministerial Conference on Dementia. Since then, DAI has worked tirelessly to make a reality of that demand. In April 2016, the ADI Council committed its 85 member associations to a policy "based on human rights and full access to CRPD and other Conventions".

DAI's Human Rights Adviser, Professor Peter Mittler, Kate Swaffer and other DAI Board Members have attended UN and WHO meetings in New York and Geneva to present a dementia perspective on CRPD and to insist on the full inclusion of people with dementia in the implementation of this Convention by the 172 governments who are committed to it in international law by ratification. In collaboration with national, regional and local groups, as well as many individual dementia advocates, we are collectively ensuring a human rights based approach for people with dementia. We are asking for an approach that includes not only timely diagnosis and better care including palliative care, but a proactive approach at the time of diagnosis which includes rehabilitation and support for our disabilities.

Treasurer's report



Andrew Ketteringham

I am pleased to report we have managed our finances competently this year, increasing our unrestricted net assets (reserves) by \$74,000 (compared to \$93,000 in 2015).

We are not in business to make money but it is important that we hold sufficient reserves to ameliorate any unexpected reduction in income or adverse conference result. The Board has agreed a reserves policy, which is that we aim to hold funds to cover 4-6 months of central costs, less an allowance of 35% in respect of central costs attached to project activity. We are not yet at the desired level of reserves, and so we are continuing to manage our finances towards achieving that end.

Conference activity each year continues to be a significant proportion of total income and expenditure and also a source of uncertainty. Our current policy is to select conference destinations that enable us to avoid drawing on general funds to cover conference costs. When funds allow, we aim to build a separate conference reserve, to cover future events.

Much of ADI's work continues to be based on projects supported by specifically allocated funds from external bodies. This restricted fund activity requires careful management. Wherever possible, these projects include amounts to cover a suitable proportion of our core costs to ensure full cost recovery.

We very much appreciate those trusts, foundations, corporations and individuals that support the work of ADI. In particular we would like to thank those donors listed in the box over the page, including our Global Foundation Partners and Global Supporters. We are also grateful for the continuing support of all our member associations.

I would like to give thanks to the Chair, Council, Elected Board, Executive Committee and particularly the staff and volunteers who endeavour to deliver ADI's objectives within our financial constraints.



Dr Mary Radnofsky, a member of Dementia Alliance International, presenting during the 31st International Conference of ADI.

Financial statements

Statement of Financial Position

At June 30, 2016

	Unrestricted \$	Temporarily Restricted \$	Total \$
Assets			
Current Assets			
Cash	522,987	-	522,987
Accounts Receivable	6,477	-	6,477
Due from Conference	-	-	-
Grants & Contributions Receivable			
– Net of Allowance for Uncollectible Accounts			
of \$30,000 for 2016 and \$10,000 for 2015	-	318,209	318,209
Prepaid Expenses and Other	48,640	-	48,640
Total Current Assets	578,104	318,209	896,313
Property and Equipment			
Furniture and Equipment	40,482	-	40,482
Less Accumulated Depreciation	(36,214)	-	(36,214)
Net property and equipment	4,268	-	4,628
Other Assets			
Interfund Balance	(96,986)	96,986	-
Total Assets	485,386	415,195	900,581
Liabilities and Net Assets			
Current Liabilities			
Accounts Payable and Accrued Liabilities	214,692	-	214,692
Net Assets	270,694	415,195	685,889
Total Liabilities and Net Assets	485,336	415,195	900,581

Statement of Activities and Changes in Net Assets

For the Year Ended June 30, 2016

	Unrestricted Funds \$	Temporarily Restricted Funds \$	Total \$
Support and Revenue			
Dues	415,828	-	415,828
Contributions and Grants	249,808	686,263	936,071
Conference Revenue	729,412	-	729,412
Interest and Other	214	-	214
In-Kind Contributions	6,058	-	6,058
Gain (Loss) on Currency			
Exchange Transactions	(42,152)	-	(42,152)
Net Assets Released from Restrictions:			
Satisfaction of Program Restrictions	746,488	(746,488)	-
Total Support and Revenue and Assets Released from Restrictions	2,105,656	(60,225)	2,045,431
Expenses			
Program Services			
Conference	585,770	-	585,770
Information	59,394	-	59,394
Member Support and Development	485,340	-	485,340
Promotion and Awareness	547,024	-	547,024
Research	106,962	-	106,962
Total Program Services	1,784,490	-	1,784,490
Support Services			
General and Administration	157,269	-	157,269
Fund Raising	89,847	-	89,847
Total Support Services	247,116	-	247,116
Total Expenses	2,031,606	-	2,031,606
Change in Net Assets	74,050	(60,225)	13,825
Net Assets, Beginning of Year	196,644	475,420	672,064
Net Assets, End of Year	270,694	415,195	685,889

Income

ADI is a 503(c)(3) non-profit organisation, incorporated in the state of Illinois, USA.

The figures in this report are for the 2015-16 year, which ended on 30 June 2016.

ADI member Alzheimer associations pay dues according to their own income, which in 2015-16 made up 20% of the total income. ADI also receives contributions and grants from corporations, foundations, trusts and individuals. The ADI conference is supported by sponsorship and participants' registration fees.

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

Expenses

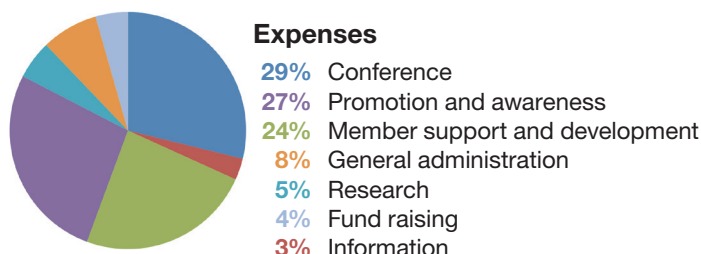
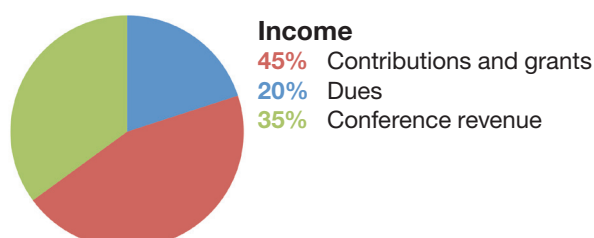
ADI's expenses are classified into seven functions: the five main areas of programme work, management and administration, and fundraising.

'Member support and development' includes the Alzheimer University training programmes and other support and advice provided to Alzheimer associations. 'Information' covers the Global Perspective newsletter, website, factsheets and booklets. The key event for 'Promotion and awareness' is World Alzheimer's Month, and ADI staff and Elected Board members also take part in other conferences and meetings to promote our work and our cause. This also includes ADI's public policy work, including the World Alzheimer Report. The spending on 'Research' is mainly through support of the Global Observatory for Ageing and Dementia Care at King's College London. There is a heading for the ADI International 'Conference'.

Thank you

Bupa	\$177,100
Eli Lilly	\$146,800
Roche	\$110,600
Biogen	\$109,600
Janssen	\$60,000
Lundbeck	\$50,500
Merck/MSD	\$50,000
Nutricia Clinical Nutrition	\$36,200
Home Instead	\$28,000
Otsuka	\$20,000
John S Latsis Foundation	\$7,200
TIMA Charitable Foundation	\$7,200

All those contributing over \$5,000 are listed, except for member associations, and trusts and individuals that have requested anonymity.



Alzheimer's Disease International

Our Vision Our vision is prevention, care and inclusion today, and cure tomorrow.

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

Elected Board

AS AT JUNE 2016

Mr Glenn Rees, Australia, Chairman
Mr Dale Goldhawk, Canada, Vice-Chairman
Mr Andrew Ketteringham, UK, Treasurer
Dr Serge Gauthier, Canada, Chairman of Medical and Scientific Advisory Panel
Ms Faraneh Farin, Iran
Mr John Grosvenor, UK
Dr Mariella Guerra, Peru
Mr Markus Löfström, Finland
Ms Birgitta Martensson, Switzerland
Mr Gerald Sampson, USA
Ms Kate Swaffer, Australia

President

AS AT JUNE 2016

Princess Yasmin Aga Khan, USA

Honorary Vice Presidents

AS AT JUNE 2016

Dr Daisy Acosta, Dominican Republic
Prof Henry Brodaty, Australia
Ms Wendy Fleming, New Zealand
Dr Nori Graham, UK
Mr Brian Moss, Australia
Dr Jacob Roy, India

Staff

AS AT JUNE 2016

Marc Wortmann, Executive Director
Johan Vos, Deputy Executive Director
Jane Cziborra, Conference and Events Manager
Saskia Dean, Conference and Events Coordinator
Sarah Kerr, Publications Officer
Michael Lefevre, Finance and Technology Manager
Anastasia Psoma, Fundraising and Membership Manager
James Smith, Communications and Administration Coordinator
DY Suharya, Deputy Regional Director, Asia Pacific Regional Office
Francis Wong, Regional Director, Asia Pacific Regional Office

Members

AS AT JUNE 2016

Asociación de Lucha contra el Mal de Alzheimer (Argentina)

Alzheimer's Disease Armenian Association
Fundacion Alzheimer Aruba
Alzheimer's Australia (AA)
Alzheimer Angehorige Austria
Alzheimer Society of Bangladesh (ASB)
Barbados Alzheimer's Association Inc.
Ligue Nationale Alzheimer Liga (Belgium)
Alzheimer's Family Support Group (Bermuda)
FEBRAz (Brazil)
Compassion Alzheimer Bulgaria
Alzheimer Society of Canada
Alzheimer's and Dementia Association of the Cayman Islands
Corporacion Alzheimer Chile
Asociacion Colombiana de Alzheimer (Colombia)
Asociación Costarricense de Alzheimer y otras Demencias Asociadas (Costa Rica)
Alzheimer Croatia
SCUAL (Cuba)
Stichting Alzheimer Curaçao
Pancyprian Association of Alzheimer's Disease (Cyprus)
Česká Alzheimerovská Společnost (Czech Republic)
Alzheimerforeningen (Denmark)
Asociacion Dominicana de Alzheimer (Dominican Republic)
Egyptian Alzheimer Society
Asociacion de Familiares Alzheimer de El Salvador
Muistiliitto ry (Finland)
Deutsche Alzheimer Gesellschaft (Germany)
Alzheimer's and Related Disorders Association Ghana
Greek Association of Alzheimer's Disease and Related Disorders
ERMITA (Guatemala)
Asociación Hondureña de Alzheimer (Honduras)
Hong Kong Alzheimer's Disease Association
Hungarian Alzheimer Society (Hungary)
Alzheimer's and Related Disorders Society of India (ARDSI)
Alzheimer Indonesia (ALZI)
Iran Alzheimer Association
The Alzheimer Society of Ireland
Alzheimer's Association of Israel
Federazione Alzheimer Italia (Italy)
Alzheimer's Jamaica
Alzheimer's Association Japan (AAJ)
Alzheimer's Association Lebanon
Macau Alzheimer's Disease Association (MADA)
Association of Alzheimer Disease - Skopje Macedonia
Alzheimer's Disease Foundation Malaysia (ADFM)

Malta Dementia Society
Alzheimer Association Mauritius
Federacion Mexicana de Alzheimer (Mexico)
L'Association Monégasque pour la recherche sur la Maladie D'Alzheimer (Monaco)
Association Marocaine Alzheimer et Maladies Apparentées (Morocco)
Alzheimer and Related Dementia Society Nepal (ARDSN)
Alzheimer Nederland (Netherlands)
Alzheimers New Zealand
Alzheimer's Disease Association of Nigeria
Nasjonalforeningen for folkehelsen (Norway)
Alzheimer's Pakistan
Asociacion Peruana de la Enfermedad y Otras Demencias (Peru)
Alzheimer's Disease Association Philippines (ADAP)
Polish Alzheimer's Association (Poland)
Alzheimer's Disease China (ADC)
Asociacion de Alzheimer y Desordenes Relacionados de Puerto Rico
Romanian Alzheimer Society
Help For Patients With Alzheimer's Disease And Their Families (Russia)
Saudi Alzheimer's Disease Association (Saudi Arabia)
Alzheimer Scotland
Alzheimer's Disease Association Singapore (ADA)
Sint Maarten Alzheimer Association
Slovak Alzheimer's Association (Slovak Republic)
Spomincica – Slovensko zdruzenje (Slovenia)
Alzheimer's South Africa
CEAFA (Spain)
Lanka Alzheimer's Foundation (LAF - Sri Lanka)
Alzheimerforeningen i Sverige (Sweden)
Association Alzheimer Suisse (Switzerland)
Syrian Alzheimer and Memory Diseases Society (Syria)
TADA (Chinese Taipei)
Alzheimer's and Related Disorders Association of Thailand (ARDA-T)
Alzheimer's Association of Trinidad and Tobago
Association Alzheimer Tunisie (Tunisia)
Turkish Alzheimer Society and Foundation (Turkey)
Alzheimer's Society (England, Wales and Northern Ireland)
Alzheimer's Association (USA)
Asociación Uruguaya de Alzheimer y Similares (Uruguay)
Fundacion Alzheimer de Venezuela
Zimbabwe Alzheimer's and Related Disorders Association



Alzheimer's Disease International

The global voice on dementia

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Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc. is incorporated in Illinois, USA, and is a 501(c)(3) not-for-profit organization

Cover image:
Launch of the Indonesian national plan in March 2016