Alzheimer’s Disease International

ADI was founded in 1984 in Chicago with pioneers from the Alzheimer’s Association in the USA and similar groups from Canada, Australia and the UK. In the 24 years since then, the number of members has risen to 77, coming from all continents of the world.

**Vision and aims**

ADI wants to improve the quality of life for people with dementia and their families throughout the world. We aim to build and strengthen Alzheimer associations and raise awareness about dementia worldwide.

We work by facilitating the sharing of expertise and resources that exist within our community. ADI is a forum through which established and emerging Alzheimer associations can learn from one another. Stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers.

**What we do**

- Encourage the creation of new Alzheimer associations in countries where there is no organisation
- Support the development and activities of our member associations around the world
- Bring Alzheimer organisations together to share and learn from each other
- Raise public and political awareness of dementia at national and international levels
- Stimulate research into the prevalence of Alzheimer’s disease and dementia in populations around the world

**Dementia**

Dementia is the general term used to describe brain disorders that affect a person’s memory and behaviour. Alzheimer’s disease accounts for 50-60% of all cases of dementia. In 2001 the number of people worldwide with Alzheimer’s disease and other forms of dementia was estimated to be 24 million. In 2008 the number will increase to 30 million. As a result of global ageing with people living longer, researchers expect this number to rise to 59 million by 2030 and over 100 million by 2050.

Every 7 seconds there is a new case of dementia somewhere in the world. Dementia affects more people than those who have the illness, as the pressure on families is immense. This is why they need support mechanisms such as national Alzheimer associations.

At the moment, researchers are working hard to understand what causes dementia. There is no cure for Alzheimer’s disease and only a few drugs that slow it down, mostly in the earlier stages. Therefore early detection is vital but because of the lack of awareness and stigma surrounding dementia it is very difficult for people to realise or accept that they may have the disease. One of the main roles of Alzheimer’s Disease International (ADI) is to break the taboos and raise awareness about dementia, stressing that it is a disease and not a normal part of ageing. If we talk openly about dementia, we can also educate people so that they can understand and cope with it and achieve a better quality of life.

**Projected growth of dementia 2008–2050**

- 2008: 30 million
- 2030: 59 million
- 2050: 104 million
Following 2006, a year of transition at the end of which I took over as Executive Director, the year 2007–2008 was used to solidify ADI’s fundraising income for the future, further develop our important Alzheimer University and Twinning programmes for member associations, organise the annual conference in Caracas and work towards getting the World Health Organization (WHO) to put dementia on their agenda.

These were not easy tasks, but with the help of my dedicated staff, the involved members of the Executive Committee, the Elected Board and many of our supportive member associations we were able to do all these things. It took some time in fundraising to develop the right proposals and find the right foundations and corporate sponsors. After spending a considerable part of our reserves thanks to a large donation made in 2005, we were convinced by the end of 2007 that further funding was within reach for our programmes. This could not have been done without the efforts of our Chairman, Orien Reid, who played an important role in developing new contacts and convincing potential sponsors that their support was crucial to ADI.

Alzheimer University programmes took place both in London for emerging associations and in Taipei for ADI members from the Asia Pacific region. The Twinning Programme had results from the first three pairs of twinned associations, three more pairs started in 2007 and a further three in 2008. The preparation of the conference in Caracas, Venezuela, met with some challenges, but with the hard work of Mira Josic de Hernández, Aquiles Salas and Jesús Mazzei from the Fundación Alzheimer Venezuela and their colleagues, an excellent meeting took place in October, again gathering people from around the world from all disciplines and backgrounds. I also want to mention the role of our Vice Chairman Daisy Acosta, who played a crucial role in making this event successful and also became Chairman-Elect at the meeting.

Finally we were able to take our first steps towards a greater role within the WHO and advocating successfully for the needs of people with dementia and their families at an international level.

I want to thank everyone for their warm and ongoing support, especially our members who contribute with their dues, but also with their time and involvement. It has been an exciting year.

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**Facts and figures**

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<td>ADI founded</td>
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<tr>
<td>ADI’s legal status</td>
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<tr>
<td>Estimated people with dementia worldwide in 2008</td>
<td>30 million</td>
</tr>
<tr>
<td>Estimated people with dementia worldwide in 2050</td>
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<td>Estimated global cost of dementia</td>
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<td>Number of ADI member associations</td>
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<td>Number of provincial and local chapters</td>
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<td>ADI staff (31 December 2007)</td>
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</table>
Annual international conference
Our conference is unique in that it brings together everyone with an interest in dementia: people with dementia, families, health and care professionals, researchers and staff and volunteers of Alzheimer associations around the world.

Alzheimer University
A training programme to build and strengthen the capacity of Alzheimer associations.

Twinning Programme
A formal, two-way partnership between two Alzheimer associations for mutual benefit.

World Alzheimer’s Day
The opportunity to raise awareness about dementia and its impact on families and the important work of our members throughout the world.

10/66 Dementia Research Group
The network of researchers in developing countries, affiliated to ADI, that does research into the prevalence, incidence and other aspects of dementia in developing countries and works to disseminate the results.

Advocacy and the World Health Organization
We want to make Alzheimer’s disease and dementia a global health priority and put them on the agenda of the World Health Organization and governments worldwide.

Providing information
We produce a regular newsletter, a range of printed materials and a website to ensure our members and stakeholders are informed about topics relevant to running Alzheimer associations, as well as developments in dementia care and research.

At the ADI conference members of the 10/66 Dementia Research Group came together from all over the world to share their latest research.
Regional meetings

The 10th Asia Pacific regional meeting took place in Perth, Australia on 29 May – 1 June 2007, in conjunction with the conference of Alzheimer’s Australia. ADI held a one-day business meeting with its members from the Asia Pacific region who exchanged ideas and agreed on future collaborations. Delegates also visited several dementia care services in Perth. ADI is very grateful to Alzheimer’s Australia WA (Western Australia) for organising this event and providing some travel grants to participants.

ADI was also represented at other regional conferences and meetings. The Alzheimer Europe conference was held in Estoril, 9-12 May 2007, and the Alzheimer Iberoamerica meeting took place on 9 October in Caracas, before the ADI conference. There was also a conference attended by members in the Middle East region on 27-28 October in Athens, Greece.
Alzheimer University

The Alzheimer University is a training programme that ADI runs each year with the aim of building the organisational capacity of Alzheimer associations.

Depending on demand and funding, we run two types of course: one for emerging associations and the other for more developed associations to help them increase their effectiveness in specific areas.

Over the last year we have run two Alzheimer University workshops. The first was in London, UK, for associations just starting out, and was made possible by the kind support of the Helen Bader Foundation. The other was focused on fundraising for more established associations, and was held in Chinese Taipei, supported by a donation from a trust. Both events were additionally supported by a grant from Eli Lilly.

London April 2008

Volunteers from new and emerging associations in Armenia, Aruba, Ethiopia, Kenya, Mauritius and Suriname travelled from across the globe to attend the Alzheimer University training programme in London.

Representatives from established Alzheimer associations and a leading development training body, together with ADI staff, led the programme and over three days guided the attendees through a range of topics that aimed to equip them with the skills to run a successful and sustainable Alzheimer association.

Taipei June 2008

For the first time ADI conducted a one-day Alzheimer University event entitled ‘Fundraising to make a difference’. This event took place during ADI’s Asia Pacific regional meeting, organised by TADA Chinese Taipei. Participants from Alzheimer associations within the Asia Pacific region took part in a full day of workshops and group activities all aimed at building their capacity to fundraise effectively.

‘What an exceptional, positive experience. I feel lucky to have a clearer vision of our future plans. I am very enthusiastic to put what I have learnt into practice’.
Hovhannes Manvelyan, Armenia

‘Today I have learnt that nothing is impossible’
Lorraine Tamitegama, Sri Lanka
We are now entering the third year of the ADI Twinning Programme, a project that forms a relationship between a pair of member associations to exchange ideas and provide mutual support to their organisations.

The project has been kindly supported by A & S Burton 1960 Charitable Trust.

Along with the twinning relationships established in 2006 and 2007, we announced new twins for 2008: Brazil and Portugal, Malta and The Netherlands and Sri Lanka and Scotland. ADI provides financial and administrative support for the twins and monitors the development of the reciprocal relationship.

We are happy to report stories of success from earlier twinning relationships. The Alzheimer’s Society (England, Wales and N. Ireland) have visited the Alzheimer’s and Related Disorders Society of India (ARDSI) twice and have developed a comprehensive action plan on how they can work together over the coming years. They have jointly held several meetings in the UK involving the Indian community living in the UK and this has resulted in the formation of a new organisation called Friends of ARDSI, which is now a registered charity in the UK with the purpose of fundraising on behalf of ARDSI. They have already held events including a photography exhibition and sale.

In Pakistan, with the help of Western Australia, a new day care centre was inaugurated in Lahore in February 2007. All the other twins have been conducting site visits and establishing their plans of action.

Opening of care home in Lahore, Pakistan, developed with the collaboration of Alzheimer’s Australia WA

Twinned associations

**2006**
- Canada and Trinidad and Tobago
- Pakistan and Australia (WA)
- Greece and Ireland

**2007**
- Israel and Bulgaria
- UK and India
- Mexico and USA (Los Angeles chapter)

**2008**
- Malta and The Netherlands
- Sri Lanka and Scotland
- Brazil and Portugal

Debbie Benczkowski, Canada, and Norma Inniss, Trinidad & Tobago, promote their twinning work
Alzheimer associations ran a wide range of activities for World Alzheimer’s Day 2007, including lectures and symposia, Memory Walks, open days, fundraising events, national awareness weeks, art and music activities, which secured them three television interviews and provided a great start to their awareness campaign, as well as being visited by Keith and Lillian Turner from the UK. Keith has dementia and has worked with the Alzheimer’s Society in the UK as an advocate. 

A survey was conducted to find out the needs of people with dementia and their carers. People with dementia and carers were interviewed in Brazil, Canada, France, Germany, Spain and the USA. The main findings were presented on several occasions and will be publicised in a leading journal in 2008. Key findings were that most people with dementia and carers maintain a warm relationship with their families and want to go on with their normal lives as much as possible. The survey also found that the main source of information for people is their primary physician and that the use of services provided by Alzheimer associations is more significant in Europe than in Brazil or North America.

The participation of governments and policy makers was another prominent feature of World Alzheimer’s Day 2007, with the involvement of government leaders and ministers in Argentina, China and the Philippines.

Students in the Philippines parade in Baguio City to raise awareness of dementia

**Raising awareness**

ADI coordinates World Alzheimer’s Day on 21 September every year. ADI produces materials including a bulletin, posters and stickers for member associations to use and adapt. ADI also provides advice and support to members in their awareness raising activities, and facilitates international communication of the events taking place. These events attract media attention, including radio and TV interviews.

The chosen theme for 2007, ‘No time to lose – people with dementia speak out!’ was embraced by associations, many of whom used the day to focus on the reality of life with dementia as seen by the people with the disease themselves.

As the tradition of World Alzheimer’s Day grows and ADI’s membership expands we are very pleased to see the day being celebrated by many new and emerging Alzheimer associations. The Caribbean island of Aruba launched the Alzheimer’s Teal Ribbon Week, including a fundraising concert. In Lithuania, a marathon was held in the capital, Vilnius, and in Armenia a memory walk and round table attracted the attention of the country’s media and research community.

The association in Jamaica received a visit from Orien Reid, chairman of ADI, and students in the Philippines parade in Baguio City to raise awareness of dementia.
An estimated 66% of people with dementia live in developing countries but only 10% of all population-based research into dementia is conducted in those countries. The 10/66 Group comprises over 130 researchers from 36 countries, and aims to add information about dementia in developing countries to that already available in the developed world.

The 10/66 team has now completed studies of the prevalence, impact, health service utilisation, and risk factors of dementia in eight developing countries. The Group is developing an intervention to be delivered by local health workers which teach carers how to cope with the day-to-day tasks of caring and to deal with the behavioural problems that are associated with dementia. The intervention has shown benefits when evaluated in randomised controlled trials in India and Russia, and more trials are underway.

The 10/66 Group works to disseminate results widely through its website and newsletter as well as publications in journals, including The Lancet.
Advocacy and collaboration

Involving people with dementia and forging partnerships with appropriate organisations are integral to ADI’s work

Advocacy and the World Health Organization

After discussion at the Asia Pacific meeting in June 2007 in Perth, the members in the region asked ADI to formulate a strategy aimed at getting the World Health Organization (WHO) to make dementia a global health priority. ADI created an Advocacy Working Group with members from Australia, Canada, Dominican Republic, Germany, Scotland, Sri Lanka, Switzerland and USA. The group developed the text of a charter, to be released on World Alzheimer’s Day 2008. The group also discussed further implementation of the WHO Strategy. In September and October 2008, ADI representatives will visit the six WHO Regional Committee meetings to make statements and encourage the WHO to put dementia on its agenda.

Involving people with dementia

The two Alzheimer University programmes in the past year included speakers with dementia. This encouraged members to involve people with dementia in their organisations and recognise the power this can have in raising awareness and reducing stigma.

After a visit from Keith Turner, who has dementia, and his wife Lillian, Dundeen Ferguson of Alzheimer’s Jamaica said:

‘Keith’s visit certainly had an impact in raising awareness of Alzheimer’s disease in Jamaica. The sharing of his personal experience living with dementia made it real to many persons and his affirmation of early detection was meaningful. Speaking as a carer, Lillian’s personal experiences and challenges was something a lot of families and carers could relate to. By sharing their life experiences on living with dementia Keith and Lillian’s visit had an enormous impact in changing people’s perceptions of the nature of the disease and its effects.’

The theme for World Alzheimer’s Day 2007 focused on people with dementia speaking out which was backed up by an international survey that ADI, with the support of Novartis, undertook investigating the unmet needs, challenges and communication gaps faced by people with mild-to-moderate Alzheimer’s disease and their carers.

People with dementia spoke out at the conference in Venezuela, sharing directly their experiences and demonstrating how they can make a difference and inspire others to take action.

The Global Alzheimer’s Disease Charter has been produced in 16 languages
How people with dementia and their carers benefit

People with dementia and their carers benefit directly from the work of our members. If there is no Alzheimer association in a country, the voices of people with dementia and carers are not heard and there are no basic services like helplines, support groups or independent websites. Alzheimer associations also advocate for and advise on improving health care systems, reimbursement of drug use and recognition of the disease.

Australia was the first country in the world that made dementia a national health priority in the year 2004, followed by South Korea in 2006. France started a major initiative in early 2008 and several other countries are successfully campaigning for similar national plans.

ADI brings together information about all these issues and supports associations through its conferences, training and twinning programmes and individual communication with staff. Through this exchange many good practices are transferred from one country to another, including not only medical practice, but also care practice, day care centres, training of professionals or volunteers, the support people with dementia and their families or even advocacy. Our work creates stronger and more effective Alzheimer associations which are better able to meet the needs of people with dementia and carers.
Treasurer’s report

During 2005 it was acknowledged that ADI could not continue as a financially sustainable organisation without some radical re-appraisal of its resource base. In essence ADI had been fortunate to have been in receipt of a significant one-off contribution that allowed some short term respite but a longer term re-alignment was necessary.

Although the accounts for 2007 reflect a further application of reserves this was anticipated in the new five year financial review reflecting the momentum of the past. More encouragingly I am pleased to report that the first signs of financial improvement are beginning to become evident. For example, new funds have been secured in 2007 that can be applied in 2008 and the reduction in costs, in the ADI office in particular, will begin to have a full year impact in 2008.

Despite these difficult financial circumstances ADI has been able to maintain its ambitious strategies of raising awareness and supporting member associations across the world. The new financial plan, as it becomes increasingly embedded, is designed to facilitate these objectives.

As ever we remain greatly indebted to those trusts, foundations, corporations and individuals that support the work of ADI. In particular we would like to thank those donors listed opposite. We are also very grateful for the continuing support of our member associations.

Finally I would like to thank the Chairman, Council, Board, Executive Committee and especially the staff who have worked so hard in these challenging times to maintain the vision of ADI whilst achieving a new financial context.

Income

ADI is a 501(c)(3) non-profit organisation, incorporated in the state of Illinois, USA.

ADI member Alzheimer associations pay dues according to their own income, which in 2007 made up 42% of the income total. ADI also receives contributions and grants from corporations, individuals, foundations and trusts.

Total income in 2007 was somewhat lower than in recent years, due mainly to achieving a lower level of large grants and contributions from corporations and foundations. Intensive work on fundraising in 2007 has seen results for 2008. The financial statements for 2007 include some $318,000 of income restricted for projects to be carried out in 2008 or future years. This means that the level of unrestricted net assets (‘reserves’) at the end of 2007 has been significantly reduced.

Interest, investments and other

Contributions and grants 44%

Dues 42%

Conference 2%
ADI receives a share of the revenue from the international conference. In 2007 that contribution came from Fundación Alzheimer de Venezuela, which hosted the conference in Caracas, Venezuela.

ADI also received support from Friends of ADI, the UK registered charity which enables ADI to receive support tax-effectively from donors in the UK. 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.

‘Membership support and development’ includes the Alzheimer University training programmes, the ADI Twinning Programme 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 Day, but ADI staff and board also take part in other conferences and meetings to promote our work and our cause. The spending on ‘Research’ is through support of the 10/66 Dementia Research Group, and there is a heading for the ADI International ‘Conference’.

In 2007 ADI received grants to support specific projects managed by member associations, in addition to core activities run by the ADI staff.

**Reserves policy**

At the end of each year, unrestricted net assets held by ADI should broadly represent between six and eight months of total annual expenditure, excluding any exceptional variations. This policy is considered appropriate in light of ADI’s aims and its ongoing commitments to members, donors and staff.

**Investment policy**

ADI aims to effectively invest funds that are held in reserve or for planned future use. ADI seeks to maximise the long-term growth of funds while maintaining a level of income necessary for current programmes. Investments will be a mix of low and medium risk, so as to maximise return without unduly risking invested capital. Direct investments in companies that have a significant interest in the tobacco, alcohol and pharmaceutical industries will be avoided.

**Thank you**

Organisations that supported ADI and Friends of ADI in 2007:
- Helen Bader Foundation
- Novartis Pharma
- GlaxoSmithKline
- GE Healthcare
- A & S Burton 1960 Charitable Trust
- Alzheimer’s Australia WA
- Loke Won Tho Memorial Foundation
- Mark Krueger & Associates
**Statements of activities and changes in net assets**

FOR THE YEARS ENDED DECEMBER 31, 2007 AND 2006

<table>
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<tr>
<th>Year</th>
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<th>Temporarily Restricted</th>
<th>Percent of Support &amp; Revenue</th>
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<td>Funds</td>
<td>Funds</td>
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<td>337,580</td>
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**Support and revenue**

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<tr>
<td>Dues</td>
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<td>313,409</td>
<td></td>
</tr>
<tr>
<td>Contributions and grants</td>
<td>33,494</td>
<td>46,527</td>
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</tr>
<tr>
<td>Share of conference revenue</td>
<td>14,031</td>
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<tr>
<td>Fundraising event</td>
<td>720</td>
<td>720</td>
<td>0.09%</td>
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<td>In kind contributions</td>
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<td>29,856</td>
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<td>Unrealized loss on investments</td>
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<tr>
<td>Gain (loss) on currency exchange transactions</td>
<td>50,765</td>
<td>50,765</td>
<td>6.37%</td>
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<tr>
<td>Net assets released from restriction: Satisfaction of program restrictions</td>
<td>65,000</td>
<td>-65,000</td>
<td>0</td>
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<tr>
<td></td>
<td>543,449</td>
<td>253,168</td>
<td>796,617</td>
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**Expenses**

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<td>Realized gain on investments</td>
<td>7,084</td>
<td>2,084</td>
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</tr>
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<td>Unrealized loss on investments</td>
<td>-3,287</td>
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<td>-0.41%</td>
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<tr>
<td>Gain (loss) on currency exchange transactions</td>
<td>50,765</td>
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<td>6.37%</td>
</tr>
<tr>
<td>Net assets released from restriction: Satisfaction of program restrictions</td>
<td>65,000</td>
<td>-65,000</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>543,449</td>
<td>253,168</td>
<td>796,617</td>
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**Liabilities and net assets**

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<thead>
<tr>
<th>Description</th>
<th>2007</th>
<th>2006</th>
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</tr>
</thead>
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<tr>
<td>Dues</td>
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<td></td>
</tr>
<tr>
<td>Contributions and grants</td>
<td>33,494</td>
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<tr>
<td>Share of conference revenue</td>
<td>14,031</td>
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These are extracts from the financial statements, which are available in full from www.alz.co.uk/financial
Elected Board
(as at December 2007)
Princess Yasmin Aga Khan, USA, President
Mrs Orien Reid, USA, Chairman
Dr Daisy Acosta, Dominican Republic, Vice Chairman
Mr Martin Else, UK, Treasurer
Prof Bengt Winblad, Sweden, Chairman of MSAP
Mrs Lilian Aliche, Brazil
Dr Ang Peng Chye, Singapore
Mrs Wendy Fleming, New Zealand
Mrs Norma Inniss, Trinidad and Tobago
Mr Hussain Jafri, Pakistan
Dr Claudia Lai, Hong Kong SAR China
Mr Pekka Laine, Finland
Mrs Christine McGregor, UK
Dr Juan de J Llibre Rodriguez, Cuba
Dr Jacob Roy, India
Mr J A ‘Tony’ Salgado, Puerto Rico
Mr Niall Tierney, Ireland

Honorary Vice Presidents
(as at December 2007)
Prof Henry Brodaty, Australia
Dr Nori Graham, UK
Mr Brian Moss, Australia
Mr Jerome Stone, USA

Staff
(as at June 2008)
Marc Wortmann, Executive Director
Jodie Cross, Membership Development Manager
Michael Lefevre, Finance and Technology Manager
Jane Cziborra, Conference and Administration Officer

Members
(as at December 2007)
Argentina
Australia
Austria
Barbados
Belgium
Bermuda
Brazil
Bulgaria
Canada
Chile
PR China
Colombia
Costa Rica
Croatia
Cuba
Cyprus
Czech Republic
Denmark
Dominican Republic
Ecuador
Egypt
El Salvador
Finland
France
Germany
Greece
Guatemala
Honduras
Hong Kong SAR China
Hungary
Iceland
India
Indonesia
Iran
Ireland
Israel
Italy
Japan
Lebanon
Malaysia
Malta
Mexico
Netherlands
New Zealand
Nigeria
Norway
Pakistan
Panama
Peru
Philippines
Poland
Portugal
Puerto Rico
Romania
Russia
Scotland
Serbia
Singapore
Slovak Republic
South Africa
South Korea
Spain
Sri Lanka
Sweden
Switzerland
Syria
TADA, Chinese Taipei
Thailand
Trinidad and Tobago
Turkey
Uganda
Ukraine
United Kingdom
United States
Uruguay
Venezuela
Zimbabwe
The cover photo of Nicole Haas and Ruth Nelly Stocker was taken by Ruedi Haas, Switzerland. It was a runner up in the amateur category in ADI’s centenary photo competition in 2006.