25 years of Alzheimer’s Disease International
1984–2009
Marc Wortmann

When people ask me how things are going at ADI, I always tell them: we haven’t found a cure. Many of us working in this area would welcome the day that a cure is found for Alzheimer’s disease and other dementias.

However, we must remember that, while awaiting this breakthrough, we must continue to live with this devastating disease as best as we possibly can. It is important that we persist in educating the world and letting them know there is still life after a diagnosis of dementia and help is available.

ADI is doing well after 25 years working hard to promote these very important messages worldwide. Working alongside national Alzheimer associations and partner organisations, such as Alzheimer Europe and Alzheimer Iberoamerica, we have now begun to consider our next steps in strengthening this movement and I am certain that is going to happen.

I feel very privileged to be working, day-by-day, with so many dedicated and motivated people in the global dementia movement, as part of associations, services, research and industry. This publication presents just a few of those who have been crucial to strengthening the work of ADI by helping to raise awareness, collect funds, influence policy makers or support people with dementia and their carers. There is always so much to be done that I have never faced a dull moment in the eleven years I have worked in this field; seven years in the Netherlands and now four years for ADI.

I believe that working together on solutions, no matter what difficulties you face, is the real purpose of life and this is reinforced in this book. I hope this spirit will touch you as well and I am sure ADI will become stronger and make even more progress in the years to come, together with our member associations. It is essential for people with dementia and their carers that we continue to make a difference!

I hope you enjoy reading this publication and feel inspired by the work of so many committed pioneers and advocates around the world!
### Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How it began</strong></td>
<td>2</td>
</tr>
<tr>
<td>The beginning</td>
<td></td>
</tr>
<tr>
<td><strong>Interview</strong> Jerome Stone 3</td>
<td></td>
</tr>
<tr>
<td><strong>Interview</strong> Princess Yasmin Aga Khan 4</td>
<td></td>
</tr>
<tr>
<td><strong>25 years of ADI members</strong></td>
<td>5</td>
</tr>
<tr>
<td>When ADI members joined</td>
<td></td>
</tr>
<tr>
<td>Alzheimer University</td>
<td>6</td>
</tr>
<tr>
<td>Twinning Programme</td>
<td>7</td>
</tr>
<tr>
<td><strong>Interview</strong> Henry Brodaty 8</td>
<td></td>
</tr>
<tr>
<td><strong>Interview</strong> Jacob Roy 9</td>
<td></td>
</tr>
<tr>
<td><strong>25 years of conferences</strong></td>
<td>10</td>
</tr>
<tr>
<td>ADI annual International Conference</td>
<td></td>
</tr>
<tr>
<td>Regional meetings and conferences</td>
<td>12</td>
</tr>
<tr>
<td><strong>Interview</strong> Brian Moss 13</td>
<td></td>
</tr>
<tr>
<td><strong>25 years of campaigning</strong></td>
<td>14</td>
</tr>
<tr>
<td>World Alzheimer’s Day</td>
<td></td>
</tr>
<tr>
<td>Advocacy</td>
<td>15</td>
</tr>
<tr>
<td><strong>Interview</strong> Nori Graham 17</td>
<td></td>
</tr>
<tr>
<td><strong>Interview</strong> Yoshio Miyake 18</td>
<td></td>
</tr>
<tr>
<td><strong>25 years of research</strong></td>
<td>19</td>
</tr>
<tr>
<td>10/66 Dementia Research Group</td>
<td></td>
</tr>
<tr>
<td>Supporting research</td>
<td>20</td>
</tr>
<tr>
<td><strong>Interview</strong> Daisy Acosta 21</td>
<td></td>
</tr>
<tr>
<td><strong>25 years of sharing information</strong></td>
<td>22</td>
</tr>
<tr>
<td>Publications</td>
<td></td>
</tr>
<tr>
<td>Global Perspective</td>
<td>23</td>
</tr>
<tr>
<td>Medical and Scientific Advisory Panel</td>
<td>24</td>
</tr>
<tr>
<td>ADI website</td>
<td>25</td>
</tr>
<tr>
<td><strong>Interview</strong> Elizabeth Rimmer 26</td>
<td></td>
</tr>
<tr>
<td><strong>Interview</strong> Zaven Khachaturian 27</td>
<td></td>
</tr>
<tr>
<td><strong>25 years of working with our allies</strong></td>
<td>28</td>
</tr>
<tr>
<td>Involving people with dementia and their carers</td>
<td></td>
</tr>
<tr>
<td>The Stroud Series Symposia</td>
<td>29</td>
</tr>
<tr>
<td>Alzheimer Europe</td>
<td></td>
</tr>
<tr>
<td>World Health Organization</td>
<td>30</td>
</tr>
<tr>
<td><strong>25 years of making it work</strong></td>
<td>31</td>
</tr>
<tr>
<td>Governance</td>
<td></td>
</tr>
<tr>
<td>ADI staff</td>
<td>32</td>
</tr>
<tr>
<td>The brand</td>
<td></td>
</tr>
<tr>
<td>Friends of ADI</td>
<td>32</td>
</tr>
<tr>
<td><strong>Interview</strong> Orien Reid 33</td>
<td></td>
</tr>
</tbody>
</table>

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### 25 years of ADI members

When ADI members joined
- Alzheimer University
- Twinning Programme

**Interviews**
- Henry Brodaty
- Jacob Roy

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### 25 years of conferences

ADI annual International Conference
- Regional meetings and conferences

**Interviews**
- Brian Moss
There is a story behind how it happened. I was instrumental in getting people to gather for the first time. It involved meeting Dr Franz Baro who was then with the World Health Organization (WHO) and was a university professor.

As an active member of the Detroit, Michigan chapter of the Alzheimer’s Disease and Related Disorders Association, USA (now the Alzheimer’s Association) at the time and a Board member of the Association, I attended a lecture Dr Baro gave at the University of Michigan in Ann Arbor, USA. When he heard I was a member of the Alzheimer’s Association’s Board, he took me aside and asked me to do him a favour and carry an important message back to Jerome Stone and the rest of the Board. He had written a letter of invitation to the Alzheimer’s Association to attend a meeting in Paris, France to explore the possibility of organising an international society. The official WHO communication was sent via a New York address but Dr Baro had never received a reply. According to WHO rules, he was not allowed to send a second letter, so this communication needed to be personal; in addition the meeting was to occur in just a few weeks from then (October 1984).

As luck would have it, our next Board meeting was within the next 10 days. I carried the message to Jerry Stone who put it to our Executive Committee meeting. It was decided to accept the invitation immediately and Ethan Hitchcock volunteered to be our emissary.

At the Paris meeting it was decided to move forward and plan a formal organising meeting later that year and that occurred in Washington, DC, in 1984. Those present included myself, Jerry Stone, Henry Brodaty, Brian Moss, Anne Brown, Franceska Jordan and several other people. I sure do remember all the drafts of the bylaws, I was the one typing up most of them. Not long into this, Princess Yasmin got involved as our President....
Throughout the history of the formation of Alzheimer’s associations and their chapters worldwide, it is usually individuals directly affected by the disease in some way or other who come forward to forge their commitment. One such pioneer is none other than the founder of ADI, Jerome Stone, whose late wife had been diagnosed with Alzheimer’s disease back in the 1970s at the early age of 50. With some bare bones support from people struggling with the same problem, he decided to do something about it and started sharing his experience with interested people all over the USA. With no organisational support whatsoever in the beginning, it was around 7-8 years before the National Institutes of Health in the USA took notice and eventually called together like-minded people interested in Alzheimer’s disease to form the Alzheimer’s Association in New York, followed by Chicago in 1980.

Jerry Stone became Chairman of the USA Alzheimer’s Association amidst keen interest also generated from other countries about their activities. In 1984, at a meeting in Washington, representatives from existing Alzheimer associations in Australia, Canada and the UK joined the Alzheimer’s Association with observers from Belgium, France and Germany. He was pleased when Princess Yasmin Aga Khan accepted his offer to become the President of the organisation. This also gave ADI the opportunity to gain increased publicity, as Princess Yasmin spoke of her experience of caring for her mother, Rita Hayworth.

In the very beginning, Jerry remembered ADI operating as an extension of the Alzheimer’s Association. Nonetheless, there was a lot of strength and unity, and efforts continued to grow its membership from other countries. It would take some time before ADI was duly recognised by other organisations such as the World Health Organization. That was certainly the stage of maturity and brought with it benefits of making the cause known throughout the world. Jerry sees that ADI’s growth over the 25 year period from 4 to 71 members as testimony to the devoted efforts of inspired people around the world to help others. He hopes to attend the ADI International Conference in Toronto in 2011 and, even though he would have liked to attend the 25th anniversary celebrations, he is somewhat limited in his travel now due to being diagnosed with Parkinson’s disease a year ago.

Jerry reminisces about ADI’s International Conference, explaining that, ‘I myself have made many personal friends, like Nori Graham, Henry Brodaty and Lonnie Wollin through the years’. He feels that Orien Reid brought her own individual stamp to the organisation as a very articulate spokesperson. ‘I am proud of all these people that I have worked with and that ADI has grown far beyond my influence.’

His favourite anecdote from an ADI conference was in Brussels, Belgium. The meeting venue was a centuries old university chapel. There was the feeling of recognising centuries of interest in morality and progress. He remembers with fondness the wonderful social affairs connected with that meeting. One of the organisers personally took a couple of the Alzheimer’s Association Board members to the historic city of Bruges, which included a meeting and lunch with the mayor. It was a most ‘romantic luncheon spot’ for furthering understanding and friendship. As he mused about walking the streets of this hallowed ground and seeing the old canals as a hallmark, he wondered if ADI would stand the same test of time as that romantic city.

Jerry believes that the main challenge facing ADI in the future is finance. While he is pleased that ADI has been able to balance its budget, he feels the time is ripe to have ‘foundation money’ involving contribution from donors interested in extending long-term commitments. With a current low budget of 1 million US dollars a year, Jerry believes that doubling the budget is imperative. He is full of praise for the ADI staff and had special commendations for Marc Wortmann, the current Executive Director, who has been ‘a very good spokesman for the dementia movement’. Jerry also feels that it is special to have an international group making up ADI’s Medical and Scientific Advisory Panel, enabling people from countries with insufficient access to obtain valuable information.

Jerry’s hope for the next 25 years of ADI is that the organisation will achieve worldwide renown for its stature and efforts. To do this, he feels it is important for ADI to ‘Keep doing what they are doing and more of it. ADI is now an organisation that is set up to do even more global things in a systematic way. We just need to find a way of balancing the finances with the need.’
Princess Yasmin Aga Khan’s involvement with the Alzheimer’s Association in the USA started at a very young age, when her famous mother, actress Rita Hayworth, was diagnosed with Alzheimer’s disease in her 50s. Princess Yasmin was her mother’s primary caregiver for eight years. 

Even though the disease had first been described by Alois Alzheimer in 1906, there would be absolutely no help for carers and people with dementia for decades to come. In former times – and even so now in countries with lesser awareness – people with dementia were usually shut away in mental institutions. At the time that her mother was diagnosed in the early 1980s, antipsychotic drugs were prescribed for the behavioural changes. In her mother’s case, doctors prescribed a powerful drug, Haldol, but without clear instructions about dosage. Ultimately it was a process of trial and error for the young daughter and the nurse’s aide to work out which dose would be safe and effective for her.

The actual diagnosis took place in 1981 through CT scan and memory testing and the physicians did use the term Alzheimer’s disease – which itself was quite amazing for that time. Once the news was made public via the press, Jerome Stone approached Princess Yasmin and thus began her dedicated involvement in the cause of Alzheimer’s disease and related disorders: ‘It’s a lifelong journey for me,’ she shares.

Princess Yasmin noted the astounding growth from a nucleus of carers in 1984, increasing into an incredible organisation. ADI has reached out across the world with its dedicated and passionate efforts in increasing public awareness. ADI is dedicated to guiding and helping carers. To her ‘it’s a dream come true.’

Before the formation of ADI, there were carers across the globe who had no help or support, and nobody to advocate on their behalf. Princess Yasmin believes ADI is special and unique in embracing not only carers and people with dementia, but also medical professionals, researchers and social workers, bringing them together for a common dialogue – to improve the quality of life of carers and people with dementia.

She hopes that, over the next 25 years, there will be a greater global awareness of ADI with the organisation being able to assist all countries in need. The fact that dementia was discussed recently at the World Economic Forum in Davos, Switzerland, is another step towards that global awareness. There are, of course, many challenges facing ADI, of which to reach out to the governments of various nations and seek interventions in providing affordable and quality care and services is the most important. Central to this is education about diagnosis as well as post-diagnosis.

Health care across countries is disparate, so ADI tries to reach out to those countries that don’t have that ability. There is so much that needs to be done in providing continuing care: ‘We have really only just started, even though we are in our twenty-fifth year,’ she added.

An incredible quality of ADI’s is that, increasingly, people with dementia have come forward to deliver keynote speeches and share their experience at the annual international conferences.

Princess Yasmin has attended numerous ADI conferences through the years but declined to choose a favourite: ‘Every conference is special in its own way. For me it’s a wonderful feeling of excitement to meet with other carers and share their story.’ Her hope is that, in her lifetime, there will be a cure and the end of dementia. With new research showing that diabetes, hypertension and heart disease are risk factors for Alzheimer’s Disease, the next best thing to do is to take care of one’s mental and physical health through lifestyle changes such as diet and exercise. Thus prevention should be on the agenda as well.
When ADI members joined

1984: Australia, Canada, UK and USA
1986: Belgium, France, Ireland and Sweden
1987: Germany, Italy and New Zealand
1988: Mexico and Scotland
1989: Finland and Netherlands
1990: Argentina, South Africa and Switzerland
1991: Chile, Denmark and Puerto Rico
1992: Japan
1993: India, Israel and Spain
1994: Austria
1995: Romania, South Korea and Uruguay
1996: Brazil, Guatemala, Hong Kong and Venezuela
1997: Greece, Poland and Singapore
1998: Colombia
1999: Cuba, Czech Republic, Dominican Republic and Turkey
2001: Pakistan
2002: China, Cyprus, Peru, Philippines, Sri Lanka and Thailand
2003: Costa Rica, Egypt and Panama
2004: Nigeria, Trinidad & Tobago and Zimbabwe
2005: Lebanon and Taiwan
2006: Bulgaria, Croatia, El Salvador, Iran, Malta and Portugal
2007: Barbados, Honduras, Malaysia and Syria
2009: Bangladesh, Bermuda, Hungary, Indonesia and Jamaica
Alzheimer University

The Alzheimer University, a series of workshops to help new and potential members strengthen their associations, was piloted in London in April 1998 and the first programme welcomed sixteen participants from eight counties.

The aim of the Alzheimer University was to give participants the tools to identify their aims, involve people, provide information, raise money and awareness, and influence public policy. Following attendance at the Alzheimer University, participating associations were followed up on their progress after six and twelve months. This practice continues and a similar programme for developing associations is now run every year.

In April 2003, ADI brought together representatives from twelve countries for an Alzheimer University focussed on leadership. This was the first of the Alzheimer University programmes to be run for established member associations. ADI created a programme to equip participants with skills to get the best out of individuals and to enhance the learning ability of their organisations. A similar programme took place in 2004, attended by representatives from 15 Latin American Alzheimer associations. This event marked the first Alzheimer University programme to be run outside of London and in Spanish.

Representatives from twelve Alzheimer associations in the Asia Pacific region met in May 2005 in Singapore for an Alzheimer University programme on strategic advocacy and organisational growth. Participants at the event were invited to share their experiences in areas such as engaging politicians and meeting diverse needs. Alzheimer University programmes held during regional meetings have now become more frequent, with a demand from members for programmes that specifically suit the needs of Alzheimer associations within the region.

Following feedback from members, ADI ran an Alzheimer University programme centred on advocacy in Copenhagen, Denmark in 2006. The three-day event, which was attended by representatives from eighteen countries, saw participants sharing details of their country’s political situation and advocacy work while case studies of national advocacy campaigns were presented. The programme also featured a session on media training and participants were each asked to set future objectives as the event concluded. A second programme, Campaigning for Change, took place in July 2007 in Milwaukee, USA, with twenty-one participants.

The first Alzheimer University programme on fundraising was held in Taipei in 2008. Participants from 12 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.

In the first 25 years of ADI, representatives from 92 countries have participated in an Alzheimer University programme.

“If you have a chance to attend the Alzheimer University, don’t hesitate.”

BIRGITTA MARTENSSON, ASSOCIATION ALZHEIMER SUISSE, SWITZERLAND, 2002
Twinning Programme

The creation of ADI saw a number of Alzheimer associations across the world drawn together to share and exchange ideas. This practice has been a running theme throughout the past 25 years and it is common for two ADI member associations to discover similar interests or assist each other in their work. A number of unofficial partnerships began to develop as more and more Alzheimer associations were taken on as members of ADI.

In 2004, the possibility of developing a programme to support ADI members in these partnerships was discussed and the Twinning Programme was launched a year later at the ADI Council meeting in September 2005. The programme offers great potential for sharing knowledge and skills between Alzheimer associations. As part of the programme, a developing association is paired with a more developed one to strengthen both organisations by tackling shared issues together.

The first step of the Twinning Programme sees representatives from the developed association visiting their twin to establish their objectives and create an action plan for their three-year relationship. During the partnership the associations maintain regular contact and arrange visits in order to work together to achieve their objectives.

The first year of the programme saw the Greek Association of Alzheimer’s Disease and Related Disorders paired with the Alzheimer Society of Ireland, Alzheimer’s Pakistan and Alzheimer’s Western Australia united, and Alzheimer Society of Canada working in partnership with the Alzheimer’s Association of Trinidad and Tobago. A further twelve associations have benefited from the programme since its creation.

The programme has seen a number of successes so far. In 2007, Alzheimer’s Pakistan opened their first day care centre in collaboration with Alzheimer’s Australia WA. Alzheimer’s Society in the UK and ARDSI in India have worked closely together on a number of projects, one of which was the formation of Friends of ARDSI, a UK-based charity raising money on behalf of ARDSI. The Alzheimer Society of Canada and Alzheimer’s Association of Trinidad and Tobago devised a workshop in 2008 on building global solidarity, which took place during the first world Eldercare Mediation summit in Canada.

The Twinning Programme continues to appeal to Alzheimer associations across the world and it is hoped that many more associations will benefit from it in the future.

‘I am humbled to have worked for two weeks with people who are volunteers and work out of commitment from their hearts. I can only pay the highest level of tribute to them.’

JIM JACKSON, FORMER CEO OF ALZHEIMER SCOTLAND, OF THE LANKA ALZHEIMER’S FOUNDATION, 2008
At the inaugural meeting in 1984, initiated by Jerome Stone in Washington, DC, there was representation from the USA, Canada, UK and Australia and an observer from Belgium. It was there that we decided to form ADI.

I am privileged to have been a member of the ADI executive in various capacities since the beginning. When we had regional representation, I was vice-president for Oceania. I served as Chairman of the Medical and Scientific Advisory Committee (later Panel) from 1993 to 2001, and Vice Chairman of ADI, and then from 2002 to 2005, Chairman of ADI. In 2006 I joined former chairmen, Brian Moss and Nori Graham, as an Honorary Vice President, which is a life position.

ADI was small and informal when I first became involved. Jerry, who was the dominant force, created us and kept us on track. He invited Princess Yasmin Aga Khan to be our president, attended every meeting and was particularly concerned with finances. Brian Moss became our first Chairman in 1990 and was succeeded by Nori Graham, me, Orien Reid and Daisy Acosta. We had a part-time administrative officer, Rachel Billington, who was based at the Alzheimer’s Association office in the USA. This helped develop ADI and reach out to other non-Anglo countries. ADI really launched on to the world stage and became more professional once Nori became Chairman and we appointed a full-time CEO and moved the office to London.

The charity has become more competitive and more business-like; less like a family cottage industry. However, we still need to spend more time and money on marketing and developing a funding base.

ADI is the only worldwide organisation devoted to improving the quality of life of people with dementia and their families. It is not driven by scientific glory or personal aggrandisement. I believe that ADI is truly democratic. It embraces all people irrespective of nationality, religion or affluence and maintains its ethical values. I regard ADI as family and that is what makes it special for me. We support others and our members support ADI.

One of ADI’s challenges is how to penetrate and reach countries where there is little awareness of dementia and no Alzheimer association. ADI also needs to reach people in those countries with associations but where membership equates to a small percentage (usually less than 5% of the total number of people with dementia and their families). Over the next few years we need to secure funding for ADI, work to make dementia a global health priority with the World Health Organization, and look to the sustainability of our member organisations. Volunteer organisations go through cycles and we need to encourage our members to allow new faces and ideas in. This is essential for an organisation’s regeneration; it should be built into constitutions.

I remember being star struck in Helsinki and totally impressed in Stockholm by the Queen of Sweden. It is really encouraging when royalty or presidents really understand the issues and give their support to our cause. In 2003, Christine Bryden became the first person with dementia to join the ADI Board. This set an important example for national associations.

I have really enjoyed all of ADI’s conferences: join ADI and see the world! The best moments for me at all conferences are the Council meetings when each country introduces itself. I feel as if we are one and so proud of what everyone is doing. The events outside the formal conference are most memorable: renewing friendships each year; catching up; site visits; the dinners and dancing; the wonderful hospitality. More specifically though, I remember the 1988 Brisbane conference. It was the first Alzheimer’s conference in Australia and, at that time, the biggest that ADI had held. It coincided with the World Expo in Brisbane. I also remember the 1998 Cochin conference very fondly as this was the birth of the 10/66 Dementia Research Group.

I foresee a hundred and twenty member countries with flourishing organisations OR (very unlikely) the demise of all Alzheimer associations and ADI after the cure for Alzheimer’s disease and all dementias is found!
My association with ADI goes back to 1992. My first contact with the charity was through Rachel Billington, then Secretary General, who was based in Chicago, USA. That was the year the Alzheimer’s and Related Disorders Society of India (ARDSI) was formed. We gained provisional membership of ADI and then, in 1993, we travelled to the ADI conference in Toronto, Canada, where we were admitted as full members.

We were the first Afro-Asian Alzheimer association to become full members of ADI. I vividly remember attending the ADI Council meeting in Toronto where I was the only brown-skinned person. I mention this not because it was a problem, but to show how under-represented my part of the world was in ADI in those days.

Soon after the Council meeting Nori Graham, who was then Vice Chairman, walked up to me and extended an invitation to visit her in London on my way home. I still remember the warmth and fellowship I experienced during these visits. I became a member of the Executive Committee in 1996, took the role of Vice Chairman from 1998 to 2001 and continued to serve in various capacities within ADI until 2009.

Over the last 16 years I have seen ADI going from strength to strength. Initially the majority of ADI members were from developed nations, but gradually this has changed. With 71 members, ADI has now become truly international. Through its international conferences, meaningful workshops and advocacy role, ADI has started to address the real challenges of emerging member organisations. ADI – its staff and members – now show a greater understanding of the problems faced by Alzheimer associations in the developing world.

I think ADI is special because it works like a global family. It’s the mouthpiece of the global dementia movement.

Not surprisingly, the ADI conference I remember most fondly was the 14th ADI conference in Cochin, India. I was the organising secretary. It was the first ADI conference in Asia and one of the few ADI conferences held outside a national capital. The event was attended by delegates from more than 50 countries and was organised with a real blend of local tradition and culture. It was at this conference that the 10/66 Dementia Research Group was formed and where the first Asia Pacific regional meeting was held.

There are a number of countries in Asia – and more in the Middle East and Africa – where ADI still has little representation. Extending ADI into these under-represented areas will be a big challenge. Another issue is how to make ADI financially stable and less reliant on pharmaceutical industry support.

In the future, I would like to see ADI emerge as an even stronger international organisation. It is the platform for all those working for and with people with dementia and their families around the world so it should be able to influence world governments to make dementia a health priority. It needs to help each member country develop its own national dementia strategy and assist in putting this into practice.

I would like to see a world where dementia is treated on a par with other chronic diseases like cancer or stroke, where people speak openly about the condition and where all those affected receive a timely diagnosis and appropriate treatment and care.
25 years of conferences

ADI annual International Conference

From its inception in Brussels, Belgium, in 1985, ADI’s annual International Conference has offered people around the world with a common interest in dementia the opportunity to meet and exchange ideas and information. ADI members have also been offered the opportunity to publicise their own work through exhibition stands at the conference.

There is always a medical and scientific component that provides an update on dementia research. Sessions for and by professional carers and representatives from related fields are also included.

In 1989, at ADI’s 5th International Conference in Ireland, Dr Rory O’Hanlon, Minister of Health for the country, addressed conference delegates, informing them of the proposed steps the Irish government would take to improve the lives of people with dementia in the country. Fifty speakers were present at the conference, talking on such issues as technical research and medical aspects of dementia and problems faced by carers. Dr O’Hanlon went on to host a reception for conference delegates at the Royal Hospital Kilmainham. The presence of a member of national government has been a key feature at a number of ADI’s conferences.

The conference in Ireland attracted 250 people representing 22 countries. Just two years later, around 400 delegates registered for the conference held in Amsterdam, the Netherlands. The same year a Conference Committee was formed to review applications from members wishing to host future ADI conferences.

ADI’s 9th International Conference in 1993, held in Toronto, Canada, attracted over 700 delegates from more than 30 countries. In 1994, ADI’s International Conference, A Decade of Change – Looking back ... Looking forward, hosted by Alzheimer Scotland – Action on Dementia in Edinburgh, saw ADI organise its first consensus conference, Predictive genetic testing, where delegates were given the opportunity to question a panel of experts in the dementia field. The following year a second consensus conference, Screening for dementia in general practice, took place.

In 1997, ADI ran a series of workshops aimed specifically at member associations, during the 13th International Conference. These workshops provided excellent opportunities for associations to come together and share their experiences. ADI has continued to arrange workshops encompassing a variety of subjects for a range of different groups, with particular focus on the work of Alzheimer associations.

ADI’s highest-attended conference to date took place in 2004 in Kyoto, Japan, with over 4,000 delegates. The event generated 73 million media impressions throughout the country as Japanese people with dementia spoke publicly for the first time about their experiences.

‘A deep and lasting personal impression of the conference was the atmosphere of friendship and encouragement in which I was able to work together with so many excellent colleagues.’

PROF ALEXANDER KURZ, GERMANY

1988: Brisbane, Australia
In 2006, it was decided that the International Conference should be moved from later to earlier in the year in order to avoid conflicting with World Alzheimer's Day in September. This was implemented in March 2009 with the 24th conference held in Singapore after there had been no conference in 2008.

People from all over the world are invited to give presentations and attend the conference. It has become a significant international event that helps raise awareness about Alzheimer’s disease in the host country and sends a message to the wider world about the growing unified effort that stands by people with dementia and their families.

An important outcome of ADI conferences is their impact subsequently. It is as if the light is switched on by the arrival of hundreds of international visitors and the attention of the media. India is an excellent example. Following the 1998 conference, the Alzheimer’s and Related Disorders Society of India became stronger and saw a higher level of awareness within the country.
Regional meetings and conferences

Meetings and conferences between Alzheimer associations in the same world region have been of great benefit to those involved. Sometimes facilitated by similarities in language or culture, these meetings have provided an opportunity to establish and strengthen networks and channels of communication. ADI members recognised that, within a world region, many of the problems and challenges facing Alzheimer associations were very similar: stretched resources; difficulties in getting government recognition of their work; or the challenge of reaching marginalised populations within the country. Regional meetings have given ADI member associations the chance to talk about their activities and services and learn from, and be inspired by, the work of their neighbours.

In 1998, ADI’s Latin American member associations hosted their first regional conference in Caracas, Venezuela. The objective of the conference was to exchange information and skills between the different Alzheimer associations in the region, with a particular focus on the prevalence of dementia, education of professionals, support groups, fundraising and carer support. In 2008, members in the Latin American region decided to launch a formal Alzheimer Iberoamerica regional group.

The first Asia Pacific regional conference and meeting also took place in 1998 and was followed by a second held in Singapore in September 1999. ADI member associations within the Asia Pacific regional group have continued to develop a strong working relationship despite the wide range of cultures contained within the region. On World Alzheimer’s Day 2006, the group released a report entitled Dementia in the Asia Pacific Region: The Epidemic is Here, which highlighted the potential impact dementia could have on health systems and the quality of life of people with dementia in the region.

The regional meetings, often held during the conferences, have also provided regional groups with the opportunity to discuss where improvements could be made to strengthen the group and how ADI could work with member associations to implement the necessary changes.

“Our regional meeting in Monterrey showed us that we can work together! We exchanged ideas and took steps to help each other. The determination to keep on working against adversity is really an inspiration.”

DAISY ACOSTA, ASOCIACION DOMINICANA DE ALZHEIMER, 2005
In 1982, I did a study tour around five countries looking at residential care for people with severe dementia. I met with Jerry Stone who had been one of the founders of the American association and we talked at length. When I returned home I got involved in setting up a similar body in the state of Victoria where I reside and then a national body. I had written to Jerry Stone and he wrote back saying that they were organising a meeting in Washington, DC, with a view to forming an international association. I think we had about six representatives at that meeting from Australia. At the meeting, they agreed to go ahead and form an international body and ADI was born.

The Americans and Canadians collaborated to write up the bylaws and the first draft was presented to a meeting following year in New York. At the first meeting in Washington, because I was the convener and had become the Chairman of Alzheimer’s Disease Australia, I was appointed as a Vice President representing the Pacific region.

In 1987, we had another meeting in Chicago. Princess Yasmin Aga Khan never chaired a meeting and we didn’t have a Chairman as such. As I was a Vice President, they asked me to chair the meeting. I must have done something right because I chaired subsequent meetings and was formally appointed Chairman when we adopted a new set of bylaws in 1990. I was Chairman until 1996.

When I first became involved, ADI was very embryonic. It was very interesting, very challenging. The American association offered to facilitate the workings of ADI from their office, but I always felt that it didn’t get enough attention. We would resolve things at meetings and, twelve months later, not much action had followed. Later the Americans offered to pay for a Secretary General and nominated Rachel Billington who had been on their staff and was their Chief Executive at one stage. That was a help because at least we had someone who we knew could get on and do things. At the meeting in Edinburgh in 1994 we accepted an offer of the UK’s Alzheimer’s Disease Society to act as the secretariat and employ a Secretary General based in London. I think some of the Americans weren’t too happy about that because they could see themselves losing control, but it was the best thing we did because we were able to move on and get things organised.

There’s been enormous change within ADI since I became involved, particularly the growth in membership. At the beginning we had four members and, when I retired as Chairman in 1996, we had forty and now there are seventy-one. There have also been a number of changes to bylaws. We had several changes over the years, but bylaws should always be under review as things develop.

ADI is special because it is an international body helping people from all different countries develop services. It is facilitating and one of the wonderful things about it is that one country has been there and done that and learned a process and can share and tutor another country. You don’t see that happening in other fields. The international society is sharing and caring for its members.

I think funding is the main challenge ADI faces, particularly maintaining a commitment from member countries. Some countries might get a little frustrated, ‘we work hard to raise our own funds, why should we be contributing to ADI’, but I think if you want ADI to have that special purpose it has to have adequate funding to do the job.

Unfortunately, because nobody has been able to put their finger on the cause there is going to be a huge growth in the number of people with dementia. I hope that somebody discovers how to prevent it and in the next 25 years we may come to a point where ADI doesn’t need to exist. I doubt that will happen, but if it doesn’t happen then I’d hope that ADI can continue to grow and attract the funding that’s necessary to finance the work that it does without having to beg and scrape money from different sources.
ADI's Public Relations Committee, formed in 1991, presented a proposal on the potential and feasibility of introducing a World Alzheimer's Day in cooperation with the World Health Organization.

On 21 September 1994, ADI marked the first World Alzheimer's Day™ and raised worldwide awareness about dementia through the promotional efforts of member associations. These efforts were supported by the contribution of Public Service Announcements and an international video news release. At the launch of World Alzheimer's Day, ADI's President, Princess Yasmin Aga Khan, was joined by Dr José Manoel Bertolote from the World Health Organization in witnessing ADI Chairman Brian Moss sign the declaration challenging everyone to make themselves more aware of dementia.

In 1997, ADI made the decision to launch a global theme for World Alzheimer's Day to unite member associations across the world. The theme for 1997 was *A race against time* and members were encouraged to use this theme in their activities. A charter, highlighting the ever-increasing number of people with dementia worldwide, was also developed and translated into several languages. Nancy Reagan, wife of President Ronald Reagan, and Pope Giovanni Paolo II sent messages in support of the charter and copies of a special bulletin were disseminated worldwide.

To mark 20 years of the global dementia movement, ADI hosted an international reception at the House of Commons in London, UK on World Alzheimer’s Day 2004. People with dementia, carers, ambassadors and high commissioners from ADI's member countries, medical professionals and representatives from Alzheimer associations attended the event where they were encouraged to sign ADI's charter of principles for the care of people with dementia and their families.

Each year, ADI produces promotional materials, which are distributed widely to Alzheimer associations worldwide, providing the general public with important information and advice on how to seek help.

The Alzheimer's Association in the USA developed Memory Walk™ events, and helped ADI to take the concept and spread it to associations around the world. Many of ADI's member associations now organise a Memory Walk in their country, city or town. Members of the public are invited to take part in one of the walks, which work to raise awareness of dementia and the work of the national association.

In 2003, World Alzheimer's Day was observed in 57 countries around the world, which marked the largest participation until then.

In 2009, 63 Alzheimer associations worldwide organised World Alzheimer's Day activities.
An informal gathering of representatives with a wish to change public policy to benefit people with dementia emerged in 1990 and met twice during ADI’s International Conference in Mexico. The Ad Hoc Public Policy Committee, consisting of representatives from Australia, Canada, France and the USA, discussed the problems and opportunities related to communicating effectively with governments about improvements in the levels of dementia care services. The Committee set a number of action points to be used in preparing for ADI’s work in this area, such as developing a glossary of terms used in the field of dementia care and asking all members for details of their public policy programmes or goals.

The Public Policy Committee was formalised in 1991 and the ADI Bylaws stated that the objectives of the Committee were to ‘identify, develop, and analyse information about existing national programmes of support designed to meet the needs of patients and families and make recommendations to the Council for improved public policy needed for patients and families affected by Alzheimer’s disease and related disorders.’

The Public Policy Committee conducted a survey of ADI members, collecting information on the prevalence of dementia and programmes they offered. The results of this survey were presented during ADI’s annual Council meeting in 1993. The Committee were also offered space in ADI’s newsletter, Global Perspective, to pass on useful advice to ADI’s members about effecting change.

ADI produced a charter of principles for the care of people with dementia and their carers in 1999, with the assistance of a working group made up of representatives from member associations. The charter outlined eight fundamental principles and acted as a guidance document for members to use in their campaigning work.

On World Alzheimer’s Day 2004, ADI sent letters to 192 health ministers around the world, urging them to make dementia a higher healthcare priority. This activity has been repeated a number of times since and has proven to be effective in a number of countries to support national Alzheimer association’s advocacy work.

To mark 100 years since the first diagnosis of Alzheimer’s disease, ADI launched a series of awareness raising activities in 2006. ADI produced and widely distributed postcards urging governments to put dementia on their agenda and make it a national health priority. British pop star Sir Cliff Richard agreed to be the centenary patron and two competitions were run. Through both the photography competition and journalist award, ADI aimed to encourage the media to portray a more positive and accurate image of dementia. The centenary celebration also saw a team of volunteers from across the world reaching the summit of Mount Kilimanjaro in Tanzania in the Ascent for Alzheimer’s.

During 2007, ADI supported the work of Youth For Dementia, a venture run by young people in London, UK. The aim of Youth For Dementia was to raise money and awareness of dementia.

Ways of effectively influencing public policy are regularly discussed by ADI’s Advocacy Working Group. The group came together to develop the Global Alzheimer’s Disease Charter in 2007 and has continued to work on various projects to support ADI’s advocacy activities. The Global Alzheimer’s Disease Charter was released on World Alzheimer’s Day 2008. This document sent out a clear message

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such as the regional meetings, to make the case for dementia to be a global health priority. ADI representatives were present at five of the six WHO regional meetings in 2009.

ADI continues to produce new publications based on research and encourages member associations to make use of these in their advocacy work. ADI’s Advocacy Working Group continue to work together on a regular basis, looking at ways in which to approach the World Health Organization and support members’ advocacy work worldwide.

to governments around the world detailing the urgent action needed to help the millions of people with dementia, their carers and families around the world. Promotion of the Charter aimed to increase respect for people with dementia as members of the community and argued for appropriate access to health and social care. The Charter was made available in 17 languages. A supporting website, featuring a short accompanying film, A Cup of Tea, was developed for people around the world to endorse the Charter by signing a petition and leaving a message of support. By April 2010, over 50,000 people had signed the Charter.

Although in official relations with the World Health Organization (WHO) since 1996, ADI felt that more priority should be given to dementia within the WHO in order to encourage governments across the world to improve care and services in their countries. ADI developed a strategy targeted at the WHO in 2007 and since then has been increasingly active in attending WHO events, such as the regional meetings, to make the case for dementia to be a global health priority. ADI representatives were present at five of the six WHO regional meetings in 2009.

The World Team, who climbed Mount Kilimanjaro to mark 100 years since the first diagnosis of Alzheimer’s disease

The World Team, who climbed Mount Kilimanjaro to mark 100 years since the first diagnosis of Alzheimer’s disease.
In 1987, I was Chairman of the Alzheimer’s Society (UK). Brian Moss, then the Chairman of ADI, approached me and asked if I would be interested in joining the Board. I have always been interested in international activity and was delighted to accept. Subsequently, in 1996, I was elected Chairman of ADI and went on to serve two terms in the Chair until 2002 when I was made an Honorary Vice President. I remain involved with the work of the organisation and attend all the international conferences. I am often invited to attend the committee meetings. I continue to participate actively at the conferences, especially in Quality of Life workshops that I run jointly with Barry Gurland and Sube Banerjee.

In 1987, ADI was a much smaller organisation with 11 countries in membership. ADI was then based in the office of the USA’s Alzheimer’s Association and was run by one part time staff member. Its aims at that time were to increase the world vision of dementia, to bring together national associations, who were mainly in the developed world, and to hold an annual conference.

Since I became Chairman in 1996 there have been several significant changes. ADI now focuses on helping countries to form national associations and to provide subsequent support for them. Its influence has been greatly extended to cover many less developed countries; most new members are from the developing world.

The involvement of people with dementia in ADI’s work is another significant change. ADI currently has a person with dementia on its Board and people with dementia are encouraged to attend the annual conferences and to contribute. ADI also encourages its national members to involve people with dementia in their work.

The 10/66 Dementia Research Group, started in 1998 by Prof Martin Prince and his team, has been ADI’s special area of research and the one to which it has given some financial assistance. It covers 20 countries, all in the developing world, and in each of which there are active collaborators. This research has focussed both on the prevalence of dementia and on the different caring arrangements in the countries involved. The results of this research have armed national associations with the facts and figures they need to influence public policy.

ADI is special for a number of reasons. It runs a unique series of Alzheimer University courses, training individuals engaged with dementia in a country how to set up and run an Association. ADI is unique in its increasing emphasis on the developing world. It has a Board with wide geographical representation that includes people with dementia: something that would have been unthinkable twenty years ago.

The ADI annual International Conference is also special in the way it attracts participants from all relevant disciplines. Carers are always well represented, as are people with dementia, policy makers and researchers. ADI has a small highly focused office staff, well-defined aims and the exercise of tight financial controls.

The first time I spoke at an ADI event was a plenary session at the opening of the conference in Ireland in 1989. I was speaking as Chairman of the Alzheimer’s Society (UK) but was a generally unknown face in ADI circles at the time. I had prepared my talk on catalogue cards; there was no PowerPoint in those days. To my horror, I realised as I got to the airport that I had left the cards in my bedroom where I had been practising the night before. I wasn’t sufficiently well practiced to do without them so, in a panic, I called my son who at the time happened to be doing a temporary job in an office. Thankfully, he was able to send through my talk to Ireland in one long scroll of faxed paper. As I arrived at the conference venue I was greeted by the then Chairman of the Ireland association, Michael Coote, with the news that a ‘special message’ had arrived for me by fax that morning. Needless to say, I did the talk, and the incident gave me an amusing anecdote with which to begin!

I also have very fond memories of the Indian conference: the colour, the smells, the food, dancing, the elephants and the clothes. It was wonderful and the enthusiasm was almost tangible.

I hope, in the future, that governments throughout the world will recognise dementia and provide appropriate culture-sensitive services with easy access to simple information on dementia and its management. Education and training is a key requirement. Similarly, I hope that the WHO will recognise that the situation of older people is critical to the health of the whole population and address the dementia issue more directly than is currently the case. I hope that, in time, we will have a world where we know a lot more about how to prevent dementia. We also need to have more knowledge about the way care arrangements affect the quality of life of both carers and people with dementia.
Yoshio Miyake

‘ADI meetings have an impressive array of subjects.’

Japan had already started its fledgling Alzheimer association five years before the invitation to attend the initial meeting to set up ADI in 1984 arrived at their office. Initially called Association of Families Caring for Demented Elderly the name was later changed to Alzheimer’s Association Japan (AAJ).

Dr Yoshio Miyake first participated in an ADI meeting in 1990 at the conference in Mexico, following which he attended these meetings every year. Though a geriatrician, his primary concern was to support family members. Serving various roles through the years, including Vice President of AAJ and committee member of ADI, he acknowledged that the biggest event ever for Japan was hosting the historic ADI conference in 2004.

Yoshio explained that ADI has been a tremendous benefit to AAJ. At his first ADI conference, he was surprised and impressed that researchers, physicians, nurses, and family members came together as a unified group to discuss various issues related to caring. Through presentations and information sharing, the delegates also spend an enjoyable time together in a rather familial atmosphere. He was surprised at the remarkable and unique feeling of camaraderie and fellow feeling of ADI conferences and strongly felt that the Japanese Alzheimer association would most certainly benefit from its participation. AAJ became a member of ADI in 1992 and hosted the ADI conference in 2004. Overcoming various difficulties and linguistic barriers, it was the first time that a Japanese person with dementia had shared the story of their life with the disease in public. It was a remarkable breakthrough as dementia had been looked upon as taboo in Japan.

Yoshio considers ADI meetings to have an impressive array of subjects related to dementia, such as human rights, spirituality, legal and economic issues as well as fundraising. Developed associations with more experience and a longer history of involvement with ADI share information and thus it was a wonderful learning experience for AAJ. The most memorable event, to Yoshio’s mind, was at the 2001 ADI conference in New Zealand when Christine Bryden came forward as the first person with dementia to speak during a keynote session, giving a candid and inspiring account of living with dementia. Her passionate speech received a standing ovation from a packed audience.

Statistics indicate that dementia is going to become a major problem through the coming decades. Through its dynamic growth and indomitable efforts, ADI is uniquely positioned to be a leading organisation to support people with dementia and this carer-centred movement. ‘I would like ADI to preserve and continue these salient efforts,’ Yoshio states.

He feels the main challenge facing ADI is the growth in sheer numbers of people with dementia in developing countries such as India and China. The difficulty in this is to find ways of supporting these countries, while trying to understand their cultural differences. And while there has also been a great deal of progress in clinical research toward better treatments, it is important that the results of such research should benefit the family caregivers. Yoshio hopes that ADI, in collaboration with the World Health Organization, can explore ways to advocate for lower costs of treatment and care.

Sadly, Yoshio’s wife started showing symptoms of dementia about two years ago after succumbing to encephalitis, and now requires full time care. He shares that he is keenly conscious of the strain and difficulties of each day that he experiences as a primary carer: ‘On a personal level, I have benefited greatly from my association with AAJ and ADI. In my years of communicating with other carers in Japan I have learnt in countless ways from their experiences about innovative and ingenious ways of caring. AAJ has also continued to pursue the issue of social support toward family members caring for people with dementia, with a major outcome of the introduction of the Long Term Care Insurance in Japan. Thanks to that, my wife and I are able to carry on our existence. So I am very grateful for all of this.’
In 1998, less than 10% of all population-based research into dementia had been directed towards the 66% of people with dementia who lived in developing countries. These figures acted as inspiration for the naming of the 10/66 Dementia Research Group. The group was formed of a collection of researchers who linked together to try to redress this imbalance, encouraging active collaboration between research groups in different developing countries and between developed and developing countries.

The group, which is affiliated to ADI, is co-ordinated through Prof Martin Prince of the Institute of Psychiatry at King's College London, UK. The main aims of the group are to quantify the prevalence and incidence of dementia in less-studied countries, learn about the causes of dementia, describe care arrangements for people with dementia, quantify the impact of providing care on caregivers and encourage the development of appropriate support services and evaluate their effectiveness.

The first meeting of the 10/66 Dementia Research Group took place during ADI's annual International Conference in India in 1998. During this meeting, it was decided that work should begin on two small-scale, achievable pilot study designs. Collaborative research project proposals were developed for India and Sri Lanka, Africa, Latin America and the Caribbean, and China and South East Asia.

By 2000, around 90 researchers in 28 centres worldwide had been trained in dementia diagnosis and clinical practice with carer assessment measures being translated into five languages. The 10/66 Dementia Research Group pilot studies were a huge collaborative effort involving over 700 people with dementia.

In 2002, funding for five population-based studies was received from a number of sources with the studies taking place in Brazil, China, Cuba, the Dominican Republic and India. During this year the 10/66 Dementia Research Group also ran two workshops based on their work during ADI's annual International Conference in Barcelona, Spain.

In 2003, the group had their first article published in The Lancet medical journal. The article described the study to develop culturally and educationally sensitive instruments for diagnosing dementia. In 2005, the group, spearheaded by Cleusa Ferri, reported, once again in The Lancet, on the global prevalence of dementia. This was important for ADI and its members in lobbying the WHO and national governments.

‘10/66’s findings provide evidence to help us influence the state’s health policy.’

AMIT DIAS, 10/66 RESEARCHER IN GOA, INDIA, 2002

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The 10/66 Dementia Research Group was awarded a grant from the Wellcome Trust in 2006 to further their population-based studies in Latin America and China. The study entitled *Cardiovascular risk, nutrition and dementia incidence in mixed populations undergoing rapid health transition in Latin America and China* relied upon the participation of the 10/66 centres in Argentina, China, Cuba, the Dominican Republic, Mexico, Peru and Venezuela.

By 2008, the group’s studies on intervention had taken place in China, the Dominican Republic, India, Peru and Russia and were believed to be the first to directly assess the quality of life of people with dementia. As a result of these findings the 10/66 Group produced a *Helping Carers to Care* intervention package, which could be delivered by community health workers in low-income countries to help people with dementia and their families. This intervention consists of the family receiving five short, weekly visits from a health care worker, during which they receive basic education about dementia and specific training on managing problem behaviour.

The findings of the 10/66 Dementia Research Group are made available in an easy to understand and accessible format through ADI’s annual International Conferences, the 10/66 Dementia Research Group website, newsletters, policy briefings and press releases. This acts as a research network for ADI members to use to raise public awareness and promote the development of policies and services to support people with dementia in developing countries.

In 1993, ADI issued the results of the first dementia prevalence survey of its member countries, giving an early indication of the situation faced by the global dementia movement.

In 2008, ADI announced that they would be running the first award for psychosocial interventions alongside Fondation Médéric Alzheimer (FMA), a non-profit organisation based in France, dedicated to helping people with Alzheimer’s disease and their carers. The aim of the award was to promote psychosocial research and the application of best practice. The winner of the award was announced during the ADI conference in 2009. Mary Mittelman was granted the award for her project *Translating the NYU Caregiver Intervention from Research to Practice Settings*. An additional award for the most promising intervention was presented to Danny George for his *Intergenerational Volunteering* study. The second award was announced later in 2009.

On World Alzheimer’s Day 2009, ADI released the first of two reports, revealing the most accurate global figures to date of the number of people with dementia worldwide. The *World Alzheimer Report 2009* also looked at levels of mortality, disability, carer strain and dependency across the world, concluding by offering recommendations for government action in an attempt to improve the services available for people with dementia and their carers.

In 2010, ADI released the second report, highlighting the global cost of dementia. ADI and its member associations in all parts of the world will use the two reports to advocate for better services for people with dementia on a national and international level.

> ‘It goes without saying that winning the award was one of the most humbling moments of my life, and I appreciate ADI and FMA seeing fit to recognise and support psychosocial research that’s being done around the world.’

*DANNY GEORGE, USA, 2009*
I have been involved with ADI since 1994 when we founded Asociacion Dominicana de Alzheimer in the Dominican Republic. In 1998, I went to London for the first Alzheimer University where I got to know ADI better. I remember Elizabeth Rimmer, with all her characteristic enthusiasm, giving us a ‘tour’ of the aims, mission and vision of ADI; showing us the written materials that it had for members and I was captivated by the work ADI was doing for its member countries. I could immediately see ADI’s huge potential to improve the life of people with dementia and their families and make a real difference on a worldwide scale. I was part of the Nominations Committee for several years before gaining a position on the Elected Board. I was eventually voted Vice Chairman and have since become ADI’s Chairman. I never thought I could undertake such a position – coming from such a small, under-developed country and with English not being my mother tongue. However, with the support of my association in the Dominican Republic and the confidence and support of Orien Reid, my good teacher, here I am today, the Chairman of ADI, a position I never dreamed of holding and which I am extremely honoured to have.

I remember receiving the call from the Executive Director to let me know about my being voted in as Chairman. At the time, my house was flooded after being hit by hurricane George. My kids took a picture of me whilst I was taking the call, making the joke that this is what you get for electing a Chairman from the developing world!

ADI was a smaller organisation when I first became involved but with the same intrinsic qualities that it has today. It shared an office with the Alzheimer’s Society and had a great staff dedicated to the cause. We have been very lucky with this! When I first became involved, Nori was Chairman and Elizabeth was Executive Director. The cohesion between them and their great leadership was the key that led ADI to where it stands today.

ADI is unique in many aspects. The threat of dementia has huge implications for humanity and we are an institution that can make a difference for the millions of affected people and families worldwide. ADI is also unique in its number of members. This number gives us tremendous power to fight for the people we stand for. It is special in that all of us work without waiting for a salary; all we want is to make life better for people with dementia and their families. We make an effort to understand the life circumstances of people with dementia in different cultures and socioeconomic backgrounds and adapt our recommendations based on the knowledge we have. We have put the developing world on the dementia research map, through our 10/66 Dementia Research Group. ADI serves the world through a very small office with a staff of only four people. That is truly amazing! ADI is special in many ways, but most importantly in the love that it shows and delivers through its work.

My favourite conference has to be, of course, the 2003 ADI conference in the Dominican Republic! It was such a huge challenge that I never thought would be possible. However, looking back at the time, I have nothing but the warm feeling of a job well done!

This may sound crazy, but my real hope is that in 25 years from now, ADI is nothing but history. History of a worldwide movement that accomplished what it worked for and is history because dementia is also history.
In 1989, ADI facilitated a courier pack to be sent to all members to include examples of publications from other member associations. The first pack included copies of materials from the Alzheimer associations in Canada, the UK, France, Scotland and the USA. The pack contained books, booklets, pamphlets and newsletters with the combined aim of helping member associations improve their own publications and offering an overview of the work taking place in various countries across the world.

Offering member associations the opportunity to share information and knowledge has been a key feature of ADI’s work since the beginning. ADI continues to seek new methods of effectively gathering and exchanging information relating to specific areas.

An education initiative was started during ADI’s 6th annual International Conference in Mexico, with the inclusion of associations in Argentina, Australia, Canada, Mexico, the Netherlands, New Zealand, Scotland and the USA. The Trainers Network saw ADI members exchanging information on similar projects and reports on the effectiveness of the initiatives. The aim of the network was to highlight issues in training policy or resources faced by ADI members and to help members avoid duplicating the efforts of others by sharing with them beneficial materials or information.

In 1991, ADI formed a Patient and Family Services Committee whose task it was to promote the exchange of information and documentation on the services available for people with dementia and their families.

The first project of the group was a Good Practices Data Bank, a library featuring a range of information including running a self-help group, successful day care programmes and facilities, and holidays and residential or nursing care. These materials, which included printed booklets, leaflets, and audio or video guides, were stored in the Benjamin B Green-Field Alzheimer’s Library in Chicago, USA, a space dedicated to information about dementia.

As ADI membership grew it became important to produce publications sharing the wealth of knowledge available from ADI’s member associations and contacts. In 1990, ADI began producing a regular newsletter highlighting the work of ADI and its members. Booklets and factsheets were also produced and these publications were displayed and shared at a number of dementia-related conferences across the world each year, offering internationally relevant information to ADI member associations and others within and interested in the dementia field.

ADI’s annual International Conference continues to be a valuable opportunity for member associations to share their knowledge with others and hear of successful projects in other countries. The Alzheimer University and Twinning Programme also act as bridges between associations looking to exchange ideas and information.

‘It was heartening that the tips and advice that we gave were taken on board, with a real commitment to implement change.’

ANDREW OLDHAM, ALZHEIMER’S SOCIETY, UK, 2006
ADI's newsletter, *Global Perspective*, was first published in April 1990 and was initially produced twice a year. Each issue featured up-to-date news and information on improvements in care and treatment of people with dementia. Early versions of the publication also featured a focus on a specific topic, such as patient and family services, advocacy or a member association. By the end of 1990, the newsletter was already being distributed to 2,000 readers, a figure which had reached 5,000 by 1994.

The newsletter has been an outlet for members wishing to share new programmes or activities with the dementia community. The *Members’ Forum*, a regular feature, includes news on the activities of member associations, such as advocacy updates and fundraising ideas.

Since its inception the newsletter had frequently featured a research update offering the latest news on developments in the dementia field and, from 1995, this became a regular feature of the publication. Members of ADI’s Medical and Scientific Advisory Panel regularly contribute accessible articles about current research news.

*From the heart*, a page dedicated to the stories of those who care for a person with dementia, became a regular feature of *Global Perspective* in 1995. The caring experience differs greatly across the world and it is vital to ADI that this, and all sections of the newsletter, reflects that.

In 1996, with more effective communication methods, growing ADI membership and further developments in the dementia field, production of *Global Perspective* increased to three issues per year. This was maintained until 2009 when a decision was made to increase this to four issues annually.

Due to popular demand a new feature, *Living with dementia*, was introduced in 2003. This feature was originally created to provide news of achievements of people with dementia worldwide and has gone on to act as a sounding board for people with dementia who wish to share their story or put their thoughts or ideas across.

In 2008, the ADI Supporters programme was launched, giving individuals the opportunity to subscribe to *Global Perspective* and receive other news updates by email or post. The dual purpose of this programme is to raise funds for ADI while offering individuals not necessarily associated with their national Alzheimer association the opportunity to find out more about the work of ADI, member associations, the work of the 10/66 Dementia Research Group and other research developments.

*Global Perspective* continues to report on not only news from member associations, but also the work of ADI. The newsletter provides details of upcoming events and activities and reports on all areas of ADI’s work.
Initial steps were taken to form ADI’s Medical and Scientific Advisory Board in September 1989 at the ADI Council meeting in Dublin, Ireland. Nominations for positions on the Board came from scientists based in fourteen countries. Franz Baro, a director at the World Health Organization in Belgium at the time and founder of the Alzheimer’s Society in Belgium, was elected as Chair of the Board during this meeting. At that time it was decided that the Medical and Scientific Advisory Board would be made up of a Steering Committee and Executive Committee, although this practice was later abandoned.

During ADI’s 6th annual International Conference in September 1990, the Medical and Scientific Advisory Board drew up an action plan, which required the group’s Steering Committee to develop a paper with issues to be discussed by the group’s Executive Committee. This was followed by a meeting of the whole Medical and Scientific Advisory Board during ADI’s 7th International Conference in Amsterdam, the Netherlands.

In 1993, just four years after the formation of what came to be known as the Medical and Scientific Advisory Panel (MSAP), and with the election of Henry Brodaty as Chairman of the group, the Panel had recruited over 100 medical professionals and researchers from across the world. Steve DeKosky from the USA chaired the MSAP from 2002 to 2005 and Bengt Winblad from Sweden has been Chairman since 2005.

The MSAP conducted and published two surveys of use and costs of anti-dementia drugs around the world. Concerned about sensational and irresponsible media reporting, the MSAP produced a guide for the media on interpreting research findings and on responsible journalism.

In 2009, the MSAP formed an ADI Prevention Working Group to discuss research, developments and opportunities relating to preventing dementia. The group, chaired by Barry Reisberg from the USA, now meet twice a year and initial discussions and ideas are being formulated.

The MSAP often meet each year during ADI’s annual International Conference or the International Conference on Alzheimer’s Disease (ICAD), the annual conference of the Alzheimer’s Association, USA. Discussion during these meetings includes a report from ADI on new publications or relevant activities as well as the latest findings of the 10/66 Dementia Research Group. These meetings also offer an opportunity to discuss new developments in treatment or research.

‘A number of MSAP members have visited countries where they have been able to encourage the development of Alzheimer’s associations.’
HENRY BRODATY, FORMER MSAP CHAIRMAN, AUSTRALIA, 1998
In August 1997, ADI began planning for the development of a website offering information on dementia and links to the websites of its member associations and other sources of information. ADI also offered bursaries to members without Internet access in order to assist them in acquiring the necessary technology to communicate online.

In 2000, ADI launched Help for caregivers on the website as a sub-site dedicated to those who care for people with dementia, with information and advice about the best ways of caring and contact information for national Alzheimer associations.

In 2001, the ADI website was rewritten and restructured to provide visitors with easier access to the information they required. A new section about Alzheimer’s disease and other dementias was added and included Frequently Asked Questions, the treatment and causes of dementia as well as help for carers. A section for people with dementia was also developed, offering information for those who had just received a diagnosis. Links to information in various languages were also added as well as a page on the global impact of dementia. ADI’s current campaigns, World Alzheimer’s Day and the annual International Conference were also included and ADI’s publications were made available, allowing people to view and print them. Visitors to the site were also given the opportunity to make a donation online.

Sections aimed at the media and researchers were later developed and, in 2008, a separate website was created for the 10/66 Dementia Research Group.

ADI’s website continues to feature a range of information for people who have been diagnosed with dementia and their carers.

‘Your list of international Alzheimer’s disease associations is pure gold and I cannot believe that I overlooked this page during my research.’

CHRISTOPHER WALENTAS, INDEPENDENT BIOTECHNOLOGY CONSULTANT, USA, 2009
I was Executive Director of ADI for 10 years, from May 1996 to August 2006. When I first started, I was the only member of staff. I joined ADI as a part-time assistant to the then Executive Director whilst studying for an MA. Within a few months the Executive Director left and I was offered his job. ADI had 39 member countries and an annual International Conference, but no regional meetings, website or membership development programmes. It was quite a chaotic, frantic place where, at times, I felt like I was the jack-of-all-trades and master of none. The first time I met Princess Yasmin Aga Khan was at my first ADI conference in Helsinki in 1997. I was the only member of staff there and she helped me set up the room for the Council meeting, arranging the tables and putting out the papers. It was all hands on deck.

The office had just moved to London from its first home at the national office of the USA’s Alzheimer’s Association in Chicago. Gradually the ADI team developed and we took on more staff. I’m pleased to say that I managed to install the first email system (we had no computer support staff at that time!) and, together with Julian Howell, ADI’s graphic designer, established ADI’s website. Michael Lefevre joined the team and we worked from tiny rooms in the London regional office of the UK’s Alzheimer’s Society. It was a glorified broom cupboard. Then Susan Frade joined us. Admin, in particular, was really hard work. In the beginning, everything was done by fax. It would take over two hours to send a memo out to all our members; numbers would fail to connect and we’d have to start all over again.

The biggest change was ADI’s rapid growth. Membership nearly doubled in ten years and the team grew to six full-time people. We established regional networking and meetings. World Alzheimer’s Day, initiated in 1994 to acknowledge ADI’s tenth anniversary, has gone from strength to strength. During this time, we started the Alzheimer University, which was expanded to serve the needs of both developing and established members. Martin Prince founded the 10/66 Dementia Research Group, which formally became associated with ADI. Another of the most significant developments has been the gradual and increasing level of involvement of people with dementia. ADI led the way in encouraging members to actively reach out to people with dementia and involve them in governance and development of services.

I oversaw ADI’s move into its own premises, to the current site. I remember feeling that the office move was a big deal: for the first time we were paying our own rent, standing on our own two feet. We felt independent and responsible for our own development. ADI was really taking off.

For me it’s the people that make ADI special. The collective sense of a common purpose, despite cultural and language differences. The generosity members have towards each other in terms of sharing knowledge and resources. I am always amazed at how the experience of dementia links people together to achieve the most incredible things. Everyone you meet within the ADI world: carers, people with dementia, staff and volunteers of associations and researchers all feel so passionately about the cause. Countries that are in conflict with each other on a political level are brought together by ADI. I think organisations like ADI contribute to the development of global civil society as they encourage people to respect each other, work together and learn from one another.

I have many fond memories, but some of my fondest and most amusing anecdotes come from the 1998 Cochin conference. I arrived in India in January 1998 for a site visit; it was also my first time in India. I was taken to see the conference venue – a big expanse of earth with lots of sticks coming out of it and thousands of people milling around. I had some doubts that the building would be finished in time (the conference was fixed for September that year) and asked if there was a back up site. I was reassured

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Elizabeth Rimmer

‘Countries are brought together by ADI.’
When the first meeting was held in Washington, DC, to explore the idea of creating ADI, Zaven Khachaturian was a part of the planning group. Responsible for both ADI and the USA’s Alzheimer’s Association scientific programmes, he had put together the first scientific advisory board and helped to organise the ADI meeting in Brussels, Belgium. As a young adult, while still at college in the late 1950s, he developed an interest in brain mechanisms of learning and memory and this interest continued throughout his academic career. His original interest in being involved in ADI was to have an international component to the programme that was in the development stage at the National Institutes for Health in the USA. He felt that an international collaborative network was required to develop epidemiological studies, identify risk factors and develop standard diagnostic instruments so there would be a more global uniformity.

Zaven believes the most important changes in ADI took place in the 1990s when more countries got involved and the relationship between the Alzheimer’s Association and ADI was severed. ADI then became an organisational entity of its own and the torch was passed from the USA to the UK. ADI meetings became more meaningful and the events more substantial where family members from different countries exchanged ideas. In the initial stages the attitude of many countries was that other public health issues such as nutrition, childhood mortality and infectious diseases were a health priority. That dementia is now a serious global problem is being gradually acknowledged.

Zaven acknowledges that ADI is the only organisation that brings countries from around the world together to share information and experiences. ‘There is no organisation that I know of in the world that brings people with common interests to the same table,’ but continued to feel that the ‘scientific component is still very weak and hasn’t evolved as it should have through the years.’ ADI, he feels, should step up and take a leadership role.

He emphasises that the challenge facing ADI is to ‘have a single goal, a single mission, to speak with a single voice so as to accommodate the diversities and points of view to the world and to the public’ and that ‘the amount of effort in finding solutions to address this public health problem is woefully inadequate in all countries, including the USA.’ Thus the allocation of resources to dementia lags behind AIDS, cancer and heart disease.

Zaven hopes that ADI will play a more active role in harmonising global research into dementia. Without research he feels it is impossible to find solutions. He feels that ADI should play a more prominent role in strategic planning and directing global research. ‘There is a big vacuum which is currently not filled by anyone’.

**Interview**

**Zaven Khachaturian**

‘Have a single goal, speak with a single voice.’
Involving people with dementia and their carers

People with dementia are at the heart of ADI’s mission and in 2001, encouraged by a visit from Christine Bryden from Australia, ADI set up a People with Dementia working group. Just two years later Christine became the first person with dementia elected onto ADI’s Board. The aim of the People with Dementia working group was to assess ways of including people with dementia in the decision-making and activities of ADI and its member associations. In 2002, a toolkit was sent out to each national association suggesting ways in which they could make this happen.

ADI’s 17th International Conference, held in New Zealand in 2001, became the first of many ADI conferences to offer a person with dementia the opportunity to share their experience with conference delegates. This highlighted to all in attendance the differences in cultural response to dementia and levels of dementia care and treatment across the world.

In 2004, ADI’s International Conference marked a real turning point for Japan. For the first time, Japanese people with dementia were given the opportunity to speak out about their experiences of living with the disease and this received a remarkable level of media coverage throughout the country. Twenty-one people with dementia participated in the event, which featured an interactive quiet room, a press conference led by a person with dementia and a workshop for ADI members about involving people with dementia.

Keith Turner from the UK, who was diagnosed with dementia in 2004, became the first person with dementia to speak at an Alzheimer University in 2007. Following this, Keith and his wife Lillian were invited to visit Alzheimer’s Jamaica who had participated in the training programme that year. In April 2008, Keith and Lillian returned for the final day of the Alzheimer University programme for emerging associations. They spoke to participants of the importance of including people with dementia in the work of Alzheimer associations and the necessity for support groups to be set up for both people with dementia and carers. For many, this was the first time they had heard a person with dementia speak in this capacity.

In 2009, Graham Browne from the UK was invited to attend the Alzheimer University. During the three-day event Graham shared his experience of living with Pick’s disease and took part in a question and answer session on the benefits of support groups for people with dementia.

ADI continues to involve people with dementia in their activities. In 2009, the process of reserving a seat on ADI’s Elected Board for a person with dementia was begun. Lynda Hogg, a person with dementia from Scotland was co-opted onto the Board. ADI also actively seeks funding to enable people with dementia to attend the annual International Conference in order to share their experiences with the rest of the dementia community.

‘People tend to think the onset of dementia deprives you of everything, that you are lost. That’s not true. I wanted to send the message that I am getting on with my life.’

73-YEAR-OLD PERSON WITH DEMENTIA, SPEAKING DURING ADI’S 20TH ANNUAL INTERNATIONAL CONFERENCE IN KYOTO, JAPAN, 2004

Christine Bryden speaking during the ADI conference in 2004

Keith and Lillian Turner during their visit to Alzheimer’s Jamaica in 2007
The Stroud Series Symposia were developed as a collaborative effort between the Stroud Centre for the Study of Quality of Life, the Institute of Psychiatry and ADI. The purpose of the group was to collect a series of narrative insights from people with dementia and carers in order to understand quality of life in dementia.

The symposia became part of ADI’s International Conference in 2000, with Nori Graham, Honorary Vice President of ADI, Sube Banerjee of the Institute of Psychiatry, King’s College London, and Barry Gurland of the Stroud Centre for Quality of Life at Columbia University, running workshops each year inviting participants to discuss issues such as the nature of quality of life and the carer/person with dementia relationship.

The Stroud Series Symposia website was launched on 1 January 2005. The website was designed to make the growing pool of insights accessible to as many people as possible and allow information to flow directly from consumer to consumer.

The final Stroud Series Symposia workshop was run during ADI’s conference in 2009.

Alzheimer Europe was formed in September 1990 when representatives from six national Alzheimer associations across Europe met in Belgium to discuss the formation of a European presence to establish awareness of dementia with the European Council, Commission, Parliament and other national organisations. Representatives from the regional group planned to make personal contact with members of the European Parliament, keep them informed of the progress of Alzheimer Europe, and when appropriate, urge them to put forward and support proposals that would benefit people with dementia and their carers throughout the region.

Alzheimer Europe’s premises and facilities were provided in Brussels, Belgium, through its membership to the European Citizens Action Service, who existed to help strengthen the position of voluntary sector non-governmental organisations in relation to the European Council institutions. The offices have since moved to Luxembourg.

During the 17th conference of Alzheimer Europe held in May 2007, the Chairmen of ADI and Alzheimer Europe signed a partnership agreement between the two organisations to facilitate future collaboration.

Alzheimer Europe and ADI Chairmen, Maurice O’Connell and Orien Reid, sign the partnership agreement between the two organisations in 2007

‘Now I know that my quality of life is important and is directly linked with my husband’s quality of life.’

PARTICIPANT AT A STROUD SERIES SYMPOSIA WORKSHOP
In 1990, ADI were invited by the World Health Organization (WHO) to participate in developing a statement for a position paper on mental health for the elderly. Just two years later, in September 1992, ADI entered into an Official Working Relationship with the WHO. The WHO understands the critical need for raising public awareness, promoting training and education, and providing services and support to people with dementia and their families. Finding ways to collaborate on these issues is continually being explored in ADI’s ongoing relationship with the WHO.

During the annual meeting of the ADI Council in 1993, Dr José Manoel Bertolote, Senior Medical Officer for the WHO and the Designated Technical Officer in the Official Working Relationship between ADI and the WHO, addressed those in attendance and reaffirmed the potential for raising worldwide dementia awareness and increasing support for families through the collaborative relationship.

In 1994, ADI collaborated with the WHO on producing the Help for caregivers booklet, which is still widely used and is ADI’s most popular publication. In January 1996, during the 97th session of the WHO’s Executive Board, it was decided that ADI would be admitted into Official Relations with the WHO.

Representatives from ADI met with the WHO in January 1999 to discuss how they could collaborate further. Following this meeting, a message of support from Dr Gro Harlem Brundtland, the then Director General of the WHO, was sent for World Alzheimer’s Day 1999.

In 2000, ADI worked closely with the WHO to develop and evaluate services for people with dementia in the Dominican Republic, PR China, Russia and India. The WHO invited ADI to take part in both World Health Day and the World Health Assembly the following year. ADI delivered a statement during World Health Day on 7 April 2001 and were offered a stand to publicise the work of ADI and raise awareness of dementia during the World Health Assembly in May of that year.

In 2003, ADI were invited to participate in a WHO working group on mental health and, during ADI’s 2004 annual International Conference in Japan, the WHO and ADI set out the Kyoto Declaration, an action plan for dementia.

In October 2008, the WHO launched a Mental Health Global Action Plan (mhGAP). The plan described the gap between the needs and resources in all kinds of mental health, neurological and substance use disorders around the world. Following the launch of the plan, a committee was set up to work on evidence-based intervention packages. Martin Prince, coordinator of the 10/66 Dementia Research Group, and Daisy Acosta, Chairman of ADI, were chosen as members of the committee.

ADI continues to work alongside and maintain regular contact with the WHO in the mutually beneficial exchange of information and support.

‘We would have liked to have had as many professional organisations and NGOs as possible to make statements, but this is obviously not feasible, we have therefore selected ADI in view of your NGO’s key role.’

Dr Benedetto Saraceno, World Health Organisation for World Health Day 2001
ADI was founded on 21 October 1984 as a worldwide network for Alzheimer associations to share and exchange information, resources and knowledge. That year, Princess Yasmin Aga Khan was appointed as President of ADI, following her strong involvement with the Alzheimer’s Association in the USA and her experience of caring for her mother, Rita Hayworth.

A further meeting took place in 1985 in order to draw up ADI’s aims, objectives and bylaws and it was agreed that office space from the Alzheimer’s Association in the USA would be made available for ADI at their national office. When ADI’s bylaws were reviewed again in 1990, it was agreed that a Chairman should be officially appointed and Brian Moss was asked to fill this role.

Each year, since the formation of ADI, an annual meeting of the Council has taken place and it is essentially a business meeting. During this meeting, each member of ADI is represented by one person who sits at the Council table and has a vote.

During the ADI Council meeting in 1991, a number of Standing Committees were formed to assist the Executive Committee in making decisions relating to ADI and its activities. These Committees focussed on education, patient and family services, membership development, the conference, public policy, public information and public relations, bylaws, and finance. Each group was given the opportunity to meet before ADI’s annual Council meeting to discuss goals and objectives.

The ADI Bylaws Committee was asked to review the bylaws in 1992 and make their suggested changes available to ADI members for comment. The Bylaws continue to be reviewed on a regular basis to assist ADI in its expansion and improving working practices.

The ADI office was relocated to London, UK in 1995 and, in 1996, a paper on the future of ADI was prepared for discussion at the Executive Committee meeting. This paper outlined ways in which the committee structure could be improved.

In 1999, a three-year business plan was developed and, following the implementation of this plan, ADI employed a consultant in 2002 to lead the Executive Committee through a strategic review to set out priorities for the next three years. ADI has continued to regularly review its business plan, which has now come to be known as the Strategic Plan. In July 2009 work began on the latest Strategic Plan, Creating Capacity for Change.

ADI has been through a number of restructuring processes in order to improve the governance of the organisation. In 2003, it was agreed that the Executive Committee would be renamed the Elected Board and a smaller Executive Committee was formed. The new Executive Committee, made up of the Chairman, Vice Chairman, Treasurer and head of the Medical and Scientific Advisory Panel, is able to communicate more frequently than the full Board.

### ADI Chairmen

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<td>Brian Moss, Australia</td>
<td>1990 – 1996</td>
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<td>Nori Graham, UK</td>
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<td>Henry Brodaty, Australia</td>
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<td>Orien Reid, USA</td>
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<td>Daisy Acosta, Dominican Republic</td>
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In 1999, a registered UK charity called Friends of ADI was set up in order to take advantage of tax and other benefits available to charities in the UK. ADI remains registered in Illinois, USA, although the office is now based in London. The first Trustees of Friends of ADI were the then Chairman, Nori Graham, Anthony Mann from the Institute of Psychiatry in London, John Murphy, a specialist in the branding strategy field, and the late Roger Martyn, a retired lawyer who handled the legal process of setting up Friends of ADI. Although Friends of ADI is an independent organisation, it runs no programmes of its own and exists to support ADI, mainly by making grants.

In 2003, Friends of ADI received a donation of over £130,000 from the funds of an insurance company that was being wound up, based on the decision of the person handling that process who had a personal experience with Alzheimer’s disease. As well as offering the practical benefits of being a UK registered organisation, the Trustees offer their knowledge and experience to ADI.
Orien Reid first joined ADI as a representative from the USA attending ADI’s conference in Johannesburg, South Africa in 1999, as Chair of the Alzheimer’s Association. Invited by Nori Graham to observe the Executive Committee meeting in 2000, she was surprised to see ‘such a small budget’ for such a large international organisation!

In 2002, Orien was elected Vice Chairman of ADI. The then Chairman, Henry Brodaty, requested she serve as Chair of the Governance Committee entrusted with reviewing the governance structure of ADI. One of the responsibilities was to develop recommendations for involving people with dementia – the results of which were clear at the 2001 ADI conference in New Zealand. She was then elected Chairman of ADI in 2005 to serve a three-year term. During this period her goal was to make ADI a stronger and more efficient organisation and to raise the profile of ADI, including enhancing the involvement of people with dementia.

Orien has had four family members with Alzheimer’s disease – grandmother, mother, aunt and an uncle. She felt that the most positive, constructive way to address the disease was to get involved herself. She became a volunteer for the Delaware Valley Chapter of the Alzheimer’s Association in 1990, organising its first Memory Walk in 1991. Orien’s volunteer efforts with ADI have given her a broader appreciation of how Alzheimer’s disease is viewed and managed around the world. ‘In the USA we tend to assume that we have the best of care. I am impressed with the attitudes toward ageing in Chinese Taipei, Japan and South Korea. I have a better understanding of the nature of the disease and how other societies address it.’

When Orien first became involved with ADI, she ‘was sure the budget must have been in millions’ and says she was shocked when she saw the annual report. She sought confirmation from Nori Graham, thinking there must have been some mistake. Upon being told that the budget was indeed around US$350,000 per annum, she jokes that, ‘it ‘blew me away’! At that time ADI had only four full time staff. At one time ADI had a staff of six, and ‘that itself was a 50% growth!’ she said. Despite the small budget and staff, ADI has continued to show tremendous commitment to the various programmes.

ADI, Orien feels, has truly snowballed into a global organisation. She drew the interest of GE Healthcare in the USA through her presentation about ADI’s activities when she introduced this global patient-focused health care advocacy group with a focus on dementia. GE Healthcare subsequently provided funding and resources for the 2007 Advocacy Alzheimer University. From that Alzheimer University programme came a direct effort focusing on the World Health Organization to make dementia a global health priority.

Having the right ‘profile’ is what she feels is the main challenge facing ADI now. Her goal while serving as Chairman was to significantly increase ADI’s international profile, and this undoubtedly involves funding.

Orien attended ADI’s annual International Conferences from 1999-2007. She believes that, while each conference is special, the one that made a difference was when Christine Bryden, a person with dementia, gave the keynote address in New Zealand in 2001: ‘It fundamentally changed ADI, making it a world leader in involving people with dementia’.

Orien wishes that every country around the world be represented in ADI over the next 25 years, considering the growth in the sheer number of people with dementia over the next 20 years. Africa isn’t well represented at present and she would like to see more African countries become members. ADI’s goal is to improve the quality of life of carers and people with dementia around the world. Without the presence of associations in those countries, it will be difficult to fulfil this task.