

# Global Alzheimer's Disease International Perspective

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A newsletter for Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

## The 11th ADI Conference



**Beatriz Berg, President of ALMA, and Carlos Mangone MD, Chairman of the Conference Organising Committee, review this successful event**

LEFT TO RIGHT: *Dr Carlos Mangone (ALMA), Dr Nori Graham (Chairman-elect, ADI), Dr Arturo Famulari (ALMA), Horacio Ferrer, Beatriz Berg (President, ALMA), Robert Gomez (Sec General, ADI) and Brian Moss AM (Chairperson, ADI)*

**L**OOKING BACK at the 11th ADI Conference, it was not only a great challenge but also a big success. After so many months – almost a year and a half of hard work and getting together every Tuesday at noon – we must admit that we really feel, like someone told us during the event, 'almost empty and strange'. But we are also very happy that things went so well, and satisfied with the peace of mind you can only relish when you are sure you have done your best.

We sincerely hope that everyone that came from near and far enjoyed, learned and can now share what was said, shown and done. In this way we can improve, if only slightly, the patient's everyday plight and the caregivers' '36 hours burden'.

### **A dream come true**

We at Asociación de Lucha contra el

Mal de Alzheimer (ALMA), like Dr Martin Luther King said, had a dream, and that big dream of hosting the 11th ADI Conference in the very south of South America came true and was a hit – and it happened in the heart of our beloved Buenos Aires.

### **The power of knowledge**

An important objective towards defeating an illness is to know more about it. We were always convinced of the need for supportive activities that promote people's knowledge of the disease and its characteristics in an effort to enhance social awareness. The opportunity to organize this 11th ADI Conference allowed us to achieve that objective.

Although Princess Yasmin Aga Khan was not able to come this time, she sent a video with a sensitive message of encouragement to all the attendees to continue growing in this chal-

lenge against Alzheimer's disease.

This year's Conference balanced the medical and scientific aspects of the disease with the ways of caring for people with dementia and their caregivers. The leading goal was 'To share experience for more experience' and the main theme 'An interdisciplinary focus on Dementia care'.

### **Abundance of expertise**

All the attendees have been truly excited by the level of expertise of scientists, clinicians and care providers coming from 30 countries around the world. More than 15 keynote speakers, 750 participants, 4 plenary sessions, 15 round tables, 8 workshops, 3 conferences, 4 platform presentation of free papers, 1 poster session and 4 pre-congress courses made this a very busy and productive five days conference. Let's point out

some of the experts that heightened the quality of this event with their participation: Peter Whitehouse, MD (USA); Philip Gorelick, MD (USA); Nancy Lombardo, PhD (USA); Zaven Khachaturian, MD (USA); Barry Reisberg, MD (USA); Jordan Grafman, PhD (USA); Peter St George Hyslop, MD (Canada); Serge Gauthier, MD (Canada); Ramon Cacabelos, MD (Spain); Rafael Blesa, MD (Spain); Franceska Jordan (Australia); Wym Parys, MD (Belgium); Lilia Mendoza, PhD (Mexico); Nori Graham, MD (UK); Carole Archibal (Scotland); Liz Baikie (Scotland); Stuart Roth (USA); David Zimmer (Canada); Harry Cayton (UK); S. Rajkumar, MD (India); Luis Fornazzari, MD (Chile); Pilar Quiroga, MD (Chile); K Steinwachs, MD Germany).

This event was co-sponsored by the National Government, the World Health Organization, 12 National Universities, 15 Medical Societies of Neurology, Psychiatry and Gerontology and the National Academy of Medicine.

## Global Perspective

The views stated in Global Perspective are personal and do not necessarily reflect the views of ADI

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### Musical offering

In the opening ceremony and the tango gala, ALMA offered a poem and a hymn to the ADI community in hands of Mr Brian Moss, Dr Nori Graham and Mr Robert Gomez. We thought it was the best offering a developing country like Argentina could give – something coming up from its own roots. It is for us a big pleasure that this song, inspired by the patient-caregiver relationship, belongs now to all of you.

### Opening address

The opening address entitled 'Population Aging at the Dawn of the Third Milenium' was presented by Professor Osvaldo Fustinoni, President of the National Academy of Medicine. He discussed the aging rate of different nations. Professor Fustinoni considered that it is faster in those countries where the organization of care for elderly people is more advanced.

### Plenary highlights

The highlight of this Conference were the plenary sessions, which provided the opportunity for researchers, clinicians and health care professionals, as well as family members and caregivers, to come together in a positive interchange of information and to learn from the expertise of each other. Topics covered by them were: differential diagnosis of AD; genetics; importance of the caregiver in the interdisciplinary team; caregivers' burden, behavioral symptoms in AD; delusions and hallucinations; non drug solutions for behavioral problems; update in drug treatment for AD: tacrine, nimodipine, sabeluzole, xamomeline, l-acetyl carnitine and CDP choline.

### Workshops and round tables

Several local and international speakers met in different round tables to discuss critical subjects such as housing and environment; advances in the pathophysiology of AD; organization of support groups in Latin America; fundraising; tools for AD diagnosis; ethical and legal issues; neuroepidemiology of Dementia around the

World; the AD related disorders; clinical research methods in dementia; nutrition of the demented patient; neuropsychological assessment and the neurobiology of the visual disturbance in AD.

Eight very active workshops looked at essential issues such as public policy; sexuality and dementia; coping with family burden; how to start an Alzheimer's society; abuse, neglect and victimization; cognitive stimulation; environment and GP training.

Another highlight of this Congress was the Consensus Conference on 'Screening for Cognitive Impairment in General Practice' chaired by Professor Henry Brodaty and with the participation of eight prominent experts in this field: Julie Clarke, MD (UK); Mary Ganguly, MD (USA); Adrian Grek, MD (Canada); Tony Jorm, PhD (Australia); Paul Scherr, MD (USA) and Lilia Mendoza, PhD (Mexico).

### Social gathering

The 'Revival Night of the Sixties', the 'Tango Show-dancing Night' and the closing lunch 'Gaucha Party' allowed people to have a lot of fun in an appropriate environment to strengthen the relationship among the different member countries.

### Video of the event

Fortunately this wonderful event has been video-taped (the social events also...). If anyone would like to receive information on what was discussed regarding the topics aforementioned, please contact the office of ALMA in Buenos Aires.

### Thank you

Again, our most sincere gratitude for your support and cooperation and for the trust ADI put in ALMA for the organisation of this 11th Conference. The warmth and participation of all member countries truly rewarded our effort in the assiduous work for this event. It was an experience we will never forget.

On behalf of ALMA:  
Beatriz Berg  
Dr Carlos A Mangone

# Chairperson's message

**A**NOTHER YEAR has come and almost gone. By the time you read this you may well already have celebrated the coming of the 1996 year. Where does the time go?

## An eventful year

For Alzheimer's Disease International, 1995 has been an eventful year with many positive things happening. We have established a new Secretariat in London, and our new Secretary General, Robert Gomez, is making a significant contribution to the affairs of ADI. As I stated in my report to the 1995 Annual Meeting, his 'enthusiasm is infectious, he is a person who gets on with a job quickly, does not shirk from difficult decisions, yet handles sensitive issues with diplomacy'.

One of Robert's great attributes is his fluency in Spanish. I believe there are now more member nations of ADI from Spanish speaking countries than any other language.

## Conference and AGM

Our Eleventh International Conference and Annual General Meeting held recently in Buenos Aires, Argentina, were most successful events. The Conference attracted in excess of 600 delegates from around the world, and we are indeed grateful to our friends from Argentina for arranging such a stimulating and interesting programme. Their hospitality was outstanding, starting with a very warm welcome being extended to everyone arriving at the airport, continued throughout the Conference and concluded with a most enjoyable 'Gaucho Party'. Thank you ALMA. Thank you Argentina.

## Satellite Conference

I must also thank Kathleen Potts and the members of her committee for the very warm hospitality offered to Robert Gomez and myself when we attended the Satellite Symposium on Subcortical Dementia, hosted by our Alzheimer's Society of Uruguay (AUDAS) in Montevideo on 18 September.

## Growing membership

As will be reported elsewhere in this issue, the membership of ADI continues to grow, with three new member countries admitted into membership, making a total now of 36 countries. A number of other countries have indicated that they have formed a national association, and wish to pursue membership of ADI in the not too distant future.

## Nurturing new associations

One of the significant things arising from this level of interest in ADI is the awareness the Executive now has of its responsibility to assist the establishment of new associations, and to support and nurture them, especially in developing countries where it is sometimes difficult to obtain the necessary resources. Council accepted a recommendation of the Finance Committee, endorsed by the Executive Committee, and resolved to institute a levy of 40% on all member countries dues for 1996. Those members which pay only the minimum level of dues will be exempt from this levy. This is a 'one off' exercise aimed at the establishment of a fund which will be used to assist developing countries.

## Medical progress

It was also interesting to learn of developments that are occurring in research, as well as the improved care of people with dementia – both those living in the community and those needing residential care of one form or another. It is clear from obser-



*Brian Moss, ADI chairperson, addressing the Conference in Buenos Aires*

vations that care standards in many countries are improving.

## New initiatives

As a further positive sign of growth and maturity, the ADI Council is to revise its by-laws and structures. In this regard we are grateful to David Zimmer (Canada) and Evelyn McPake (Scotland).

Nonetheless, we are all faced with the one negative factor, that despite the advances being made in research there is still no answer to the riddle of how Alzheimer's disease or a related disorder afflicts people, and there is still no cure. In this connection I want to congratulate the Alzheimer's Association in the United States for their initiative in launching the Ronald and Nancy Reagan Research Institute. Let us all resolve to continue the fight so that we may reach a time when this insidious affliction will be eradicated.

All good wishes to you and yours as we approach the coming festive season, and may 1996 be a happy and successful year for you.

*Brian Moss AM, Chairperson, ADI*

**Correction:** In the last issue of Global Perspective you may have read a very interesting article outlining the merger of Alzheimer Scotland and Scottish Action on Dementia. In the same article it was noted that the resultant new association, Alzheimer Scotland – Action on Dementia, planned to merge into the Alzheimer's Disease Society in the UK (ADS) during 1995. I have been asked to point out that this statement was incorrect and that, while very close

cooperation exists between them, no such merger is contemplated. ADI apologises for this error to both parties concerned. We must have been forgiven as your new editor survived a recent trip to Scotland, where he enjoyed warm traditional Scottish hospitality at a recent AGM and Conference organised by Alzheimer Scotland – Action on Dementia, and we still occupy an office in Lower Marsh, London thanks to the generosity of ADS!



# The first journey

*Beatriz Alessandra Rose works one day a week for ADI as a volunteer, helping to support and develop Alzheimer's Disease Societies in Latin America. Here she gives an account of caring for her mother in Chile and of her experience of the International Conference.*

WHEN I FIRST ARRIVED in England almost 20 years ago, I imagined that it was just going to be a transitional period of my life. I would return to Chile sometime, enriched by the world-wide experiences which have characterised my life!

Having left a large family behind, I missed them. However, it was during their last visit seven years ago that I noticed a marked change in my mother. From the outgoing, intelligent, capable woman of the previous trip to the UK, she became disinterested, just wanted to go back home, would become depressed for no apparent reason and had developed some obsessional habits. I started to receive contradictory telephone messages from my siblings about my mother's behaviour. I suggested to them that she might be suffering from Alzheimer's disease and tried to explain to them what the future

would hold. They did not want to believe it, neither did I.

From then on, a continuous trail of trips to Chile developed – initially to get my mother diagnosed, hoping to find that she was suffering from a treatable condition. Unfortunately, the final diagnosis was Alzheimer's disease.

I have been going over to Chile twice a year since then, sometimes with the whole family sometimes on my own, every time to take on the role of an active care giver. Every time I came back to the UK, I was in pieces. Every time I thought it was the last time I would see my mother alive. In 1993, I started to work as a volunteer for the Solihull Branch of the Alzheimer's Disease Society. I had a counselling certificate and experience in counselling which proved useful.

I talked to my father about joining

the Asociación de Alzheimer's in Chile, but he would not hear of it. He never accepted my mother's illness and continuously hoped that a miracle cure would bring her back to normal.

The strain of looking after my mother finally took its toll and my father died in August 1994. My mother had to go into a home, we just could not cope. She had become incontinent, aggressive, restless and very confused.

In September 1995, as the 11th International Conference of ADI was going to be held in Buenos Aires this year, my ever supportive chairman suggested that I apply to head office for funding to attend the Conference. At the same time I could visit my mother – she is now in the terminal stages of the disease. I was grateful for his support with my application and also to ADS for partially subsidising my trip.

## **A Journey through the 11th International ADI Conference in Buenos Aires, Argentina**

Tuesday 12th September. As the plane was landing in Buenos Aires, I had pangs of anxiety – this could be a lonely experience, I told myself. Surely, they all know each other. There seemed to be people from all over the world, lots of different languages spoken and I didn't recognise anybody. Soon I had the opportunity to exchange ideas and information with carers and workers from other parts of the world.

There were concurrent sessions, workshops and plenary sessions throughout the day from 8.15am till 6.30pm. One of the highlights for me was the session on 'Coping With Family Burden' where an Argentinian

occupational therapist went through the roles of professionals and of self-help groups. It was excellent, it put into words and into perspective a lot of my personal and professional experiences.

That afternoon, I participated actively as a translator for Dr. Graham's workshop, whom I had met that morning. Her workshop on 'How to Start a Society' was very well attended and there was a lively discussion.

Every day I took back with me the feeling of impotency after meeting delegates from Third World countries. They would talk about the impossibility of providing something as basic as free information, advice or a free 24 hour help line because of the lack of funds. I wondered how many carers and even professionals

from Third World countries would have wanted to be at this Conference and could not afford it. I reflected on how fortunate I was and I resolved to do something to help these countries.

Much too soon it was time to say goodbye. I left with a feeling of affection and gratitude for the many people who are working towards a cure for this horrendous disease that is killing my mother. I felt enriched by meeting them all and I knew, by the time the Conference ended, that I wanted to do more on the national and international level, to get more involved, to help making those facilities so badly needed available to other people where resources are scarce. My feelings were very strong and my decision to offer myself as a volunteer to ADI had been made.

**YOU KNOW** all those old hands in ADI who said that things would slow down after the Buenos Aires Conference? Well, they lied!

One good thing about this, though, is that the adrenaline keeps flowing and one is almost on a constant 'high'.

The Conference in Buenos Aires will always have a special place in my heart, being as it was, my first ADI conference. Others have already written about the Conference itself so I will not dwell on this. But I would like to thank those who organised it for a job very well done. I know, better than most, just what a huge effort was put in by the ALMA team, so ably led by Carlos Mangone and Beatriz Berg, to make everything the success that it was. You would have thought from all the activity that ALMA had hundreds of people to draw on for help. Not so, everything was organised and carried out by a handful of people, the majority of them volunteers. Their commitment was a joy to experience and reinforces my belief that the determination shown by people like these is ADI's main strength. That they happened to be Argentinian was simply a bonus and enabled us to sample, in addition, their generosity of spirit so wonderfully encapsulated in their offering to the ADI community of the ALMA song 'Canción del Alma'. On behalf of all ADI members I would like to renew our thanks not only to ALMA but also to the poet Horacio Ferrer, who wrote the lyrics and to Jairo for the music.

My thanks also to Dr Bertolote of the World Health Organisation for his continuing support and for having accepted our invitation to attend the Conference. Out thanks also to the many others who travelled from many different parts of the world to be with us. I am also grateful to Kathleen Potts and her team for their wonderful hospitality during my all too brief stay in Montevideo. Not only did they run an excellent Symposium, but I found their in-house catering superb. They certainly knew – and found – the way to my heart!

One of the great things to come out of Buenos Aires, I felt, was a sense of urgency in helping members in devel-

# Reflections

## from the Secretary General



oping countries, where the need is great but resources almost non-existent. Work has started on a package to assist such countries not only with cash grants but also with training programmes. An ADI Task Force is currently being formed whose main role will be to support the development of AD Societies around the world. I hope to have more information about this in the next issue of *Global Perspective*.

To achieve the aims of this programme will require greater funding that has been available in the past and we must therefore renew our efforts in this respect. Many, like the Helen Bader Foundation, Warner Lambert-Parke Davis, Eli Lilly, Sigma Tau, and SmithKline Beecham among others, have been extremely generous in the past and I hope that they and others will continue to assist in the years to come. There is already a new sense of excitement among ADI members as to what can be achieved if we all pull together. In this context I would like to publicly thank Alzheimer Scotland-Action on Dementia, who have offered to place £15,000 (some \$22,500) at the disposal of ADI to assist in this endeavour. Stuart Roth, immediate past Chairman of the Alzheimer Association, has offered to help with fund raising in the US. I will be meeting with our President, Princess Yasmin Aga Khan early in the New Year to discuss other ways

of raising some much needed help. Dr Zaven Khachaturian, the former director of the National Institute on Aging, in the US has very kindly offered his considerable knowledge and expertise.

Work has continued apace for the preparation of the next ADI Conference in Jerusalem which I believe will offer us a very good programme. A few weeks ago I had the sad task of offering our colleagues in the Alzheimer Society of Israel, our condolences on the untimely death of Yitzak Rabin. I know that this will not deter the Israeli people from continuing the peace process and I hope that we in ADI, by our presence at the 12th ADI Conference in Jerusalem next year, can also show by example how international communities can work together to achieve a common aim.

On the home front, my excitement and enthusiasm is kept alive by my contacts with our members and the support I get from Brian Moss, our Chairperson, and the rest of our Executive Committee and in particular, Nori Graham, our Chairman-Elect, who is always there when I need her. I hope that together we can continue to make a difference to so many people everywhere whose lives have been turned upside down by Alzheimer's Disease.

**Robert A Gomez**

A very happy Christmas  
and our best wishes for 1996  
to all our readers!

## GUATEMALA



Left to right: Haydée López, President of Ermita, Robert Gomez, ADI Secretary General and Rachel Billington, former ADI Secretary General

## Grupo Ermita

### Haydée A López

GUATEMALA con 10 millones de población, segundo lugar en analfabetismo a nivel mundial y presupuestos para salud y educación muy abajo de los de otros, no escapa en ningún nivel social al impacto del Alzheimer. No hay casualidades y ERMITA nace de la inquietud de una persona familiar que súbitamente ve la necesidad de hacer conciencia de que se tiene algo grande que desbarata a la sociedad. Pronto se unen profesionales y familiares y se inician forums, programas televisivos, prensa, radio, y otros para inicialmente enseñar a la comunidad que es la enfermedad pues siendo algo relativamente nuevo, aún profesionalmente no se conoce. Luego nace la necesidad de enseñar a familiares y cuidadores y se crean cursos, teóricos y prácticos, guiados por profesionales y ya estos graduados están dando apoyo a quien lo necesite. Nada ha sido fácil pero recordando el pensamiento que dijo Kennedy, 'No preguntes que puede hacer tu país por tí - pregunta que puedes hacer tu por tu país', nos impulsa a continuar y tocando puertas y puertas se analiza, se compara y se planifica mirando a la necesidad inmediata. En los escasos 10 meses de existencia de ERMITA también se tocó la puerta de ADI y casi de inmediato nos ha dado todo apoyo intelectual, consejos y ahora que hemos sido aceptados como miembros interinos nos compromete

que con mas fuerza seguiremos luchando por el bienestar a nivel mundial del enfermo de Alzheimer sus familiares y en general por el respeto y educación para que se tenga una mejor calidad de vida para el nuevo siglo y muchos más.

## Ermita group

Guatemala, with a population of 10 million people and the second highest level of illiteracy in the world and with a budget for health and education well below that of other countries, is not immune to the effects of Alzheimer's disease at all social levels. It is not by accident that ERMITA was formed by a relative of an Alzheimer's disease sufferer when the need to raise public awareness of this illness which is affecting our society became apparent. Professionals and family members soon joined in. Meetings and seminars were set up, followed by press releases and TV programmes to explain to our community what Alzheimer's disease is. Being something relatively new it is not even professionally recognised. The need to train family members and carers became evident. Both theoretical and practical courses given by professionals were set up to provide this training. Those who attended these sessions are now helping and supporting others in need. It has not been easy, but recalling former President Kennedy's words, 'Ask not what your country can do for you - ask what you can do for your country', gives us the strength to continue with our work analyzing the results and planning our next steps. During its ten months of existence ERMITA also approached ADI and almost immediately received their full support and advice. Now that we have been accepted as provisional members we will endeavour to continue with renewed strength to improve the welfare of the Alzheimer's disease sufferers and their families worldwide and to procure the respect and better education needed to achieve a better quality of life for the next century and thereafter.



POL

## Tango and Alzheimer's Disease

Dr Tomasz Gabrielewicz  
Polish Alzheimer's Association

When Robert Gomez asked me to put down a few words concerning the ADI Conference which was held recently in Buenos Aires, I was faced with a very difficult choice. The Conference was eventful and writing a short note about so many events is almost impossible. Which one shall I choose as the most important? How can I describe its unique atmosphere?

The abundance of flags which welcomed us at the General Meeting was magnificent. It spoke for itself. On the first day, I was also impressed by the 1995 Annual Report presented by the Secretary General and by the newly published booklet 'Starting a Self-help Group'. Since Polish Alzheimer's Association became a provisional member, I have



**UNITED STATES**

**Alzheimer's Association (US) creates Reagan Research Institute**

*Stuart C. Roth, immediate past chair of the Alzheimer's Association, US*

The Alzheimer's Association (US) recently announced that it has joined together with the fortieth President and First Lady of the United States to create the Ronald and Nancy Reagan Research Institute. By doing so, we intend to accelerate development of effective treatments and even preventions for this terrible disease within the next ten to fifteen years. The specific goals of the Institute are to reduce the number of cases, the severity of symptoms and the cost of care by the time the post-World War II Baby Boom reaches the age of 65.

The Institute will have three major components:

- **Research grants**
- **Creating alliances**

The Institute will bring together investigators and funding sources to encourage information exchange, prioritization of issues and technology transfer to bring

more, and more effective, treatments to market more quickly.

- **Global outreach to investigators**

The association will reach out to scientists around the world, working in the complete spectrum of Alzheimer research, to participate in the Institute.

As Mrs Reagan said, 'The Reagan Institute was established to serve as a symbol of hope to all those who share our dream of finding a cure for Alzheimer's disease.' She will continue her involvement with the Institute and, through the association, raise public awareness for the need for Alzheimer research.

Those interested in participating in the Institute are encouraged to write Edward Truschke, President & CEO, Alzheimer's Association, 919 North Michigan Avenue, Suite 1000, Chicago, IL 60611, USA.

*You can read extracts from an interview with Nancy Reagan on page 9.*

**AND**

found very important the offer of substantial help for new members. I hope that becoming a member of ADI will improve our position and activity inside and outside Poland. I believe that it will facilitate our access to the new educational and informative materials and generally it will help to increase our credibility.

Back to the Conference. The interesting programme touched a broad spectrum of problems related to Alzheimer's disease and the lecturers represented the top world's standard. I would like to emphasize a less official but still important side of this international meeting; social contacts. Meeting new people representing over 30 countries and exchanging ideas with them was most exciting for me. I think that personal contacts are the best way to learn. The organization of the Conference was perfect. The hosts had made every effort to enable us to learn as much as possible, including tango dancing and horse riding. Admittedly it is difficult to treat them as preventive factors for Alzheimer's disease but they advance the well-being for sure.

**MEMBERSHIP NEWS**

**At the ADI Conference, Guatemala, Poland and Singapore were admitted as new provisional members and Italy, Korea, Luxembourg, Romania and Uruguay were given full membership status. Congratulations to all of them – we are proud to have them join the ADI Community.**

**Applications for full membership from Brazil, Ecuador and Venezuela were deferred until next year as was the application for provisional membership from Hong Kong. In the last three months we have received applications for membership from Peru and Colombia.**

**Current full and provisional members of ADI:**

Argentina	Ecuador	Italy	Poland	UK
Australia	Finland	Japan	Romania	USA
Austria	France	Korea	Scotland	Uruguay
Belgium	Germany	Luxembourg	Singapore	Venezuela
Brazil	Guatemala	Mexico	South Africa	
Canada	India	Netherlands	Spain	
Chile	Ireland	New Zealand	Sweden	
Denmark	Israel	Puerto Rico	Switzerland	

# Tacrine and related drugs in Alzheimer's disease

By Professor Serge G Gauthier

Professor Gauthier is the Chairman of the Medical Scientific and Advisory Committee of the Alzheimer Society of Canada. He is also the Director of the McGill Centre for Studies in Aging and Professor of the Departments of Medicine, Psychiatry and Neurology and Neurosurgery at McGill University in Quebec, Canada

## Relieving symptoms

Tacrine (chemically called tetrahydroamino acridine, THA) is the best known of a group of medications acting as blockers of the degradation of acetylcholine (cholinesterase inhibitors, CI) and used to relieve some of the symptoms of AD. Tacrine has been tested for this indication as early as 1980 by Dr William Summers and his group in Los Angeles. His publication of 1986 in the New England Journal of Medicine describing major beneficial effects using doses up to 200 mg a day created a major interest in further developing tacrine and related CI drugs.

## A forerunner of Tacrine

Physostigmine had actually been studied extensively prior to tacrine. Acting very quickly but only for a few minutes when given subcutaneously, physostigmine was actually the first CI to show transient beneficial effects in human volunteers who had been given scopolamine, a drug that temporarily blocks acetylcholine receptors and thus interferes with memory. Patients with AD have also shown some benefit from physostigmine, but this CI needs very careful titration for a safe and effective dose for each individual, limiting its widespread use.

## Side effects

Tacrine appeared, from Dr Summers report, to be very effective and safe for most AD patients when many other investigators in Canada, the United States, France the United Kingdom and Scandinavia rapidly

went to work with tacrine in order to confirm these findings. Unfortunately, frequent (up to 50% of individuals), and clinically significant liver enzymes elevations as well as dose related gastrointestinal symptoms delayed the confirmation that tacrine at doses of 120 to 160 mg a day can improve symptoms in some patients with early to intermediate stages AD. Women of small stature and body weight appear more sensitive to the side effects of tacrine. Preliminary reports show that men and women with the phenotype apolipoprotein E 3/3 (approximately a third of patients with sporadic AD) appear to be more responsive to this medication, if they tolerate doses of 120 to 160 mg/day.

## Only a few people respond

There is as yet little information on how long to use tacrine, and how to measure its efficacy in clinical practice. Because of the monitoring required every two weeks for three months in order to detect liver enzymes elevations, the lengthy period of titration to reach doses of 120 to 160 mg/day (at least three-months), its cost, and the improvement noted in only a fraction of the patients (so called 'responders'), tacrine has not been approved in all countries for general prescriptions use. On the other hand, for patients and families willing to undergo the monitoring by clinicians experienced in diagnosis of AD and the use of tacrine, this drug is worth a try.

## Another option

One other option for patients and families interested in trying medications that could offer symptomatic benefit is to join double-blind studies with other CI – E2020 from Esai, ENA from Sandoz and metrifonate from Bayer are currently under testing in many countries.

Potential advantages may be:

- Single daily (E2020, metrifonate) or twice a day (ENA) versus the four times a day doses for tacrine
- Little if any liver toxicity.

Furthermore, the designs of these ongoing studies has taken advantage of the lessons learned from tacrine in terms of:

- Measuring improvement in multiple symptomatic domains, including cognition, activities of daily living, behaviour
- Longer treatment periods in order to establish patterns of efficacy
- Predicting responders based on apolipoprotein E phenotyping.

## Results of studies

Results of these ongoing studies with CI will be available in 1996 leading to possible release for general prescription use in 1997. It may also be possible to combine a CI with other types of medications being tested in AD, which will be described in a follow-up article.

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*In some parts of the world, Tacrine is available under the brand name Cognex.*



# Nancy Reagan speaks out on Alzheimer's

*In an extended conversation with the Alzheimer's Association, Mrs Reagan shared her personal thoughts on the past year. Highlights of that conversation are reprinted here with her permission and courtesy of the Alzheimer's Association*

**Alzheimer's Association:** *Mrs Reagan, why are you and your husband committed to Alzheimer's and to finding a cure?*

**Mrs Reagan:** The truth is, we were committed to Alzheimer's way back in the early 1980s, long before it ever touched us in a personal way. As President, Ronnie supported Alzheimer research and declared November National Alzheimer's Disease Month in 1983. Back then, Ronnie's goal was to raise the level of awareness of this cruel disease, and make people realize they shouldn't be self-conscious or embarrassed. It's a disease like any other disease. That's the message we're still trying to convey now.

I suppose when an illness changes your life, it's natural to want to reach out to the many others who are suffering – to connect with them at some level. You say to yourself, 'Okay, this is happening to us, and it's frightening and cruel. Let's try to help other families'.

**AA:** *How is President Reagan doing?*

**Mrs Reagan:** He's doing well. He enjoys going into the office everyday, playing golf, and going to church. Weekends and holidays are spent with our children and grandchildren. Ronnie's illness has, thankfully, pulled our family back together, so in some ways this ordeal has turned out to be a blessing. We've learned to appreciate each other more and our time together.

I think our daughter, Patti, was right when she said we've established a 'zone of privacy,' something I think all families create to protect one another. We're all for openness, but our family life now is sacred.

**AA:** *How are YOU doing, Mrs Reagan?*

**Mrs Reagan:** The cards and letters keep coming in from people across the country. They've been such a tremendous source of comfort to me. Some of the notes I've received are so moving and touching, while others are from people who feel totally overwhelmed and lost. I want to assure them that they're not alone in all this. I want them to know that there are support groups out there to guide them through the dark moments; that there are people who understand what they're going through.

**AA:** *Why did you choose to affiliate with the Alzheimer's Association?*

**Mrs Reagan:** The Alzheimer's Association wants to defeat this cruel disease. Honestly, we can't wait any longer to step up the research. People are living longer and their well-being has to be our top priority. The Association offers people help and hope. Ronnie and I want to support that effort. If a cure can be developed, perhaps families won't have to continue losing loved ones this way.

**AA:** *Does your husband support your decision to take a public role?*

**Mrs Reagan:** Ronnie encouraged me to become involved, and we both agreed that lending our name to the Institute was the right thing to do. We've been public our entire married life, you know, and if we can make a difference through our involvement, then we've simply got to do it.

**AA:** *You've gone public before with personal health problems.*

**Mrs Reagan:** Throughout our public life, we have made every attempt to



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*‘Even when life seems bleak and hopeless, know that you are not alone’*

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share information about our medical conditions with the media and the American people. When I had breast cancer, I spoke openly and honestly. As a result, many women wrote to me, saying that my personal story and recovery – thanks to early detection – prompted them to be tested. That's why I feel it's so important to embrace these health issues. After all, nothing speaks louder than personal experience.

**AA:** *How do you feel about the establishment of this Institute in your name?*

**Mrs Reagan:** This Institute, which bears our name, isn't about Ronnie and me. It wasn't established to honor two people, but to serve as a symbol of hope to all those who share our dream of a cure for Alzheimer's.

**AA:** *What would you say to all those who are grappling with this disease – as a patient or a caregiver?*

**Mrs Reagan:** Don't ever lose hope. Even when life seems bleak and hopeless, know that you are not alone.

## Alois Alzheimer

(1864 – 1915)



# The man who discovered Alzheimer's disease

**A**LOIS ALZHEIMER was born in Marktbreit-am-Main (a small town in Bavaria), the son of a notary. He went to school in Aschaffenburg and attended the medical schools of the Universities of Berlin, Würzburg and Tübingen from 1882 to 1887. Following an internship he took a position at the Stadische Irrenstalt in Frankfurt-am-Main, where Franz Nissel joined him one year later. Here began the close co-operation which lasted a lifetime. Alzheimer left Frankfurt in 1902 to join the psychiatrist Emil Kraepelin, professor and chairman of the department of neurosurgery in Munich. These years, from

1903 to 1908, were Alzheimer's finest.

In November 1906, Alois Alzheimer presented a paper to the Southwest German Society of Neuropsychiatry concerning a 56 year old who had died in the Frankfurt Mental Hospital. The following symptoms had been noted during the years preceding her death: paranoia followed by memory loss; disorientation; and she would move things from one place to another for no apparent reason. She resisted any attempts to keep herself neat or clean and seemed unable to follow doctors' orders. This generalised deterioration extended to focal

disturbances as well. While reading she skipped from one line to another and while writing she repeated some syllables and left out others. These focal disturbances were sometimes more pronounced than at other times. On her death, the neuropathological report showed 'diffused pre-senile brain atrophy'. This first reported case describes the disease which today bears Alzheimer's name.

Before Alzheimer could demonstrate that certain changes had occurred in the brain of the patient, new staining techniques had to be developed for the study of neurofibrils and dendrites (fine branches of the nerve cells). Using these new techniques, Alzheimer's systematic study of this woman's brain showed alterations which could not be associated with any other brain disease known at this time. Psychiatry is indebted to him for his classical description of general paresis, arteriosclerosis, senility and acute delirium. He also made the astute observation that arteriosclerotic and senile processes are unrelated. Finally, he described the pathological changes underlying senile dementia and its variants, among which is Alzheimer's disease.

In 1912, Alzheimer was appointed to the chair of Psychiatry at the university of Breslau. He fell ill from a heart condition while on the train to Breslau. On arrival he was taken to hospital and had to remain there for a time before taking on the responsibilities at the university. The onset of the first world war left him without his assistants. Years of strenuous work, day and night, with no vacations, sapped so much of his strength that little resistance was left, they say, when his rheumatic endocarditis recurred. He died at the age of 52.

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***The 80th anniversary of the death of Dr Alois Alzheimer is being commemorated in his birthplace in Germany on 19 December. ADI will be there and we hope to bring you more news about this in our next issue of Global Perspective, due out in March 1996.***

# India's second national conference

*Nori Graham, Chairman-Elect of ADI, reports on her experience of the second national meeting of The Alzheimer's and Related Disorders Society of India (ARDSI)*

ARDSI held its second national meeting in Thrissur, Kerala on 5 November. I was privileged to have been invited to give a talk on the theme of 'Burden of Care-Giving' to a most enthusiastic audience of 250 people from all parts of India.

Mr Sayeed, the Union Minister of State for Information and Broadcasting inaugurated the conference. He spoke of the growing needs of 3 million people with dementia in India and the need for greater public awareness. He indicated that there should be government support.

Professor Venkoba Rao, Emeritus Professor from Madurai, opened the scientific session with an excellent talk on dementia in India. This was followed by a number of interesting presentations with perspectives on different aspects of dementia from psychiatrists, neurologists, psychologists and nurses. Professor Mohan Issac from Bangalore gave an excellent account of the impact of the disease on carers. Professor Wadia, Professor of Neurology from Bombay, chaired a lively discussion session in which home care and support for families were highlighted. This session raised questions familiar in every country; who is going to support families, how will they be trained and who will pay?

There were some excellent posters on the survey which has been carried out under the supervision of Professor Abraham Varghese from Vellore who took an active part in the Conference. This study confirms the prevalence of approximately 4% of people over 65 with dementia, very similar to prevalence studies in the developed countries. Also described was an intervention study with trained nurses who were giving support to

families identified as caring for someone with dementia. This study is being funded by Help Age International. This funding is running out and further funding is now urgently being requested to continue this invaluable work.

The meeting was unanimously declared a success and the subsequent TV and press coverage a reward for the immense amount of hard work that had gone into the meeting.



*Dr Nori Graham opens the conference with the traditional lighting of a candle*

It was brought home forcibly to me that Kerala is probably the foremost state in India in its innovative work and commitment to the problems of dementia. This is largely due to the vision, energy and dedication of Dr Jacob Roy, whose father Reverend Kuriakose, also an exceptional person, developed dementia in his late fifties and died a few years ago. The experience his family had in trying to understand the disease and the lack of information in India about dementia, led Dr Jacob Roy to start a national Alzheimer's society five years ago in Kerala, where he lives and works as a paediatrician. With virtually no resources, except for a splendid team of professional and lay volunteers, he has already built up a thriving society and organised this very ambitious and successful national meeting. Other

chapters have now slowly started in the other major cities in India.

The state of Kerala is startlingly different to the rest of India with its near 100% literacy and emphasis on education. I am told that this goes back to the influence of the Maharajas, dating back to the nineteenth century. More recently, the Marxist state government, currently not in power, has been influential over many years. The red flag embroidered with hammer and sickle still flies unashamedly in

front of many houses. The high level of education is probably an additional explanation for the urgency to start addressing the problems of caring for people with dementia. Families now have only one or two children. Many children grow up and look for jobs abroad and parents are left alone which then becomes a problem if one of them develops dementia. Similar situations are now developing in the major cities.

Again a very familiar story to that in developed countries. The need for a change of attitude by all professionals and families from cure to care was a message heard throughout the symposium.

The people of Kerala are warm, friendly, open and ready to discuss and provide information on many aspects of life both domestic and political. The experience I had was unforgettable. I have no doubt at all that the ADI meeting to be held in Kochin, India in 1998 will be an enriching experience for us all and a major boost for people with dementia and their carers in India. I sincerely hope that ARDSI will prosper and that funding will be forthcoming. ADI will do all it can to give support to one of the very few developing countries to have been admitted to ADI, but hopefully soon to be joined by many more.

## CONFERENCES

### Alzheimer Europe – 6th Annual Meeting

*Humanitarian Solidarity in Overcoming Emotional and Physical Problems of Care in Alzheimer's Disease*  
18 – 20 April, 1996  
Warsaw, Poland.

### 1996 Lancet Conference

*The Challenge of the Dementias: towards a better understanding of cognitive impairment*  
April 25 & 26, 1996  
Edinburgh, United Kingdom.

### Alzheimer's Association of Australia – 6th Annual Conference

*Hand it to the Carers*  
Sunday June 2nd – Wednesday 5th 1996. Hobart, Tasmania, Australia.

### Alzheimer's Disease Society (UK)

*The Brain Event – New Frontiers in Alzheimer's Research*  
Friday 5 July 1996. Queen Elizabeth II Conference Centre London SW1.  
Chaired by Jon Snow and Professor Dame June Lloyd DBE.

### Alzheimer's Disease and Related Disorders

24–29 July, 1996 – Osaka, Japan  
Details from: Organising Secretariat, 'Alzheimer 96', Congress Corporation Sunbird Building, 1-12-9 Oyodo-naka, Kita-Ku, Osaka, 531 Japan.  
Tel +81 6 451 7157  
Fax +81 6 454 4711

### ADI 12th International Conference

*'... to give you a future and a hope.'*  
October 8–11, 1996.  
Jerusalem, Israel.  
Details from Conference Secretariat, PO Box 50006, Tel-Aviv 61500, Israel.  
Tel +972-3-5140000 or +972-3-5140014

### ADI 13th International Conference

September 15–17, 1997.  
Helsinki, Finland.  
Details from ADI secretariat.

### ADI 14th International Conference

September/early October 1998.  
Cochin, India.  
Details to follow.

## NEW PUBLICATIONS

### Alzheimer's Disease – Starting a Self-help Group

Offers help in starting a self-help group for those who care for people with Alzheimer's disease and other forms of dementia. Available in English and Spanish free from ADI Secretariat.

### How to set up an Alzheimer's Society

Aimed at helping those starting organisations and those in the early stages. Available in English and Spanish free from ADI Secretariat.

### 'oio meguru jyuuni purasu ichi wa' (12+1 Stories on Aging)

Psychological aspects on aging (in Japanese). Dr Yoshio Miyake, Association of Families Caring for the Demented Elderly. Kyoto, Japan.  
Tel +81 75 811 8195  
Fax +81 75 811 8188.

### Alzheimer's Update

Directory of new publications relating to Alzheimer's disease and other dementias. Price: £20 per year (6 issues). Available from Alzheimer's Disease Society. Tel +44-171-306 0606.

# 12th International Conference of Alzheimer's Disease International

8-11 October 1996 in Jerusalem, Israel

### Main Topics

- Education for the patient, the family, the community
- Genetic counselling
- The rights of the demented patient – legal and ethical issues
- Treatment of Alzheimer's disease now and in the year 2000
- Organizing a safe environment
- The wandering patient
- Care for the caregivers – helping families cope
- Fund-raising for Alzheimer Associations
- Choosing the right nursing home
- Social policy

- Development of services and support groups
- Molecular biology and genetics of dementia
- Update on drug studies
- Brain imaging
- Care and caring

### Special Sessions

- Seizures in the elderly
- Seizures in Alzheimer's Disease
- EEG study of the elderly
- EEG drug studies in Alzheimer's Disease

Details from ADI Secretariat.

