



Global Perspective

Newsletter for Alzheimer's Disease International, (the International Federation of Alzheimer's Disease & Related Disorders Societies, Inc.)

Vol. 1, No. 2

August 1990

ADI's Sixth International Conference Draws Experts From 24 Countries

"We are truly excited by the impressive level of expertise of scientists, clinicians and care providers who will come from 24 countries around the world to take part in the Sixth International Conference of Alzheimer's Disease International," says Lic. Lilia Mendoza, Conference Secretariat.

Basic research scientists, health care professionals at all levels, and family members of victims of Alzheimer's disease will attend the 5-day Conference at the Hotel Seville Palace, in Mexico City, September 23-27, 1990. The Conference site is located in the very heart of a city of great historical tradition and beauty. (The

world's largest city, it has a population of 20 million).

On Sunday, September 23, the ADI Council will be convened at 2:00pm for its annual meeting. At 4:00pm representatives from Latin-American countries, Spain and hispanic persons from the U.S. will meet to establish common goals and strategies for the care of Alzheimer's patients and their families. Chairman will be Juan Carlos Caballero, MD, Spain.

On Monday, September 24, the full Conference will open with a plenary session. Participating in opening ceremonies will be Princess Yasmin Aga Khan Jeffries, President of ADI, Dr. Jesus Kumate, Mexico's Minister of Health, and Lic Lilia Mendoza,



ADI Conference planners take a moment to be photographed for *Global Perspective*, (standing) Luis Miguel Gutierrez, MD., Eugenia Castillo, MS, Marcela Feria, MA., (seated) Rosalia Rodriguez, MD., Lic. Lilia Mendoza, Alisa Alonso, MD.

President, Mexican Alzheimer's Association.

Following the opening ceremonies, keynote speakers, Dr. Franz Baro (Belgium) and Nancy Lombardo, PhD, (US) will discuss International Cooperation on Alzheimer's Disease and Public Policy Issues.

Reviewing the program, Lilia Mendoza said, "The Conference will have leading international experts discussing promising new research; diagnosis and assessment; genetics; autopsy; and Alzheimer's in younger patients. Behavioral problems; sexual issues; bereavement; the impact Alzheimer's disease has on families; relief systems for carers and legal issues in comparative terms will be discussed. Development and growth issues for member Alzheimer asso-

ciations and newly forming groups will be on the agenda."

Special tracks on basic research; diagnosis and assessment; training; caring; community services and day care programs will also be offered.

"One highlight of the Conference will be the symposium on Cross Cultural Studies in Alzheimer's Disease," Lilia Mendoza points out. "Presenters will include: Robert Katzman, MD, University of California (San Diego) School of Medicine; Jean-Francois Foncin, MD, Laboratoire Montyon La Salpetriere, Paris, France; Professor Luigi Amaducci, the SMID Center, Florence, Italy; Barry Gurland, MD, Center for

Geriatrics & Gerontology, New York, NY; Denis Evans, MD, East Boston, Massachusetts, Neighborhood Health Center; Benjamin O. Osuntunkon, MD, Nigeria; and Mingyuan Zhang, MD, Shanghai Institute of Mental Health."

One conference-related tour will be offered. It will feature a visit to Tepexpan Hospital for Chronics (situated in a former cloister). In addition to the hospital, the tour will include a visit to the 5,000 year old temples of Teotihuacan located nearby.

For more information, please contact Lic. Lilia Mendoza, Conference Secretariat in Mexico City, Tel: (525) 277-3552, or Rachel Billington, Deputy Secretary, Alzheimer's Disease International, Tel: (312) 853-3060.

Reader in England Offers Fund Raising Tips

Dear Editor, I am a paid employee of the South Cleveland Branch which is situated in the North East of England with our administration office at the Middlesborough address. In addition to other responsibilities, I am Chairman of the Branch Fund Raising Committee.

Although we are quite successful with our Fund Raising, it places a tremendous burden on the committee members, most work as volunteers in our Day Centres.

I have been campaigning for sometime to form what I call "Fund Raising Support Groups." These are groups of people or individuals who are not involved in the care of a sufferer but are friends, sons, daughters, aunts, uncles, nephews and nieces—in fact, anybody who can organise an event. A coffee morning, afternoon tea, strawberry teas, raffle, etc.

Currently, I have such groups in local "pubs" (bars to those who have not visited our shores). I have individuals who organise events in their own homes, others who plan Charity Concerts in Clubs and Community Centres.

This method of raising money serves two purposes, first it raises much-needed funds and secondly, an evening of publicity can be arranged for the presentation of a cheque (the money raised) to the local Branch.

The whole system is worth the initial effort because as far as staff are concerned, once it is established it is not labour or time consuming. It is surprising how dedicated fund raising workers become.

If you can organize twenty to fifty groups of individuals each raising cash two or three times a year, a sizeable amount can be accumulated. Quite often such supporters skills and abilities, which were forgotten or unknown, are re-awakened or established. Best of luck to all Fund Raisers.

A. Bernstone, Chairman
Fund Raising Committee

The ADI Global Perspective is published quarterly by Alzheimer's Disease International (The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.), 70 E. Lake Street, Chicago, Illinois 60601-5997. Tel: (312) 853-3060.

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Publications from Around the World

Old, Alone, and Neglected: Care of the Aged in the United States and Scotland.

Jeanie Schmit Kayser-Jones. An analysis of the effect of the development of health care for the chronically ill aged, and the effect of the two cultures and their structures on the interaction of patients and staff. University of California Press, Berkeley 94720.

Wessex Memory Manual: A Self-Help Guide for People with Everyday Memory Difficulties.

Discusses types of memory and a range of common memory symptoms in a 32-page illustrated booklet. It is intended to help persons cope with memory difficulties they may encounter in their daily lives. Contact: Dr. N. Kapur, Wessex Neurological Center, General Hospital, Southampton SO9 4XY England.

Vivir con...la enfermedad de Alzheimer,

Guia práctica para los familiares y todos aquellos que esté cercanos a una persona afectada por la enfermedad de Alzheimer. Jacques Selmes and Micheline Antoine Selmes. Write: Meditor, S. L.; Alberto Alcocer, 33, 5 Centro; 28036 Madrid, Spain.

Alzheimer's Disease and Related Disorders: Psychosocial Issues for the Patient, Family, Staff and Community.

Richard Mayeux, Barry Gurland, Virginia W. Barrett, Austin H. Kutscher, Lucien Cote & Zetta H. Putter. Publisher, Charles C. Thomas, 2600 South First Street; Springfield, Illinois 62794-9265.

The Loss of Self: A Family Resource for Care of Alzheimer's Disease and Related Disorders.

Donna Cohen, PhD.; Carl Eisdorfer, PhD., MD., W. W. Norton & Company, New York, London.

Doing Things: A Guide to Programming Organized Activities for Persons with Alzheimer's Disease.

Jitka Zgola, Occupational Therapist, Ottawa, Canada. Book is available through Johns Hopkins University Press, 701 West 40th Street, Baltimore, MD.

Research Booklet.

Alzheimer's Disease Society in England combines past newsletter features on Research. Write: ADS; 158-160 Balham High Road; London SW12 9BN.

Aging of the Brain and Alzheimer's Disease.

Proceedings of the 14th International Summer School of Brain Research, Royal Netherlands Academy of Arts & Sci-

ences, Amsterdam. Edited by D. F. Swa. E. Fliers, M. Mirmiram, W.A. Van Good and F. Van Haaren. Elsevier Science Publishers Co. Inc., P. O. Box 211, 1000 AE Amsterdam, The Netherlands.

Dementia Care: Patient, Family, and Community.

Edited by Nancy L. Mace. The Johns Hopkins University Press, 701 West 40th Street, Baltimore, and Johns Hopkins University Press, Ltd., London.

Biological Markers of Alzheimer's Disease,

edited by F. Boller, R. Katzman, A. Rascol, J. L. Signoret, and Y. Cristen, Springer-Verlag, Berlin, Germany, 169 pp., 1989, \$64.50 (cloth).

Potential Use of Nerve Growth Factor to Treat Alzheimer Disease.

C. H. Phelps, F. H. Gage, J. H. Growdon, F. Hefti, R. Harbaugh, M. V. Johnston, Z. S. Khachaturian, W. C. Morley, D. L. Price, M. Raskind, J. Simpkins, L. J. Thal, and J. Woodcock. *Neurobiology of Aging*, Vol. 10. pp 205-207. Write: Medical & Scientific Affairs; Alzheimer's Association; 70 E. Lake Street Chicago, Illinois 60601.

Neurotrophic Agents May Exacerbate the Pathologic Cascade of Alzheimer's Disease

Larry L. Butcher and Nancy J. Woolf. Laboratory of Chemical Neuroanatomy, University of California, Los Angeles. *Neurobiology of Aging*, Vol. 10 pp. 557-570. Pergamon Press, 1989.

Home is Where the Care Is,

American Association of Retired Persons (AARP). A home-study program (5 audio tapes & 3 workbooks) on: personal care, community resources, finance, law, medication, nutrition, home safety and family interactions. Contact: Lucy Theilheimer, Sr. Program Specialist, AARP, 1909 K St. N. W.; Washington D. C. 20049. Tel: (202) 872-4700.

The Dementias,

a basic pamphlet, has been produced in Arabic, Croatian, Greek, Italian, Maltese, Polish, Portugese, Russian, Serbian, Spanish, and Turkish by ADARDS (NSW) and the New South Wales Department of Health. Write: ADARDS (NSW) P. O. Box 139; Ryde, NSW 2112.

Proceedings of ADI's 6th International Conference,

will be published. Read how to obtain them in the next issue of *Global Perspective*.

New Diagnostic Test May Verify Alzheimer's Disease

The June 6, 1990 issue of *Journal of American Medical Association*, reports on a new biochemical test, developed by Abbott Laboratories, which may serve to confirm the diagnosis of Alzheimer's disease.

Hossein A. Ghanbari, PhD, and his colleagues at Abbott Laboratories and several universities report that the test, administered at autopsy, detected an Alzheimer's disease associated protein (ADAP) in 85.7 percent of Alzheimer cases studied. The researchers claim that the test is not only highly specific in detecting the presence of

ADAP in Alzheimer brain tissue, but is also reliable in confirming the absence of the protein in normal individuals and those with other neurological disorders.

It may be possible to use this test on living tissue obtained through brain biopsy, however, because of the risks involved, it is unlikely that it will become a routine diagnostic procedure. One of the next steps will be to identify these Alzheimer's disease associated proteins in the cerebrospinal fluid surrounding the brain and spinal cord. If these proteins are detected in the cere-

brospinal fluid of Alzheimer patients, a diagnostic test could be developed for living patients. This study represents a significant research finding, and eventually may provide a means to diagnose patients earlier than presently possible. However, additional research will be required before its true significance can be recognized.

Until a definitive diagnostic test has been developed and approved, autopsy remains the only way to positively diagnose Alzheimer's disease.

Diagnosis of Exclusion Rules Out "Other Conditions"

Alzheimer's associations are frequently asked about the related disorders and "other causes of dementia" that are ruled out in the diagnosis of exclusion that is required to determine if a patient has AD. A recent publication offers a current and succinct explanation which follows, in part.

"Several medical conditions can present as progressive cognitive impairments, including thyroid and other endocrine diseases, vitamin B12 deficiency, and a variety of other body system malfunctions," say Marian B. Patterson, PhD, and Peter J. Whitehouse, M.D., PhD., in *Dementia Care: Patient, Family, and Community*, edited by Nancy Mace (1990, Johns Hopkins University Press).

"The most common causes of dementia," the authors state, "are Alzheimer's disease and related degenerative diseases of the nervous system and multi-infarct dementia caused by multiple strokes."

They go on to list 31 causes of dementia, including Alzheimer's disease, saying "Many of these conditions are at least partially treatable and, therefore, require careful evaluation." They note that several neurodegenerative diseases besides Alzheimer's are associated with dementia.

An information sheet *An Overview of the Dementias* accompanies this newsletter.

Patterson and Whitehouse explain that several psychiatric conditions can also present with progressive cognitive impairments as part of the picture. "Depression is common in older people and can present with slowed thinking and memory impair-

ment. Depression should be considered in every patient, but particularly when there is a past history of depression, sudden onset of symptoms, stressful environmental events, and changes in appetite and sleep pattern." They discuss briefly other psychiatric conditions and point out that other disorders that result in dementia can have associated secondary psychiatric symptoms, including, hallucinations, illusions, paranoia, delusions, and affective signs.

"One major treatable form of cognitive impairment in older patients that must be specifically ruled out is drug misuse or abuse," Patterson and Whitehouse advise, concluding, "Aged people frequently see several physicians, who may prescribe several different drugs, which interact to produce cognitive impairment. A careful history of drug usage from both patient and caregivers is essential to the evaluation process. A drug without clear-cut medical indications can often be stopped to assess its role in adding to confusion."

ALCAR Testing

ALCAR (acetyl-L-carnitine), a drug developed by Sigma-Tau Pharmaceuticals, is being tested in Alzheimer patients. The drug is believed to exert a protective action on nerve cells; widespread nerve cell loss occurs in AD. ALCAR was tested on over 1,000 people in Europe suffering from various forms of dementia including AD. Additional testing is necessary before the drug can be made widely available.

New Theories About Amyloid

Researchers investigating the causes of Alzheimer's disease are hot on the trail of amyloid protein. Amyloid protein, along with degenerating nerve tissue, form the plaques found in the Alzheimer brain. Investigators have determined that AD amyloid is a small fragment of a much larger protein, called amyloid precursor protein, which is normally cut to produce harmless proteins. But, when improperly cut, it creates the abnormal amyloid protein associated with AD.

Scientists are searching for the events that initiate the improper cutting of the amyloid precursor protein and for ways to prevent the steps leading to the production of AD amyloid.

By using newer techniques to locate amyloid in the brain, investigators discovered diffuse amyloid deposits outside of AD-related plaques. Researchers speculate that this might mean that amyloid may be deposited prior to nerve cell death.

Lending support to that theory is the recent discovery of amyloid protein deposits in the skin and intestines of Alzheimer patients. This may mean that amyloid protein originates elsewhere and travels to the brain via the bloodstream. However, most researchers believe that amyloid protein is initially produced by the nerve cells themselves. More study is needed to determine whether amyloid protein primarily originates in the brain or in other organs of the body.

France Alzheimer Initiates Innovative Respite Program

In response to our call for news, Svante Svahnstrom, Executive Director of France Alzheimer, FAXed to us a story about a most interesting and innovative approach to respite care that the France Alzheimer association has undertaken. Following is his report.

"Three holiday stays (vacation packages) are offered to our association's families in 1990. These have been preceded by two previous stays in 1988 and 1989. In fact, we think that the first stay must have been a world premiere in this field."

"The idea originated in 1986 when a family asked us where it was possible to spend holidays together with their patient and still not have to look after him all of the time, a place where competent people would offer interesting activities for the patient—and rest, for the family."

An Idea is Born

"I quickly realized that such an institution did not exist, so I decided that it had to be created by us. We first proposed the idea to the members in 1987. But it was too near summer holidays and most families had their plans set for the following months. And then again, nobody knew if they could really trust this new idea."

So nothing was done in 1987. Then, we were hoping for 10 families in 1988, but were very near to cancelling it all because we had only three families registered. However, changing partners, we decided to make a try with only six families and did the necessary to add three more.

"Since the 1988 stay, which was a tremendous success, we have kept the number down to six of seven families (couples of spouses, siblings, or children/parents).

"The stays take place in a holiday camp, off season, together with other senior vacationers suffering from no particular handicap. The only requirement for the patients

is that they are able to move about freely. Incontinence is no problem as long as our staff is not called upon for nursing services.

Staffing is Increased

"Starting with one recreational worker trained by our association, we have in 1990 engaged two paid staff and one volunteer for taking care of the Alzheimer patients.

"The primary aim of these stays is to give families a chance to rest without having to be separated from their patients. (Some, however, won't let go of their patients for a single second, whereas others may participate in the activities arranged by the staff of the holiday camp). It is clearly understood that the France Alzheimer staff have no responsibility for clothing, washing or toileting the patients, other than in exceptional situations.

"A secondary aim is modest, but no less real—to give families and patients a chance to appear in public and be accepted participating in real life situations. As such, our stays hope to be small milestones on the way to integration in the greater society.

"Apart from programmed diversions, we also offer an opportunity for carers to speak in a relaxed way with the association's psychologist. She is available for almost two days for anyone who wishes to talk to her. In the evening, she gives an informal lecture on day to day coping strategies."

Outcome of Holiday Stays Offers Some Surprises

"A strong sense of solidarity grows among the participating families, many of whom meet patients other than their own for the first time during this week. Frightened at first, they come to realize in this ad hoc manner the true gravity of their own sufferer's impairment. Meeting and living with other families has been for all a most informative and rewarding experience."

"Closeness within the group has been strong that other vacationers have envied them, especially since they could not tell families from patients. Fellow vacationers have also at times been very helpful, and always felt very concerned.

"Another surprise was that the sufferers seemed less disturbed by the new setting and new faces than might have been expected. Most have taken part calmly and with some great pleasure in our group's activities. One critical key to success this year has been the hiring of a male staffer who provides a needed dimension to communications and activities for male patients.

"The holiday stays have helped us to a very important discovery in that this very spontaneous interdependence between group members (unexpected by the families) can lead carers to important decisions for their everyday lives. Seeing their patients interact with other people and realizing that they can feel quite secure under these circumstances, families have been able to consider accepting outside help in the home or even taking their sufferer to nursing home, with a very strongly reduced sense of guilt.

Out of Experimental Stage, Holiday Stays Program Will Continue

"In 1990, experimentally, the association took care of all staff costs, which reduced family costs by 50%. The increased demand provoked by this measure led us to add a third stay to the two originally scheduled this year. Around \$10,000 has been allotted to family holidays. We will decide during the coming months whether this experiment is to be continued.

"Holiday stays will definitely continue, but the format and costs may have to vary. Families have expressed their wish that the stays last ten days instead of seven."

What They're Doing . . .

Alzheimer's Disease Society in England reported in its July 1990 newsletter that their London Marathon raised over £20,000. In another venture earlier this year, the Society obtained a slot on the BBC Lifeline Appeal which was broadcast twice. The ten minute program consisted of a major appeal for funds for the Society by a

celebrity. Society volunteers staffed eighteen phone lines after the program to receive public donations. The final total raised by the Lifeline Appeal is £52,579.75.

A beautiful brochure describing Holiday Cards for sale came along with the Society's recent newsletter. Each card is imprinted with: *Sold in aid of: Alzheimer's Disease*

Society, The Society that cares about Alzheimer's Disease and Related Disorders.

Associazione Italiana Malattia de Alzheimer joined with other Milan health agencies in the Health Division of the Milan Trade Fair in April 1990. They distributed AIMA Alzheimer literature as well

Continued on Page 6

Caregivers' Needs Require and Get Organizational Response



Alzheimer's associations around the world recognize that most often a caregiver is a person who devotes "36 hours a day" to caring for a person with Alzheimer's disease. Such a caregiver may be a spouse, an adult child; the mother of a younger victim; a friend; or, a medical professional. No matter caregivers' relationships to the afflicted, their common goal is to provide the best available care for the Alzheimer victim.

The Caregiver's 36 Hour Day

Over the course of the disease, which may last from two years—to as many as 20 years or more, Alzheimer's gradually strips away its victims' mental and physical capacities, eventually rendering afflicted persons incapable of caring for themselves, or even recognizing family members. Alzheimer victims often require 24-hour care. As the

disease progresses, help will be needed with routine activities such as grooming, eating and toileting. Most families of Alzheimer victims choose to care for their loved ones at home for as long as possible. In the United States it is estimated that about 70 per cent of the care for Alzheimer patients is provided in the home.

The Second Victim

The devastation of Alzheimer's disease is not restricted just to the afflicted persons. The emotional,

physical and financial impact of AD upon family caregivers often renders them the "second victims" of the disease. In their desire to provide the best care for their loved ones, caregivers frequently forego their own needs, including social life, work, their own health care, as well as interaction with other family members. As a result, many become subject to more stress-related health problems such as strokes and heart attacks.

A recent survey conducted by a U.S. Alzheimer's Association-funded researcher found that, of nearly 1900 employees responding to a survey, 22 percent were providing physical, financial or emotional assistance to a person at least 60 years old. The study, by Dr. Andrew E. Sharlach, PhD, of USC's School of Social Work, showed individuals caring for a cognitively-impaired older person with a condition such as AD

have more personal and professional hardships than those caring for a physically-impaired older person.

Caregivers cited among their most serious concerns their need for respite care so that they could replenish their mental and physical strength; their need for support from friends and other family members; their fear that they may become ill or unable to fulfill their role; and their concern about the uninsured costs for adequate care in the advanced states of the disease.

The Alzheimer's experience is as individual as the persons who contract the disease—and their families. From around the world ADI receives many letters from caregivers. There is a sad, consistent, theme that runs through the individual private stories they tell of the frustration of watching helplessly as the disease decimates lives and steals away loved ones. They tell of the unwieldy, seemingly endless, burden of caring—and the pain of the "funeral that never ends."

ADI Members Understand and Support Caregivers

ADI members (national Alzheimer associations around the world) recognize the needs of family members who are caregivers. They are keenly aware of the burden and stresses involved, and for many individuals, their hard-won knowledge provides the motivation to form as associations...to stand by Alzheimer's families. (It is also the reason Alzheimer associations develop helplines to provide information and counseling in times of stress. And, it is the reason they provide support groups for "ventilating" and sharing tips on coping among peers who truly understand the demands of the caregiving experience). ADI members also recognize the critical need for respite care. They work to stimulate the development of adequate Alzheimer-appropriate respite and long term care services in their various forms.

Many of these and related issues will be discussed during ADI's Sixth International Conference in Mexico City in September. We also plan to update our readers on members' developing programs in future issues of Global Perspective.

The Netherlands to Host 1991 ADI Conference

The 7th International Conference of ADI will be held in Amsterdam, September 23-25, 1991. It is planned that Her Majesty Queen Beatrix will attend the opening ceremony. Her presence, it is felt, will emphasize the great importance of research into Alzheimer's disease and its implications for society in the decades ahead.

Conference planners have been at work for many months corresponding with scientists from around the world who will join ADI members in the historic city to discuss their research goals, methods and outcomes. Special attention will be given to the results of the large European epidemiologic investigation—EURODEM.

Amsterdam, Holland's financial, commercial and cultural capital, is one of the top ten convention cities in the world and there the RAI Conference and Exhibition Centre

(where ADI will hold its Conference) plays an important part.

Amsterdam was founded in 1275 at a dam in the river Amstel and was for centuries a leading trade centre with a large harbour. Nowadays Amsterdam is the capital of the Netherlands, with 42 museums including the Rijksmuseum, the Vincent Van Gogh museum and Anne Frank-huis.

The character of the city centre is mainly determined by 17th and 18th century architecture including the Westerkerk church, the Royal Palace (former townhall) on the Dam and the many gables along the symmetrical rings of canals, with over 1,000 bridges.

Amsterdam's old inner city is famous for its compactness. More than 7,000 historic buildings from as far back as the fourteenth century are all within walking distance.

The best way to see Amsterdam is to take

a canal trip. Every night part of the route is illuminated with thousands of lights, creating a magical atmosphere.

In the immediate vicinity of Amsterdam are historic villages and picturesque old towns. All sorts of guided tours are available, among them some that take you off the beaten track under the guidance of art historians.

Amsterdam has about 23,000 beds in 250 hotels in every class and price category. Other, more economical, accommodation are also available.

In addition to the lively and rich exchange of information that will take place at ADI's 7th International Conference, Amsterdam and its surroundings are well worth a visit.

Society Creates Identity Booklet for Wanderers

Alzheimer's Society of Montreal (ASM) has produced a 12-page identity booklet for use by Alzheimer caregivers. The booklet is intended to make the search easier when an Alzheimer victim wanders and becomes lost. Society spokesperson, Thelma Cadieux, says the booklet is the only one of its kind in Canada. "Other provinces use a registration card system," she explains. "Vital statistics are kept by police in the event a missing person report is filed. But, under Quebec law, police are not permitted to keep a medical dossier on individuals." The booklet was conceived in response to this legal obstacle.

The document contains an identification section where the person's name, date of birth, sex, distinguishing marks, eye color and other descriptive features are noted. There are also several pages for insertion of 5 x 7 inch photographs. Another section is reserved for medical information, including doctor's name and phone number, and the individual's blood group, allergies, and prescription medications. A quarterly reminder goes out to all registered booklet users in order to ensure the medical information is kept current.

Tips on how to approach someone who may be lost, how to prevent wandering in

the first place, and what to do when someone does wander, are all provided in the useful resource. The booklet also encourages caregivers to keep a file recording the person's habits and disappearance history, as well as the names, addresses and phone numbers of family, friends and previous employers. In the event that the individual does disappear, both the booklet and the information on file are provided to police to help them in their search.

The ASM has registered almost 1000 users since late 1989. With some 30,000 people in the greater Montreal area now affected by various forms of dementia, and the numbers expected to rise, the ASM has produced 30,000 copies.

The Society has also instituted an identity bracelet program to complement the booklet system. Thelma Cadieux notes that the ASM document can be easily adapted for use in other communities, and that the Society, in cooperation with GAZ Metropolitan, is willing to grant reproduction rights to interested organizations.

Info contact: Alzheimer Society of Montreal; 3974 Notre-Dame Street, West; Montreal, Quebec H4C 1R1. Tel: (514) 931-4211.

Source: Seniors Info Exchange, Seniors Secretariat, Health & Welfare of Canada.

What They're Doing...

(From Page 4) as literature from Englar U.S. and Germany. They helped publicize ADI, distributing the *Global Perspective*, and conveying the message "Alzheimer Families United all over the World to Defeat Alzheimer's Disease."

ADARDS of South Australia, recognizing the need for raising awareness about Alzheimer's disease, has arranged as part of its Awareness Week program to sponsor a series of seminars on Alzheimer's disease conducted by Nancy Mace. ADARDS, SA will also present 120 copies of *The 36 Hour Day* to their State Library System.

Alzheimer's Society of Canada has a unique program, *Making Memories Together*. Started in 1989, it has three parts: a corporate donation from Price Daxion, an employee payroll deduction plan, and a coin can campaign. This year, the program has a new twist. Proceeds from the 1990 coin can campaign (10,000 coin cans were placed in selected outlets) will be turned over to the provincial Alzheimer Associations. The Society seeks to involve local communities more fully in the *Making Memories Together* program, hoping to benefit both those faced with the disease now and those who may be faced with it in coming decades

Calendar of International Events

September 13-14, 1990

The Other Side of Alzheimer's, a national conference co-sponsored by The Family Respite Center, Alzheimer's Association; National Institute on Aging; Administration on Aging, e.a., in Washington, D.C. For more information, contact: Lyn Noyes, Director, Family Respite Center, (703) 532-8899.

September 15, 1990

The Alzheimer's Disease Society, England, Fourth Annual Meeting & Symposium on Community Care: Is There Real Choice? University of East Anglia, Norwich, England.

September 17-18, 1990

First National ADARDS Conference: *Managing The 36 Hour Day*, Perth, Western Australia. Keynote speakers will include: Dr. Henry Brodaty; Brian Howe; Dr. Zaven Khachaturian; Nancy Mace; Dr. Jon Currie; Robyn Pritchard and Professor Colin Masters. For information, Promaco Conventions, Pty, LTD; Unit 9A, Canning Bridge Commercial Centre; 890-892 Canning Highway; Applecross 6153, Western Australia. Tel: (09) 364-8311.

September 17-19, 1990

A symposium *Memory Function in Aging & Aging Related Changes*, Clarion Hotel, St. Louis, Missouri. Contact Conference Secretary, VA Medical Center GRECC (111G-JB); St. Louis, MO 63125; Tel: (314) 894-6510.

September 21-22, 1990

Diagnostic Procedures in Dementia Conference, Gothenburg, Sweden. For more information, contact: Bertil Steen, MD; Department of Geriatric Medicine, University of Gothenburg, Vasa Hospital, S-4113, Gothenburg, Sweden. Tel: 46-31-617760.

September 22-23, 1990

International Psychogeriatric Association workshop: *Diagnostic Procedures in Psychogeriatric Medicine*, Gothenburg, Sweden. Contact: Scientific Secretariat: Margareta Magnusson, Department of Geriatric and Long Term Care Medicine; Gothenburg University; Vasa Hospital; S-411 33 Gothenburg, Sweden. Tel: +46-31-61 77 61; or, Administrative Secretariat: Congress House AB; Ostra Hamngatan 45; S-411 10 Gothenburg, Sweden. Tel: +46-31-10- 15 80.

September 23-27, 1990

Sixth International Conference of ADI, Hotel Seville Palace, Mexico City. For more information, FAX to Conference Secretariat, Lic. Lilia Mendoza, Mexican Alzheimer's Society; FAX: 525-535-3842; or, call: 525-277-3552.

October 11-15, 1990

Alzheimer's Association, U. S., Tenth Annual Meeting and Conference *Preparing for the Second Decade*, in Chicago, Illinois. For more information, contact: Alzheimer's Association, 70 E. Lake Street; Chicago, Illinois 60601. Tel: (312) 853-3060.

October 25-28, 1990

19th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology, Victoria, British Columbia. Theme: *Beyond Survival: Quality of Life in Aging*. Contact: Jean-Claude Carisse, Canadian Association on Gerontology, Suite 110, 1565 Carling Avenue, Ottawa, Ontario K1Z 8R1. Tel: (613) 728-9347.

October 26-28, 1990

ADARDS New Zealand; National Conference; Blenheim, Marlborough. For further information, write: The Secretary ADARDS (Marlborough); Box 993; Blenheim, N.Z.

October 30, 1990

4th International Francophone Conference on Gerontology, Montreal, Quebec. Theme: *Interdisciplinarite*. Contact: Les services de congrès GEMS, C.P. 997, succursale Snowden, Montreal (Quebec) H3X3Y1. Tel: (514) 485-0855.

November 1-2, 1990

A conference organized by Scottish Action on Dementia will be held at Crieff Hydro, Perthshire, Scotland. For more information, contact: Ewan Davidson, Director, Alzheimer's Scotland.

November 16-20, 1990

The Gerontological Society of America, 43rd Annual Scientific Meeting, *Generations: Continuities, Conflicts, Reciprocities*. For information: The Gerontological Society of America; 1275 K Street, NW, Suite 350; Washington, DC, 20005-4006. Tel: (202) 842-1275.

August 18-23, 1991

Fifth Congress of the International Psychogeriatric Association, Jerusalem, Israel. For information, contact: Fifth Congress of the International Psychogeriatric Association; P. O. Box 50006; Tel Aviv 61500, Israel.

September 11-14, 1991

II European Congress of Gerontology; School of Medicine, Complutense University; Madrid, Spain. Host Society: Spanish Society of Geriatrics and Gerontology. Write Organizing Secretariat: GEYSECO, S.A. Capitan Haya, 60, 2º. - 28020 Madrid, Spain.

September 23-25, 1991

Seventh International Conference of ADI, Rai Congress Centre, Amsterdam, Netherlands. For more information, contact: H. T. ter Haar, Secretary General, Alzheimer Stichting Nederland, Seadwei 8, 9261 XM Oostermere, Netherlands. Tel: 05129-1202.

September 24-28, 1991

Third Familial Alzheimer's Disease Symposium. ZMBH—Universitat Heidelberg; Im Neuenheimer Feld 282; D-6900 Heidelberg, Germany. Tel: 49-6221-566809; FAX: 49-6221-566809.

Spring 1992, International Psychogeriatric Association (IPA) Workshop in Liege, Belgium. Fall 1993, Sixth International Congress of IPA, Cologne, Germany. For more information, contact: IPA 3127 Greenleaf Avenue; Wilmette, Illinois 60091, USA. Tel: (312) 251-5516, FAX: (312) 272-5312.

July 4-9, 1993

XVth International Congress of Gerontology; Budapest Convention Centre, Budapest, Hungary. The IAG is a major international scientific meeting held every four years. Host society: Hungarian Association of Gerontology. Conference Secretariat: Budapest Convention Centre; Budapest POB 233; H-1444 Hungary. Scientific information: Tel: (361) 113-5411, TELEX: 225070 sote h.

ADI Office Established; Global Perspective Needs Member Input

This year, ADI has an office in space contributed by the U.S. Alzheimer's Association headquartered in Chicago, Illinois.

ADI is in correspondence with 51 countries, some have Alzheimer organizations that plan to join ADI in the future. Others have several groups in place that seek to organize into a single national organization. Still other contacts are with individuals who plan to start organizations in their

countries. "We provide them with informative literature and will continue corresponding to provide encouragement and support," says Ed Truschke, Secretary General.

The ADI newsletter now goes out to nearly 2000 persons. Most names on the list are supplied by ADI members; others, are those who have written asking about AD.

Global Perspective is another tool for providing information and support to indi-

viduals, and nascent or developing member organizations. Please send articles or photographs to share information on research updates, your programs and goals, etc. Deadline for receiving materials for the December newsletter is November 15, 1990. Please send materials to Rachel Billington, Deputy Secretary, Alzheimer's Disease International; 70 E. Lake Street; Chicago, Illinois, 60601. FAX: (312) 853-3116.

Alzheimer's in Australia—One Country's Story

Australia is a big country of over 7,682,300 square kilometres, with only 16.5 million people, the majority of whom live along the eastern seaboard. It is divided into six States, and two Territories. The tyranny of distance and small scattered populations has had a dramatic effect on the development of the ADARDS network in this country.

In Australia, organisations aimed at providing support, information and education for the carers of people with dementia were formed in each of the six States between 1982 and 1984. They adopted the name "Alzheimer's Disease and Related Disorders Societies (or Associations), and the acronyms ADARDS or ADARDA. Many had their origins within the structure of State Associations of Mental Health, and later sought independent status. The "baby" of the family is the Northern Territory organisation, formed only last year, and covering 1,346,200 square kilometers of "Crocodile Dundee" country with a population of only 137,000!

The State organisations have always had in common their emphasis on the needs of the carers for support and education, and the need to promote community awareness about dementia. However, each has developed somewhat differently (as all community-based organisations do) according to the concerns of particular individuals and the characteristics of different environments. For instance, several have also developed an additional role in direct service provision: Queensland in Day Care; Tasmania in Nursing Home Accommodation; Western Australia in Home Respite Services. Others are cautious about the effect of such developments on their organisations. Nearly all provide carer education programmes and staff training programmes; educational resources including printed material, audio-tapes and videos,

stickers and posters. A major focus for activity is the annual National Alzheimer's Awareness Week.

By early 1990 there were more than 220 local support groups in Australia, with new ones being established at an unprecedented rate. The welcome but inadequate funding base from Federal and State Government sources is beginning to be augmented by substantial private donations in several States, and major expansion of services is occurring and being planned. Some State Associations/Societies are developing a branch structure in addition to local support groups, others see this as unnecessary.

To promote co-operation and co-ordination, the State Associations/Societies joined together in 1985 to form a national organization—ADARDS (Australia). (In our case, the children gave birth to the parent!) Although this affiliation remained without an office or paid officers until 1989, ADARDS (Australia) was pleased to host the 1988 Fourth Alzheimer's Disease International Conference in Brisbane, Queensland, and to welcome over 500 delegates.

The success of the International Conference heralded a new stage of development for ADARDS (Australia), and late last year a grant was gained from the Federal Government to establish a National Secretariat. There was a need to formalize the national organization in this way to provide a stronger lobbying voice on national issues, and to co-ordinate and facilitate the work of the State Associations/Societies. Soon after the establishment of the National Secretariat, a Federal Election was called in Australia, and this stimulated the production of a major national lobbying publication called *A Fair Go for Dementia*. This document detailed our concerns in the areas of family support services, the provision of quality residential and community

care programs, and the need for more Australian research into Dementia—the current meager research expenditure of less than 8 cents per capita per annum must be increased. A great deal of useful publicity has come out of this exercise—there's nothing like being thrown in the deep end!

More recently, ADARDS (Australia) has been reviewing its corporate image in light of the need to expand its sphere of influence. The decision—with some nostalgic reluctance—has been taken to change our name to Alzheimer's Association (Australia), and the expectation is that in time State Association/Societies will follow suit. This decision has been taken on the understanding that the related disorders must never be ignored. We are also currently developing a new logo, and our slogan will be *Sharing the Caring*.

These last few months have been exciting times for the ADARDS network in Australia. Our development covers with much heart-searching that we do not, in the process, lose our roots—that is, our primary responsibility to people with dementia and their carers in Australia.

Organisations devoted to the needs of people with dementia and their carers have developed, and will continue to develop, differently in different countries. There is no one ideal model of development—the movement may begin at a local or a national level, or somewhere in between. However it occurs, the urgency of the need, the effectiveness of the organisations, will ensure that it spreads—sideways, downwards, upwards—whatever is necessary to meet the cry for help.

Reference: Henderson, A.D. & Jorm, A.F. *The problem of Dementia in Australia* A.G.P.S. Canberra, 1986.