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ADI Global Perspective

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

President Reagan's Revelation Hailed as Courageous and Helpful to Alzheimer's Cause

Former US President Ronald Reagan announced in November that he has Alzheimer's disease. From around the world, there was a great outpouring of affection and appreciation for his courage.

Four months later, on March 4, Nancy Reagan said on CNN's Larry King Weekend show that President Reagan is doing fine but that the crippling disease was wrenching for her. Millions of carers empathize with her pain.

Mrs. Reagan has videotaped a series of public service announcements on behalf of the Alzheimer's Association (USA) and the National Institute on Aging. "When she was diagnosed with breast cancer



years ago, her public disclosure led many individuals to undergo testing," said Cathy Busch, a spokeswoman for the Reagans. "Mrs. Reagan felt it was important to reach out again, this time to the many victims and families who have been touched by Alzheimer's—and to reassure them that they are not alone."

Left: President Ronald Reagan posed with Princess Yasmin Aga Khan and Jerome H. Stone after declaring November National Alzheimer's Disease Awareness Month in the US, in 1984.

Exciting 11th Conference Will Take ADI into New Decade

Beautiful Buenos Aires, Argentina, will be the site of ADI's 11th Annual International Conference. Our Host is Asociacion de Lucha contra el Mal de Alzheimer (ALMA). President Beatriz Berg and Dr. Carlos Mangone, the Society's founder and medical advisor, promise a highly rewarding educational experience with many good opportunities to interact with family members, professional care providers, scientists and clinicians from around the world.

"The leading goal will be to share our experiences for greater understanding and experience, and the main theme will be **An Interdisciplinary Focus on Dementia Care**," say the organizers.

Plenary sessions will be: 1. *Interdisciplinary Forum on Dementia*; 2. *Behavioral and Other Non-cognitive Symptoms in Dementia*—*Clinical, Biological, 3. Environmental and Caregiving Perspectives*; and 4. *New Therapies in Alzheimer's Disease*.

Topics addressed in Regular Sessions will include: Nutrition in Dementia; Management of Incontinence; Abuse & Neglect; Sexuality & Dementia; Cognitive Stimulation in patients with Dementia; Coping with Caregiver Burden; Housing and Environments in Dementia; Neuropsychological Assessment of Dementia; Ancillary Examinations in Demented Patients; and Pathological & Molecular Biology Hallmarks in AD.

ADI's Med/Sci Committee Consensus Conference will focus on *Screening for Cognitive Impairment in General Practice*.

In addition to the excellent Conference Program Beatriz Berg and Carlos Mangone

promise lighter moments during the evening when participants will have an opportunity to enjoy a tango workshop and typical gaucho party for a taste of Argentina.

It's not too early to start making plans.

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Looking Back, Looking Forward.....Entering a New Decade

As we begin a new decade, it is our belief that 1995 offers us new opportunities and an exciting unprecedented year of growth for ADI. While we were in Edinburgh, initial steps were taken to formulate our plans for the future. Members of the ADI Executive Committee took time to reflect on ADI's ten year history, reviewed our



Brian Moss

accomplishments, and began drafting a three-year operational plan.

Looking back, we recounted the significant steps in our growth that

occurred since the four organizing societies—Australia, Canada, England and the United States—met in Washington D. C., in 1984. We have grown to thirty-three national Alzheimer societies around the world, with numbers of new groups seeking to qualify for membership.

ADI receives its operational support from its Members, individuals, corporations and foundations around the world.

We have held ten annual international conferences on AD, and developed a newsletter, the *Global Perspective*, which is now distributed to more than 5,000 persons around the globe. We have entered into an Official Working Relationship with the World Health Organization (WHO), and published the Carers' booklet in collaboration with WHO.

In 1994, we observed the first ever World Alzheimer's Day, and raised worldwide awareness about Alzheimer's disease and ADI through the promotional

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efforts of Members. These efforts were supported by the contribution of Public Service Announcements by Eli Lilly and Company, and an international Video News Release sponsored by Parke-Davis.

We activated the Medical & Scientific Advisory Committee supported by a grant from Glaxo; and held our first Consensus Conference on the challenging topic "Predictive Testing." The Consensus Conference was funded by a grant from the Helen Bader Foundation.

We surveyed our members and are developing profiles of our membership and their programs that serve persons with Alzheimer's and their families.

We developed the International Scholars Fund in two components which involves ADI Members in a mentoring program and helps fund persons from non-Member countries to attend ADI's International Conference. Major funding from the Helen Bader Foundation and Eli Lilly and Company supported development of this program.

When we look at the past decade, we recognize great advances in research on a disease that was little known ten years ago. Equally significant, each ADI Member is growing, developing and promoting its organization, working to access the news media, providing educational meetings, workshops and symposia thereby reaching out to Alzheimer families and effectively raising awareness of their special needs. As a result, we are

beginning to see improvements and availability, of services and facilities to care for them.

Members' public policy efforts, at one time ignored, are now welcomed and Member societies find themselves consulted by governmental agencies, as well as care providers who seek to improve their level of care for persons with Alzheimer's and related disorders.

Today, there are still many countries where little or no understanding about Alzheimer's exists, we are working to reach out to them to offer support, information and education—and help them develop their own Alzheimer societies.

There is more to be learned about caring for persons with Alzheimer's and their families, we must continue to study, share, and learn from each other to improve the quality of their lives at home, around the world.

It is predicted that Alzheimer's disease and the related disorders will have devastating effects on the global society and its economy. Recognizing this lends special meaning to the pursuit of our goals.

During 1995, the Executive Committee and Council will study and set ADI's goals for the future. We recognize that while we can all take satisfaction from our past accomplishments, we must continue to address the challenges and opportunities that present—until, hopefully, we can end the need for our existence.

—Brian Moss, ADI Chairperson

•••Welcome to New ADI Members•••

ADI's membership increased by five new members when the organization's Council met in September 1994. Accepted as Provisional members were:

1. Alzheimer's Disease—Ecuador
2. Association of Family Caring for Demented Elderly, Korea
3. Association Luxembourg Alzheimer
4. Alzheimer League of Romania
5. Asociacion Uruguaya de Alzheimer y Similares

New members may qualify for Full Membership status after one year. ADI's Membership Development Committee asks that

they complete a new application form to help update information about their society and its programs. The Committee will then review the application and meet with the candidate's representative at the next Annual Meeting of ADI.

In 1995, the meeting will take place in Buenos Aires, Argentina.

Currently, ADI has 33 members from around the world. Twenty-six have Full Membership status and seven are Provisional Members. Profile reports of the new members appear on pages four and five of this issue of *Global Perspective*.

Advances in the Battle Against AD Highlight ADI's 1994 Conference

"In light of the current status of Alzheimer research, we can see stronger treatment options on the horizon (perhaps, even some within the next decade) that would permit slowing the progression of Alzheimer's disease," says Dr. Peter Whitehouse. The Professor of Neurology and Director of the University Hospitals of Cleveland Alzheimer Centre (USA), Dr. Whitehouse gave an update of research findings and treatment implications in a plenary session that focused on Drug Treatments and the Ethics of Research.

More than 800 persons from nearly 40 countries attended the 10th International Conference of Alzheimer's Disease International, September 21-23, in Edinburgh, Scotland! The theme *A Decade of Change: Looking Back, Looking Forward* commemorated ADI's tenth anniversary.

Mary Hope, President of Alzheimer's Scotland—Action on Dementia, her Conference Committee, and the staff of ASAD received congratulations for planning and executing a great "best ever" conference.

During the two and a half day event,

experts addressed advances made in Alzheimer research, treatment and care, over the past decade, and offered a unique opportunity for carers and professionals from all disciplines and from around the world to come together.

Planners offered four main tracks—with more than 50 different sessions—on Developing Services; Carers; Public Policy and Medical & Scientific Update.

A highlight event was ADI's Medical and Scientific Advisory Committee's Consensus Conference on Predictive Testing. A written outcome statement will be provided ADI members for use in responding to queries from families and the news media.

In another plenary session, *The Great Debate* was held. The motion for debate: "The government should contribute less and families more to the care of people with dementia." The Main Proposer: Clare Mc Connell, Winner, Scotsman Newspaper Debate, 1988; and National Finalist Scotland; Observer Mace, 1986-1988, Scotland. The Main Opposer: The Most

Reverend Richard F. Holloway, Bishop of Edinburgh, Primus, Scotland.

The United Kingdom has a long tradition of formal debating. This debate offered an opportunity to look at both sides of the controversial issue and to influence the outcome by participating in the discussion and ultimately by voting.

Jim Jackson, ASAD Executive Director reports that the vote was 783 against to one for the motion, no abstentions!

Social activity was not overlooked. To the delight of attendees, conference planners included two noteworthy highlight events. On Tuesday, September 20, 1994, ADI Member representatives were welcomed to Edinburgh by The Right Honorable Norman Irons, Lord Provost, City of Edinburgh District Council at the magnificent Edinburgh Castle. On Wednesday, September 21, a Scottish Evening and Ceilidh Dance was held at the exquisitely beautiful Royal Museum of Scotland. Early in the evening, Her Highness Princess Alexandra attended and received members of ADI and ASAD.

Alzheimer Scotland and Action on Dementia Merge to Form Dynamic Program for Alzheimer Families

Three years ago, Alzheimer's Scotland bid to Host ADI's 10th International Meeting and Conference in Edinburgh. Approved to host the event, the Society immediately went into planning mode and created a highly successful conference. At the same time, it was "business as usual" for all the society's program aspects.

Alzheimer Scotland, a member of ADI since 1988, is a vigorous organization with 30 branches, 14 caring projects and more than 100 employees, and has been a pioneer in the field of respite services, both day and in-home. The Society's successes include:

- the UK's first 24-hour telephone Helpline for carers,
- 30 day care centers
- flexible home care schemes around Scotland
- 42 carers' support groups
- the SHARPEN report identifying services for dementia as a top priority

for health boards

- establishment of Dementia Services Development Center
- publication of influential reports including *Dementia and the Law: the challenge ahead* and *Consent to Treatment and Consent to Research*.

On April 1, 1994, Alzheimer's Scotland and Scottish Action on Dementia joined forces to form one organization. The merger brings the benefits of combining a carers' group with a public policy organization to effectively:

- be the national voice of people with dementia and their carers.
- improve public policies for people with dementia and their carers.
- provide and secure the provision of high quality services both for people with dementia and for their carers.

The change has brought about a new name, logo, and colors. However, the belief that people with dementia should

be treated with dignity and respect, carers should not be taken for granted and more and better services are possible—remains the same.

The new organization anticipates improving services for people with Alzheimer's disease and related disorders, and their carers. To do this the organization will use three means to achieve national and local impact:

- persuade the Government and local authorities and health boards to give the needs of people with dementia prominence.
- continue to provide services of highest quality for people with dementia and their carers.
- strengthen and nurture the dementia movement—carer support groups and branches play a crucial part in public awareness-raising, creating local action.

In 1995, ASAD plans to merge into the Alzheimer's Disease Society of U.K.

ADI Membership Grows, Reflecting Worldwide Impact of AD

The ADI Federation was increased to thirty-three members when five national Alzheimer societies were approved for Provisional Membership Status in Edinburgh Scotland on September 20, 1994. The new members are located in Ecuador, Korea, Luxembourg, Romania and Uruguay. Following are profiles on each one, as derived from their applications and interviews.

Alzheimer's Disease-Ecuador (ADE)

This young society has three chapters. It was organized in 1992 by Galo Andrade, a retired civil engineer, whose wife has Alzheimer's Disease. ADE is headquartered in Quito, Ecuador. Its office is run by two able volunteers.

The population of Ecuador is 10,000,000; and, while the country has not yet gathered data on the numbers of persons with Alzheimer's, we are told that approximately 10% of the population is over age 65, and 5% over age 85.

The Society's Board meets twelve times a year, and 80% of its members are family members of persons with Alzheimer's or a related disorder.

ADE is dedicated to helping Alzheimer families, and to keeping abreast of advances in scientific research, and disseminating information about Alzheimer's disease. ADE has a telephone Helpline staffed by trained volunteers. The Helpline operates five days a week, eight hours a day.

Association Luxembourg Alzheimer (ALA)

ALA was founded in 1987 by a group of physicians and concerned caregivers. Its initial mission was to inform the public about Alzheimer's disease and related disorders, to increase national awareness and thus develop and improve caregiving and national dementia service programs. Since 1989, however, ALA itself became the main initiator of and implementor of concrete national dementia services and structures. It is now operating two day care centers for demented persons in Luxembourg City - for which the association is allocated on a yearly basis and through convention, a budget from the Ministry of Health - and offering numerous other services on a national basis that are mainly financially sustained through private do-

nations. For 1996, the organization expects to open a dwelling group, a small unit of collective housing for eight permanent residents in Luxembourg town.

The mission of ALA and its day care centers is to provide a multidisciplinary service for family members of, and individuals with a diagnosis of Alzheimer's or a related disorder who live alone or with their families in the community.

• ALA's goals for caregivers are:

— to give them the opportunity for respite time by allowing ALA to take care of the patient at one of the day care centers.

— To procure family assistance and develop caregiver support programs: through training, support and counseling, day care programs can assist caregivers to adapt better to the continued decline of the patient.

— To develop and communicate management techniques, by organizing support groups to allow families to learn and share specific approaches that can make daily living easier and more enjoyable. Caregivers often feel less helpless when they have information and proven management techniques at their disposal, and families report satisfaction in becoming active participants in the case of their demented relative.

— To provide crisis intervention, a support and referral to families facing crisis associated with the care of their relative, such as the need for nursing home placement, violence in the home, and medication difficulties.

ALA's goals for the patients, i.e., the cognitively impaired visitors of the day care centers and users of home helping services, are to maintain or improve the client's ability to function safely in the home for as long as possible by increasing self-esteem and functional abilities through socialization, activities and sen-

sory stimulation.

• Beyond those of patient care and caregiver support, ALA has a variety of goals, including the collection and dissemination of information. Caring for a group of patients over an extended period of time provides an opportunity to collect a lot of valuable information and data. Sharing this information with other groups, on a national and international level, having the same or similar interests stimulates the formation of new care programs and reminds constantly the importance of self-criticism.

The objective of ALA and its day care centers is to achieve on the basis of European and international cooperation and collaboration with similar organizations a high level of expertise in the field of care programs to be elaborated, demonstrated and evaluated for the demented persons on a national level.

Luxembourg has a population of 370,000, with persons over age 65 being 50,000 ± and those over age 80 being 72,000 ±.

Association of Family Caring for Demented Elderly, Korea (AFCDE Korea)

Our organization was founded four years ago as a day care centre for the elderly, which became a civilian organization called, "Association of Family Caring for the Demented Elderly, Korea (AFCDE Korea)," in 1994. Currently, we have 520 family members and three supporting chapters throughout the country.

We have had family support groups for these four years in which we dedicated our effort to educate the families and society that dementia is not simply senility, but a serious disease. We also focused our education to develop guidelines for families with Alzheimer disease patients, caregivers to provide quality care, regardless of the circumstances under which patients were living. Owing to facility's efforts, the social comprehension of Alzheimer's disease has been widely disseminated.

There are 2,450,000 elderly persons over the age of 65 in Korea, which equals 5.5% of the entire population. Currently, it is

estimated that 260,000 persons over 65 years of age suffer from Alzheimer's disease. This figure has not been officially confirmed, and it seems that there is a higher percentage of dementia in the country than in the city.

Traditionally, for more than 1000 years, Koreans have supported their elderly in their homes. AD has been called "Nomang" in Korea, which has been considered very shameful, and kept as a secret among families. Presently, more than 90% of the persons with dementia are neglected, and considered as an "unimportant matter." Only 8% of the patients receive proper hospital care and treatment. As the number of the elderly increases and the nuclear family increases, the dementia problem is the most serious issue in Korea.

There are only four hospitals for the elderly in Korea, none of which is for demented persons. What is worse is that their admissions are usually rejected by the clinics. There is practically no social service providing for persons with dementia.

The demented persons' bizarre behaviors cause many problems at home. The mental and physical stress on caregivers can lead a family into destruction. The family caregivers eventually seek day care services, home health care, family caring and training programs.

The Korean Government plans to solve these problems by building three facilities each year in the metropolitan and province areas.

The private companies begin to have their own programs to support the elderly. Even more, several pharmaceutical companies develop drugs for multi-infarct dementia patients, and participate in family meetings to discuss patients' problems. Besides, the Neurologist Association, the Korean Gerontological Society and the Hospitals want more information regarding caregiving, research programs and having seminars.

Chungam Welfare Foundation for the Elderly supports AFCDE Korea and currently provides services as follows: the Hot Line Phone Counselling; a Seminar held once a year; Family Meetings, Caregiver's Training; a periodic publication called "Hyoshim" (Filial Respect), and through its nursing home facility provides a day care centre for the local community. Our intention is to build more provincial chap-

ters, train expert caregivers and dispatch home helpers where they are needed. We are also planning to build a special dementia care facility, through a fund raising program.

We believe that in order to make continuous progress to educate general public, it is important that ADI member countries keep in touch for exchanging information including caregiving methods and newest ideas.

Alzheimer League, Romania (ALR)

At the initiative of some members of the Romanian League for Mental Health and with the WHO office of Romania and some other WHO experts, The Support Society for People Suffering of Alzheimer's Type diseases (now, Alzheimer League) was founded, and officially registered in Bucharest, in 1992.

They have a Meals-on-Wheels program wherein food is delivered three days a week, on Monday, Wednesday and Friday; the portions with hot meals are for two days. The Programme Coordinator is charged to pay home visits to the persons involved in the Programme, on Tuesday and Thursday. During those home visits, the Meals-on-Wheels Coordinator and the volunteers which she guides, talk with the clients, tracing out their problems and needs, and the kind of help entailed.

ALR also has two day care centers, open three days a week, Monday Wednesday and Friday, from 9:00 am to 2:00 pm. The Centers have diversified activities, including physical exercise adapted to the individual participants, video films, conversation on social topics, a painting class, museum visits, etc. The Day Centers are operated with paid staff and pensioner volunteers—a retired sport teacher who organizes the exercise program, others help with maintenance. Another volunteer is a nurse and student in Sociology, she works with the Centers' Coordinator to maintain client files.

On Tuesday and Thursday, the Day Center Coordinator and a Carer volunteer make home visits. Based on the information from clients and those supplied by the Social Assistance Office and the Church in the area, the team is trying to trace out the persons with problems including neurological and other chronic diseases. Their

goal is to discover and help those in the most hopeless situations—loneliness, without families or abandoned, with low or very low incomes, unable to fight for their rights, without access to the services provided for them by the existing medical assistance system.

The ALR seeks to continue the development of the above programs while also providing training courses and community information sessions.

Asociacion Uruguaya De Alzheimer y Similares (AUDAS)

One hundred percent of AUDAS board members are family members of persons with Alzheimer's disease. They have 12 Support Groups and with the help of service volunteers, they are actively developing more support groups around the country.

AUDAS has a telephone Helpline which operates with trained volunteers Monday through Friday from 1:00 pm to 5:00 pm.

AUDAS Medical & Scientific Advisory Committee comprises nine specialists in mental problems and geriatrics, who are all on the faculty at the School of Medicine.

Uruguay has a population of 3 million, 16% are over age 65, and 7.5% are over age 80. AUDAS estimates there are about 30,000 persons with Alzheimer's disease in the country, based on adaptation of statistics from countries with younger populations.

The mission of AUDAS is threefold: to support the carers of persons afflicted with Alzheimer's Disease and/or similar dementias; to raise public awareness of these afflictions; to foster scientific research and disseminate its results to concerned publics.

The stated goals of the organization are to: 1. Give support to families and others concerned; 2. Provide practical help and information; 3. Provide guidance to carers and training for concerned professionals; 4. Promote and make public the objectives sought, and try to obtain adequate services of high quality; 5. Raise public awareness of Alzheimer's disease and similar disorders through use of the media and other means.

Early Stage Alzheimer Patients Find Comfort in Their Own Support Group

Support Groups for Early Stage Alzheimer patients are receiving attention. Twenty-six Alzheimer's Association (USA) chapters have such groups. Following are two articles we believe you will find interesting.

The first article was written by Inge Gatz, a social worker at Friendship Senior Day Care Center, in Santa Barbara California, and facilitator of the Early Stage Alzheimer's Support Group, we believe it will be of interest to family carers and professional carers as well

Working with families that are dealing with Alzheimer's disease, most of us focus on family members who are doing the caring—be it husbands, wives, sons, daughters, daughters-in-law. It wasn't until Delilah Makature, a charming and delightful 55-year-old woman, walked into my office with her daughter and told me that she'd recently been diagnosed with Alzheimer's disease, that I became acutely aware of the emotional needs of the Alzheimer patient.

Delilah proceeded to talk about other people's negative reactions to her diagnosis. Yet she herself talked about it comfortably. She feels, and rightly so, that it's nothing to be ashamed of. She is anxious to get on with her life and wants to focus on her assets instead of what she has lost, and knows she will continue to lose.

When she came to the Friendship Center, Delilah was looking for a new social life. She lives alone and because of impaired judgement, can no longer drive to get around. Although her daughters live close by and are very supportive, she knew she needed outside interests.

Delilah was looking for people with whom she could share her concerns, feelings, and fears about Alzheimer's disease. She was looking for people who were experiencing what she was experiencing.

Delilah's openness and forthrightness took me completely by surprise. As I listened to her talk, I realized that we needed a support group for persons in the early stages of Alzheimer's disease.

Most of us still talk about Alzheimer's disease in a soft voice. Often, the name of the illness is not mentioned directly; sometimes not at all. Dr. Erno Daniel, a

local gerontologist who treats many Alzheimer's patients, says that socially Alzheimer's is being dealt with the way we dealt with cancer 30 years ago. It was not confronted; often the patient wasn't told. We dealt with it in the dark and frequently the patient suffered in silence.

The Early Stage Alzheimer's Support Group of Santa Barbara—sponsored by the Friendship Center and the Santa Barbara chapter of the Alzheimer's Association—first met in September and continues to meet weekly in the library of All Saints By The Sea Church. This group is not suffering in silence; they created their own

This group is not suffering in silence—they created their own voice

voice. The six women in the group range in ages from 55 to 71. Two are in their 50s, three in their 60s, and Mary is 71. Three received their diagnosis while still employed and then withdrew from their active careers.

Our meetings cover every area of their lives, but especially how Alzheimer's has affected their relationships. What we do most of though is laugh, even about changes that are taking place because of Alzheimer's disease. Concerns are shared about their children. Is the disease hereditary?

Beverly Wheeler talks about how Alzheimer's has brought her and her husband so much closer together.

Pat talks about how much she enjoys those things she passionately loves—hiking, walking and dancing. She can still do these things. She is grateful for that.

Sylvia talks about how she dislikes being treated like a child. She may have a poor memory and gets confused but nevertheless is still an intelligent adult.

Beverly mentions that jokes about Alzheimer's are never funny. In the group when someone loses their train of thought or can not think of a word, they help each other out—they don't laugh at each other.

When Delilah talks about how she is losing words faster over the last few weeks, the group responds with love.

When I asked the group what they would like to share with the readers (I asked for their permission to write this article), they said: the support of the group has added so much understanding and warmth to their lives. Judy remarked that for the first time in a long time she has felt like a human being; she feels whole. And Delilah feels that since there is no cure at this time, talking about her illness to other people who understand is the next best thing to a cure. These women are facing their lives with great courage and dignity. Facilitating this weekly group has made me aware that we have actually ignored a large population who are struggling with Alzheimer's disease—the persons with the diagnosis. It is time to pay more attention!

More on this topic from the national newsletter of Alzheimer's Association (USA).

It's Thursday morning. Five men greet each other, help themselves to coffee and take a seat around the conference table. The day's bad weather is the first item of discussion for what appears to be an informal business meeting. But these men have recently been diagnosed with probable Alzheimer's disease and are gathered with a group facilitator for their monthly Support Group meeting.

Support groups for caregivers have existed for many years. Today, with increased public awareness and improved assessment techniques leading to earlier diagnosis, support groups are also gaining in popularity among those who are diagnosed while in the early stages of Alzheimer's disease.

Contrary to popular belief, individuals

—Continued from previous page

in the early stages of Alzheimer's are often willing and able to talk about the disease and how it affects their lives. These groups focus primarily on the needs of the person with the disease. "We talk about a variety of issues," says George Clayton, who was diagnosed with Alzheimer's last year and regularly attends a support group. "We've been talking a lot about driving recently. Some group members have had to give it up and the rest of us know we will too, at some point. It helps to talk about it."

The purpose of the group meeting may be different for each group. A group may meet a set number of times or be ongoing. Some also sponsor work projects and social outings for members. For example, group members may visit a local museum, go shopping or see a movie together. "Our group likes to go to plays at a local theater," reports Denise Heinrichs, executive director of the Alzheimer's Association's Mississippi Valley Chapter in Davenport, Iowa. "We preview all of the dress rehearsals, which works out great. Our group is more comfortable in a less crowded theater and the actors appreciate the audience."

Robyn Yale, a clinical social worker and author of two training manuals for professionals who facilitate support group meetings, believes that participation in a support group can help a mildly impaired person adjust, cope and plan for the disease as it progresses. "These programs provide a place where people with

Alzheimer's can talk with peers who face similar circumstances, in a tolerant and accepting atmosphere." She also believes that support groups for those with the disease indirectly benefit caregivers. "Positive group interaction outside of the family may help alleviate some of the feelings of stress and isolation often experienced at home," reports Yale. "When I come to a support group meeting, I'm reminded that I'm not the only one who's living with this disease," says Clayton. "The meetings are positive and comforting."

Involvement in a support group may not be for everyone. "It's a wonderful experience for someone who is comfortable with the idea and interested in participating," says Yale, "and it's definitely worth considering, if there is a program available in your area."

For more information about "early diagnosed" support groups, contact Sam Fazio, Program Specialist, at the national office of the Alzheimer's Association (USA). Tel: +(1 312) 335-5179; or, Fax: +(1 312) 335-1110. He will be pleased to send you a bibliography and informative articles on the topic, several models of such support groups, and a list of the 26 Chapters in the U. S. that have successfully developed these groups.

(Editor's question for the future: Is it possible that support groups for the early diagnosed may help prepare the person with Alzheimer's and perhaps even help to lessen some of the more difficult behaviors carers must deal with

1995 IPA Research Awards in Psychogeriatrics

The International Psychogeriatrics Association is pleased to announce its fourth, biennial Research Awards in psychogeriatrics. These awards are offered every two years for presentation and recognition at each IPA International Congress. The 1995 Awards will be presented as part of the opening of IPA's Seventh Congress, October 29-November 3, 1995, in Sydney, Australia. The winning papers will be presented at a special session during the congress.

The 1993 awards were presented to scholars representing three continents at IPA's Sixth Congress in Berlin, September 1993. The winners were: K. Blennow, MD, PhD (Sweden) for his paper "Ubiquitin in Cerebrospinal Fluid in Alzheimer's Disease and Vascular Dementia," G. W. Small, MD (USA) for "Subjective and Objective Age-Associated Memory Loss: Initial Neuropsychological, Family History, and Brain Metabolic Findings of a Longitudinal Study," and E. L. Teng, PhD (USA, Japan) for her "Cross-cultural Epidemiological Studies of Dementia."

As part of IPA's commitment to research into the mental health of the elderly, the awards are given for the best submitted original research papers in the field of psychogeriatrics. Review and selection of the award winning contributions will be by an international committee.

Dreamtime Story—Aids Study of Aboriginal and Torres Strait Islanders

In Australia today there is limited documented evidence of Aboriginal Torres Strait Islander people who have Alzheimer's disease, the most common cause of dementia amongst the general population. However, dementia is a reality amongst the indigenous population. It has been identified in the younger age groups as a result of head injuries, alcohol, STD and stroke. The issue of dementia in the Aboriginal and Torres Strait Islander people needs to be addressed in a culturally sensitive way.

The Federal Government asked a group

of older Aboriginal and Torres Strait Islander people the best way to describe the effects of dementia on individuals, families and communities.

It was decided a story would be the best way. Consequently, a dreamtime story has been written to put dementia in a culturally appropriate way for Aboriginal and Torres Strait Islander people to understand.

"Dementia is like a 'bad hawk' it takes away from your mind—little bit, little bit—then nothing left." Written by Brian Lampton, the story illustrates clearly and

simply how bad this bird is, but not to be afraid of it, if you know what to do and who to see when his shadow is upon you.

The story aims to disseminate information about dementia to tribal, mission, fringe dwellers and urban people. It is written and illustrated in simple Aboriginal and Torres Strait Islander ways.

This project has been co-ordinated by the Alzheimer's Association in South Australia for the national Alzheimer's Association (Australia) and is currently at the publishing stage.

—Alzheimer's Association (South Australia)

What—in the World—We're Doing



WORLD ALZHEIMER'S DAY

Numerous reports about how ADI Members (and non-Members) observed World Alzheimer's Day in 1994 have arrived at the Secretariat. Space is limited, so only a cross-section of them appears on page 18.

INDIA

Alzheimer's and Related Disorders Society of India (ARDSI) carried out a study showing that 9% of the rural population of Kerala are above 60 years of age and 10% have disturbances in memory who are suffering from a type of dementia. This ongoing project will look into the prevalence and incidence of dementia and the usefulness of various types of intervention techniques.

ARDSI is planning its Second National Conference to be held at Thrissur, Kerala State, on November 5, 1995. Theme for the Conference is "The Burden of Care-giving." Keynote speaker will be Dr. Nori Graham, ADI Vice Chairperson.

JAPAN

Association of Families Caring for the Demented Elderly, Japan (AFCDE Japan)) in Tokyo was commended for its volunteer activities at the 42nd Tokyo Metropolitan Social Welfare Convention.

The Society reports—the Ministry of Welfare estimated by 2010 the number of conjugal elderly households in Japan will increase to 5.3 million, while those who live alone will rise up to 4.6 million.

On October 16, the 10th National Study Session of AFCDE Japan was held at the Ryukoku University in Shiga Prefecture. The main theme was "The network for Supporting the Demented" and over 500 people from the whole country gathered to study and share experiences.

AUSTRALIA

Alzheimer's Association, Australia (AAA) announced the results of its research project on General Practitioners in 1994. Recommendations arising from the survey include: development of an assessment protocol and screening instrument,

regular cognitive check ups for people over 75 years, educational programs, improved coordination with Aged Care Assessment Teams and Community Services, inventories and registers of local community services and residential facilities, and appropriate medicare rebates.

The New South Wales (NSW) chapter of the Association each year holds a short story competition for NSW school students. The aim of the competition is to help create among young people a better understanding of dementia. In 1994, about 200 entries were judged by a panel of judges who are all professional writers.

Wonderful, sensitive, stories are the outcome of the competition which is judged at Senior and Junior levels. In the Senior Section, prizes are: a Certificate and \$500 for 1st Place, a Certificate and \$250 for 2nd Place, and a Certificate of Achievement for 3rd Place; in the Junior Section, a Certificate and \$300 for 1st Place, a certificate and \$150 for Second Place, and a Certificate of Achievement for 3rd Place.

In 1994, the Society focused its Alzheimer's Awareness efforts on children. Volunteers visited 10 schools throughout Australia to educate 3rd graders about the disease. In response, the children created posters and murals for display in the schools. Also, an Alzheimer's

Awareness Month poster contest was held for grade 6 students. The society's Education/Awareness Committee obtained permission from the school board to approach principals about the contest. Several schools participated in the contest and 30 submissions were received.

SCOTLAND

Alzheimer Scotland Action on Dementia (ASAD) *Living with Dementia* was the theme of Dementia Awareness Week in 1994. Publicity efforts focused on how people with dementia can maintain enjoyment in life. Also, *Facing Dementia*—a booklet providing information on early diagnosis—was launched. Throughout Scotland, a variety of events were held including: information stalls, seminars, bungee jumps and gala days.

CANADA

Alzheimer's Society of Canada (ASC) is participating in deliberations on Alzheimer's testing for the future. Members of the society are part of a team to deal with ethical concerns around genetic testing. The team is concerned with the difficulties in implementing genetic testing and performs in an advisory role. The team is set up through geneticists at the University of Columbia

ASC Granted \$92,000

Alzheimer Society of Canada received \$92,000 from Max Bell Foundation. The funds were designated to evaluate the Society's training package *Alzheimer disease: Care at Home*. The package was created to enhance home support workers' understanding of Alzheimer's disease (AD) and approaches to care.

"A well-trained person providing the home support services is a necessity—the training program must be evaluated so families will be assured the delivery of services and care is appropriate, helpful, and sensitive," says former caregiver Dian Goldstein.

The evaluation is the last of a three-part joint project with Alzheimer Society of Canada and Home Support Canada. The first two parts consisted of a needs assessment of the home support sector, and development of a seven module, bilingual training package designed to train home support workers in caring for people with AD.

Use of the package will lead to improved home care for people with AD. The donors receive feedback from trainers, agency management, front line workers, and family members to assure the training packet makes a difference.



Alzheimer Society of Canada's National Research Program has raised nearly a million dollars through provincial associations and local chapters. Provincial chapters raised \$210,000 in 1994, three times more than 1993. The money was distributed to 17 research projects chosen through National's peer review process. Funds are divided between biomedical and social/psychological research.

The Society is participating in the Pharmaceutical Manufacturers Association's *Knowledge is the best medicine* Campaign to address the inappropriate use of medication and the substantial health and economic cost associated with it. Television and print advertisements to inform consumers of the appropriate use of prescription medicines are being used.

Also, a toll free number +(1 800) 363-0203 can be accessed from across Canada to obtain free information. Callers can receive written information on specific diseases or conditions, and a variety of Alzheimer pamphlets are available.

UNITED KINGDOM

Alzheimer's Disease Society (UK) has created an open learning program offering 4 courses for carers. The 1st course is a resource pack for home carers and the 2nd course is for paid care workers in residential/nursing homes. Other courses aim to assist the Society's carers contacts and domiciliary workers. The carer resource pack consists of tips and information for carers. The care workers course promotes the best possible practice in care for elderly persons with dementia, and includes a video, booklet, and posters. The course is to be studied in six one hour sessions and people can apply for a certificate on successful completion of the course and a test.

The Society's *Research Now-Old Gold* appeal raised a significant amount of money for research. The appeal grew to \$27,812. Branches contributed \$11,500.

Here's how it works- People donate pieces of gold and silver jewelry and the Society converts the items into money. The outcome, the Society has awarded

research fellowships to seven young scientists. Money raised will cover the Fellows' salaries, their costs and consumables. 100% of the money raised from the *Research Now* appeal will go to the fund.

FRANCE

Association France Alzheimer (AFA) plans and arranges respite holidays for both the person with Alzheimer's and the carer. Seven couples are sent to holiday

larly issues vital to Alzheimer's families including long term care and health research. The award was presented at the association's public policy forum, titled *Families in Action*.

Alzheimer's Association (USA) has published a new booklet *Respite Care: What's Right for You*. A user-friendly publication, it defines types of respite care and how to select the appropriate one according to current need. It has an

Finland Society Uses Memory to Inform

Alzheimer's Society of Finland publishes a quarterly magazine *Muisti* (Memory). *Muisti* aims at relatives and caregivers of persons with dementia, and members of local Alzheimer's societies. The publication is filled with valuable information offering such topics as: The future of organizations; Experiences of validation therapy; Joy for all life long; Reader's writings and other relevant topics. Last year, a doctor's issue was produced and delivered to every doctor in Finland. This issue included topics such as Cognitive changes in aging; Views for medical treatment of AD; Lewy-body disease; Technical aid for people with memory disturbances and more. Also, the society delivered free of charge 60,000 guide booklets to carers and professionals throughout Finland.

resorts. The couples can be husband/wife, or parent/child. And, each group is accompanied by specially trained volunteers from the Society. This greatly benefits the person with Alzheimer's providing a pleasant change of atmosphere away from the usual environment. The carer benefits by being able to visit and enjoy activities with the guests.

UNITED STATES

Alzheimer's Association (USA) presented its Humanitarian Award to First Lady, Hillary Rodham Clinton for her leadership on health care reform, particu-

excellent format to provide a patient history and profile. It may be ordered through Order Fulfillment, Alzheimer's Association; 919 N. Michigan Avenue; Chicago, Illinois 60601. Tel: +(1 312) 335-5794.

SPAIN

Associacio Familiars Alzheimer Catalunya held a seminar attracting 1,055 participants! This free seminar was divided into four working sessions. Lectures were led by: neurologists, psychiatrists, geriatricians, nurses, family caregivers, social workers, lawyers, all specialists in geriatrics and more.

Survey reports needs of demented elderly and their families in Korea

74% of persons with dementia in Korea are female, and two-thirds of them are without spouses. The main caregivers include daughters-in-law (42%), spouses (19%), married daughters (17%) and unmarried daughters (7%). Utilizing day-care services, Helpline and caregivers' meetings; most of them want to continue home caregiving; at the same time there is a demand for social support, such as, qualified caregiving provided by geriatric hospitals and nursing homes.

TELLING THE TRUTH: Should Persons with Alzheimer's Disease be Told Their Diagnosis?

Recently, a Member wrote asking if we had a recommendation about telling persons diagnosed with Alzheimer's the truth about their condition. Telling the truth seems a demonstration of respect. But, what does truth really mean? How much do we discuss in the telling?

The following is from the Alzheimer's Association (Western Australia) Newsletter (they acknowledge the newsletter of Alzheimer's Association of Greater Pittsburgh, USA, as a source for the article):

The question of whether or not to tell a newly-diagnosed Alzheimer patient of the diagnosis is asked over and over again in doctors' offices and during support group meetings.

Something obviously must be said to the suffering person who asks, "What is happening, am I going crazy?" Something, too, needs to be said to the Alzheimer's disease patient who yells, "leave me alone, let me drive (or cook, etc.). You don't think I can do anything."

Each family confronting similar and different situations knows there is no right or wrong answer. Each family must make its own personal and private decision. Should "The Truth" be told? Isn't truth relative? Some people can absorb it only in small amounts.

Two physicians serving on the Greater Pittsburgh Chapter's Professional Advisory Board offered the following thoughts when we posed the "to tell or not to tell" question to them:

"My usual approach is to tell a patient s/he is suffering from memory loss which is progressive. Whether or not I use the word Alzheimer's depends on the patient's level of memory impairment and the family's perception if the patient would want to know. The bottom line is not to deny the patient knowledge or information he wants. Along with 'telling' goes information about ways to cope with changes that are occurring."

From: Judith S. Black, MD, St. Margaret Memorial Hospital Classic Care:

"Decisions about what to tell a dementia patient require sensitivity, tact, and a measure of experience with the art of medicine. The most important issue is to first consider the patient's feelings and

future. If a patient is only mildly cognitively impaired, and capable of understanding the diagnosis of AD and its implications, to withhold such information is unfair and unethical, since the (competent) patient is deprived of the right to know about his or her diagnosis. I often explain this to well-intentioned family members who want to "spare" a loved one from unwelcome news, and discuss with them the alternate ways of presenting the information which makes both family and patient comfortable.

Severity of the cognitive impairment and the level of insight the patient has into his or her disability are important factors in determining what to tell. In general, when patients are only mildly impaired it is helpful to tell them the diagnosis, emphasizing the mild state and the possibility of further decline. Not to tell

Should persons with Alzheimer's disease be told their diagnosis?

PROS

- Maximizes individual autonomy
- Affords opportunity to seek best possible information and choose or reject treatment even if experimental or unconventional
- Accommodates need to formulate specific advance directives and complete financial and personal planning and identification of surrogates
- Respects individual's intrinsic right to know the truth
- Offers opportunity for individual to express themselves, resolve conflicts and make known last wishes before opportunity is lost forever
- Acknowledges patient's preference based on past knowledge

CONS

- Diagnosis of AD cannot be assigned with perfect accuracy & prognosis is imprecise
- Therapeutic options are limited — may lead to hopelessness and compromise quality of life
- The patient may not have ability to understand the diagnosis
- Avoids severe depression or catastrophic reaction, or unnecessary functional decline or suicide attempts
- Acknowledges patient's preference based on past knowledge

such individuals robs them of the chance to engage in activities which they might want to do while in the best of health, including travel, preparing advanced medical directives, and so on.

If a patient is relatively severely impaired, he or she will not remember the diagnosis when told about it anyway; yet, when it (the telling) is done in the presence of family members, it serves as a catharsis. There are now no more 'secrets', grandmom has been told, and she will likely forget the diagnosis and/or fail to adequately understand its implications.

Most family members who have been convinced to have a family diagnostic discussion (doctor, patient, and family) have been happy that they have done so, and find that anticipation of the event worse than the event itself or the aftermath. There are circumstances which speaking in more vague terms of memory loss rather than a specific diagnosis, and professing uncertainty about the future course of the deficit are appropriate, such as in some cases of sensitive or depressed individuals. These cases are the challenge to deal with sensitively and thoughtfully, with both concern for the patient and consideration of the family."

From: Steven DeKosky, MD, Alzheimer Disease Research Centre, University of Pittsburgh:

"Once again, this decision is a personal and private choice. There needs to be a certain sensitivity to what the loved one is not asking when they appear to be wanting answers. The Alzheimer's Association encourages families to contact a spiritual adviser and/or other family members and friends while processing this decision.

Following is an excerpt from "Facing the Abyss—Medical Ethics and Alzheimer's Disease," a 1990 White Paper prepared by Alzheimer's Association (USA).

Considerations for Family Discussion:

1). In your recollections about the patient's past wishes and values, how did they feel about speaking the truth or facing situations squarely?

2). How would you wish to be treated

Wandering Program Introduced in Japan

The January 25 issue of the Bulletin of AFCDE Japan features an article about a wandering program recently begun there.

Kushiro City of Hokkaido, the most northern island of Japan, is the first city where a wandering network has started to function.

Five years ago, a member of the regional group of the Hokkaido Branch died after a long period of wandering because the family hid her dementia and the police dealt with her as an ordinary runaway.

After this, efforts of the members have born fruit; the network includes 31 groups and organizations such as police, public health centers, hospitals, welfare facilities, transportation facilities, and the local governments of Kushiro city, towns and villages there.

—Continued from previous page

under various conditions of health and illness?

3). From whom among the older people that you know, could you obtain thoughtful answers about quality of life despite increasing frailty or vulnerability.

4). How do you think your parents, spouse or other relatives feel about the family and its special significance?

5). Did your family member ever discuss what gave him/her the greatest pleasure or gave life particular value?

6). What kind of decision-making process will work best for your family? Who needs to be brought into the process? Who is likely to differ from basic family values—and what grounds?

7). Are there special ways that your family expresses love and affection that can be carried over to the person who has essentially lost cognitive abilities?

8). What methods do you now use to discuss matters with health care professionals? Are you able to ask questions and if need be, assert your own point of view?

9). Can you decide, in advance of the need, who will be the lead family decision maker?

10). How might you begin a conversation about death and dying within your family?

AD BILL OF RIGHTS IS INTRODUCED

In a recent article published in the September/October issue of *The American Journal of Alzheimer's Care and Related Disorders & Research*, David Troxel, MPH, outlines a 12-point Alzheimer's disease Bill of Rights meant to serve as a touchstone for families, professionals, and in some cases those with the disease to evaluate quality of care.

The article looks at the changing trends in Alzheimer's disease research. Trends such as:

- The shift from caregiver issues to a greater focus on the individual with dementia.
- New drug therapies that will delay the progression of the disease.
- More complex ethical issues as individuals with earlier-stage dementia be-

gin participating more in the decision-making process.

- New demands and pressures on healthcare and other services as the number of persons with dementia increases.

Troxel says that the need for an Alzheimer's disease Bill of Rights has never been greater. This is due in part to the new trends noted above. It is his conviction that every person diagnosed with Alzheimer's or a related disorder deserves a life of quality and dignity.

Although this Bill of Rights is not absolute and must be applied in the context of each individual's cognitive abilities and medical situation, if used, they are certain to result in a better plan of care and improved sensitivity to the individual's needs. —Source, Santa Barbara Chapter newsletter

An Alzheimer's Disease Bill of Rights

Every person diagnosed with Alzheimer's disease or a related disorder deserves:

- To be informed of one's diagnosis.
- To have appropriate, ongoing medical care.
- To be productive in work and play as long as possible.
- To be treated like an adult, not a child.
- To have expressed feelings taken seriously.
- To be free from psychotropic medications if at all possible.
- To live in a safe, structured and predictable environment.
- To enjoy meaningful activities to fill each day.
- To be out-of-doors on a regular basis.
- To have physical contact including hugging, caressing, and hand-holding.
- To be with persons who know one's life story, including cultural and religious traditions.
- To be cared for by individuals well-trained in dementia care.

Focus on Public Policy

Carers Services Bill

Westminster, UK—Malcolm Wicks MP (Labour—Croydon NW) has announced that he will be promoting a Carers Services Bill this parliament, following his success in the Private Members Ballot last month. The Alzheimer's Disease Society (UK), together with the Carers National Association, is backing the Bill to give carers a statutory right to a separate assessment and to respite care services.

Evidence from the first 18 months of community care shows that many carers are not having their needs assessed and so are not receiving the services they need to take time off from caring. Earlier this year, the Society found that 60 per cent of carers of people with dementia had not had their needs assessed whatsoever, and that only 13 per cent had had their need assessed separately.

The Bill is likely to have its Second Reading early in 1995 and its passage through the House of Commons will be dependent on it getting widespread support amongst MPs.

NHS Continuing Care: The House of Lords debated the continuing uncertainties over finance for long-term care on 30 November. Lord Ashley called for national guidelines on National Health Service (NHS) continuing care to end the "mish-mash of decision making...eroding, even destroying, the equitable provision which is the real strength of our proud National Health Service." —ADS 1/95 Newsletter.

Systematization of Services

Kyoto, Japan—AFCDE in Japan reports that in July, a representative of the Nagano Prefecture Branch presented a demand for systematization of services to Mr. S. Ide, the Minister of Health and Welfare, in his native town, Nagano.

A New Gold Plan

The Ministry of Health and Welfare announced "A New Gold Plan," revision of the Government's Decade Plan for Social Health and Welfare for the Elderly. Its Fundamental ideas are to support independence, to develop combined services

and to retain general and regional efforts. This plan needs an increase of manpower; care workers, formal carers, physical and occupational therapists; and also efficient training for the professionals. Target figures have been set twice as high as the first plan; the number of home helpers has been moved to 200 thousand from 100 thousand, day service centers, to 20 thousand from 10 thousand; and short-period stay services and accredited nursing homes, 20 percent more than the original plan.—AFCDE Oct. 1994 newsletter.

Families Urge Congress to Continue Key Programs

Chicago, USA—As the new Congress wrestles with budget cutting and shrinking the role of government, Alzheimer families all over the country are preparing to make their case that continued investment in key programs now will prevent disaster for families today and the country tomorrow.

In recognition of budgetary restraints, Alzheimer families will ask lawmakers for a modest increase in research funding, up \$50 million from the current level of \$311 million, to maintain momentum on recent encouraging developments. Research is necessary to find treatments, or delay the onset of the disease, in order to significantly reduce the cost of Alzheimer care to families and society, according to the Association.

Maintaining Medicaid and Medicare for families caring for Alzheimer patients will preserve the only safety net that exists for many families, according to the Association. For instance, many Alzheimer families turn to Medicaid because they have spent everything they have caring for their loved one, and have no other options. If cuts are made to these programs, the current family care system will collapse, and this will greatly increase the need for more expensive institutional care.

Hundreds of family members will attend the Alzheimer's Association's 7th Annual Public Policy Forum, "Alzheimer Advocacy: Don't Stop Now," to be held April 8-11, 1995, at the Hyatt Regency Capitol Hill in Washington, DC. For more information, call: +(312) 335-5764.

Public Policy Sub-committee Illuminates Family Needs

Christchurch, New Zealand—Alzheimer's Society NZ established an advocacy sub-committee to promote the needs of members to policy makers. The purpose of the sub-committee is:

- to develop effective communication between members and Alzheimer's Society of NZ on advocacy matters.
- encourage members to advocate at a local level and to act as a resource for advocacy.
- to be responsible for written submissions and policy papers and lobbying on national issues.

A priority for the committee is to set up an efficient system of communication with member groups. To do this, each group will appoint an advocacy contact person. Also, the committee will prepare an advocacy kit to be distributed to all members.

Benefits of an effective advocacy service will include: a prompt response to urgent issues, coordinated approach to advocacy, a higher profile for the Alzheimer's Disease Society of NZ while pursuing a Fair Go for Dementia.

Some Stats on Alzheimer's

Although a growing number of people in their 40s and 50s are being diagnosed with AD, the percentage who have the disease by age 60 is still low. According to a study by Harvard Medical School, the incidence rises to 3 percent of those 65 to 74, and 19 percent at ages 75 to 84. For those over age 85, the chance of developing it is estimated to be 47 percent.

According to World Health Organization studies, there are 15 million persons with Alzheimer's disease in the world.

Alzheimer's disease is not an inevitable result of aging, the exact cause is still unknown. Currently, researchers suspect a combination of genetic and environmental factors.

Some scientists say that if an individual reaches the early 90s without having contracted Alzheimer's disease, chances are that s/he will not in the future.



Publications from Around the World

Just For You: For People Diagnosed with Alzheimer Disease. The booklet is meant to provide persons in early stage Alzheimer disease information about what they may be experiencing and offers suggestions on how to make life easier. Published by Alzheimer Canada; 1320 Yonge Street, Suite 201; Toronto, Ontario M4T 1X2, Canada.

El Centro de Día para enfermos de Alzheimer. By Ricardo Moragas Moragas, Ctra. N-340, km. 1.245,3; 08750 Molins de Rei (Barcelona) Tel: (93) 668-6263. Fax: (93) 668-5656.

Alzheimer's Disease and Marriage. Discusses the effect of AD on the marital relationship (sexual relations, household chores, commitment, companionship, and tension). Presents perspectives of the caregiver and spouse with AD; and, shows professional caregivers how to assess the situation and intervene, if/as needed.

Remember Me. By Margaret Wild & Dee Huxley. A book about dementia for children, tells a story of a girl and her grandmother—who has Alzheimer's. The difference between short and long term memory loss is explored. The story is accompanied by full color illustrations and appeals to the 4-8 year old age group. Published by Margaret Hamilton Books, Australia. Hardback \$29.95.

Working with Alzheimer's Disease. By David Sutcliffe. A training manual for professional workers and volunteers in the community, hospitals and in homes for elderly. The manual gives a deeper understanding of the world of the person with Alzheimer's and the carer. Available from: David Sutcliffe; 9 Milton Crescent, Eastbourne, East Sussex. Tel: 0323 724886. Cost: 1/\$2.30, 10/\$13.25.

Implementing the Community Care Act: a survey of local authority care home free arrangements and contract conditions. Available from: Lang and Buisson Publications Ltd. Lymehouse Studios, 38 Georgiana Street, London NW1 0EB. Tel: 071-284 1268.

Aging in Japan. By Shigeyoshi Yoshida. Available from: Japan Research Institute (JARC), 1-9-5, Hirakawa-cho Chiyoda-ku, Tokyo 102, Japan. Tel: Tokyo 3265-2343.

Classification & Diagnosis of Alzheimer's Disease: an international perspective. By Theodore Hovaguimian. Available from: Hogrefe & Huber Pubs.; PO Box 51, Lewistown, NY 14092. U.S.A. Tel: (716) 282-1610.

Epidemiology and Aging: an international perspective. By Jacob Brody & George Maddox. Available from: Springer Pub. CO. 535 Broadway, New York, NY 10012. U.S.A. Tel: (212) 431-4370.

Aging of the Brain and Alzheimer's Disease: proceedings of the 14th International Summer School of Brain Research, held at the Royal Netherlands Academy of Arts and Sciences, Amsterdam, The Netherlands, 26-30 August 1995. Available from Elsevier Science Pubs. Co. 655 Avenue of the Americas, New York, NY 10010. U.S.A. Tel: (212) 989-5800.

Alzheimer: le long crepuscule (French). Available from: Canada—Agence de Distribution Populaire Inc. 955, Rue Amherst, Montreal H21 3KL. Tel: (514) 523-1182. France, Africa—INTER FORUM 13, rue de la glaciere, 75013 Paris. Tel: (1) 43-37-11-80. Belgium, Portugal, and states to the East—S.A. VANDER, Avenue des Volontaires, 321, 1150 Bruxelles. Tel: (32-2) 762-98-04. Switzerland—TRANSAT S.A. Route des Jeunes, 19, C.P. 125, 1211 Geneve 26. Tel: (22) 42-77-40.

The Early Story of Alzheimer's Disease. By Katherine Bick, Luigi Amaducci and Giancarlo Pepeu. Distributed Internationally. Available from: Raven Press; 1185 Avenue of the Americas, New York, NY 10036. U.S.A (212) 930-9500.

Dementia Research Register. Offered on an annual subscription basis. Available from: Alzheimer's Disease and Related Disorders Association (Australia) Inc. National Secretariat, P.O. Box. 51 North Ryde NSW 2113. Tel: (02) 878-4466.

Progressive Accommodation for Seniors: Interfacing Shelter and Services. Covers the most current thinking on a variety of topics related to seniors housing. Featuring: Choice, Control and the Right to Age in Place; Social Policy Models for Shelter and Services: An International Perspective; Realities and Challenges in Providing Services to Seniors: The

Home Care Perspective. Available from: The Gerontology Research Centre; #2800-515 W. Hastings Street, Vancouver BC V6B 5K3, Fax: (604) 291-5066.

Dementia Units in Long Term Care. By Philip Sloane and L. Mathew. For anyone planning to establish a dementia unit and concerned with quality of long-term care for persons with dementia. Available from: The John Hopkins University Press; 2715 North Charles Street, Baltimore, MD 21218-4319. Cost: 436.00. Tel: 1-800-537-5487.

Help Wanted: Wednesdays Only. About a young boy whose life is turned upside down by his grandfather's illness. Napoleon Publishing; 5334 Yonge Street #147; North York, Ontario M2N 6M2 Canada.

VIDEOS

Dance Therapy and Dementia: Activating Alzheimer's Patients. By Israel dance therapist Shoshanna Hirsh. This educational video, presents the problems of dementia and the use of dance therapy with Alzheimer's patients. A segment of an actual session—useful both to professionals and family members—is included. Proceeds from the video go to funding the Melabev Day Care Program. Available from: North American Association of Jewish Homes and Housing for the Aging; Dr. Herbert Shore, Executive VP, 10830 North Central Expressway, Suite 150, Dallas TX 75231. Or Melabev, Community Clubs for Impaired Elderly; P.O. Box 3235, Jerusalem 91031 Israel. Tel: 02-555-049, 555-198. Cost: From Israel to Europe: \$5; to S. Africa, U.S.A, and Canada: \$7; to S. America \$9. Time: 26 Minutes.

It's My Turn Now: The Choice of Older Women to Live Alone. This documentary explores myths surrounding older women living alone. The video follows 16 senior women, as they work with an academic researcher, interviewing over 175 women on the experiences of older women living alone. Conclusions are surprising and inspiring. A dynamic partnership between academic and community researchers is revealed. Available from: Gerontology Research Centre Simon Fraser University; 515 W. Hastings St., Vancouver BC Canada V6B 5K3. Tel: (604) 291-5062. Cost: \$20.00 (Includes GST & Postage). Time: 21 minutes.

Members Go Creative to Observe World Alzheimer's Day

Even as news cameras and flashbulbs dominated the scene in Edinburgh, the World Alzheimer's Day message rang out loud and clear around the world as ADI Members labored successfully to raise awareness about AD and encourage support for Alzheimer families. Following is a sampling of Members' reports about their World Alzheimer's Day activities.

MONTEVIDEO, URUGUAY — Asociación Uruguaya de Alzheimer y Similares (AUDAS)—A Press Conference was called for 12:30 pm, September 21. It was attended by representatives of the radio, newspapers and TV media. Dr. Roberto Ventura, medical advisor to AUDAS, and one of its founding members, outlined the association's history, and gave a talk on AD. The publicity agency ICARO made all arrangements, rented a 29" television and video, and the PSA video received from ADI was shown. There was an interesting discussion among those present, well into the afternoon.

In the evening, the members of all the self-help groups in Montevideo were invited to join in a gathering. "It was a very friendly event and it was good to see that although they didn't all know each other, there was an atmosphere of unity, proving that what is expressed in the opening readings of group meetings is a reality; it strengthens and deepens the friendships that are born in the group meetings," Says Kathleen Potts, AUDAS President.

Dr. Ventura's talk was important to this gathering, too. Following it, several members testified as to how much AUDAS had helped them. At the end, two videos were shown, the one received from ADI and one filmed some time ago at the home of Mrs. Kathleen Potts, in which she recounts the history of AUDAS and explains how self-help groups function.

As a result of the publicity campaign during the month, and especially on World Alzheimer's Day, many telephone calls were received asking for information and assistance. "In the interior of the country, there are two groups functioning, they also had a lot of World Alzheimer's Day publicity on the radio, TV and newspapers," Mrs. Potts reports.

SYDNEY, AUSTRALIA—In Australia, we marked the day by issuing media releases which focussed on the need for research into all aspects of dementia in Australia. We also took the opportunity to announce our two research grants for 1994.

Dr. Jim Phillips, from the Psychology Department at Monash University, Victoria, received a grant of \$9,788 for a study of the "*Cognitive-motor processes contributing to dementia.*"

Professor Irena Madjar and Ms Isabel Higgins, of the Faculty of Nursing, at the University of Newcastle, received a grant of \$9,968 to study the "*Detection and management of pain in nursing home residents suffering from dementia.*"

Alzheimer's Association (Australia) is currently exploring the concept of a major fundraising event in Canberra for World Alzheimer's Day in 1995.

KUNNAMKULAM, INDIA—In addition to normal media efforts on behalf of World Alzheimer's Day, Alzheimer's and Related Disorders Society of India (ARDSI), published a special issue of its quarterly news bulletin *Dementia News* to commemorate World Alzheimer's Day.

This 32-page publication was eminently successful in that it not only called attention to World Alzheimer's Day, but also informed readers about AD, dealt extensively with caring issues and gave information about ARDSI and its programs. The newsletter also reviewed the first national conference held at Madras, February 1994, and announced the 2nd National conference which is to be held at Thrissur on November 5, 1995.

UNITED KINGDOM—Alzheimer's Disease Society (ADS) and Alzheimer Scotland—Action on Dementia (ASAD) took action to highlight World Alzheimer's Day in the European Parliament. They obtained the cooperation of Mr. David Martin MEP, a senior Member of the European Parliament, who agreed to table a resolution at the September plenary session of the Parliament in Strasbourg, drawing attention to World Alzheimer's Day and the difficulties faced by people with dementia and their carers. The reso-

lution called for action by the European Commission, Council and Member States to:

- promote awareness and understanding about AD and other dementias
- ensure the provision of adequate practical and financial support for people with dementia and their carers
- increase investment, direct and motivate, research into the causes and treatment of Alzheimer's disease

Additionally, the ADI Members wrote to EC members of the Alzheimer's Europe federation requesting each to write to their respective MEPs asking them to support the motion.

JOHANNESBURG, SOUTH AFRICA — The Alzheimer's & Related Disorders Association reports: "On the evening of Wednesday, September 21, a most outstanding cocktail function arranged and sponsored by the Mayor of Johannesburg, Councillor Dr. Piet Pretorius was held.

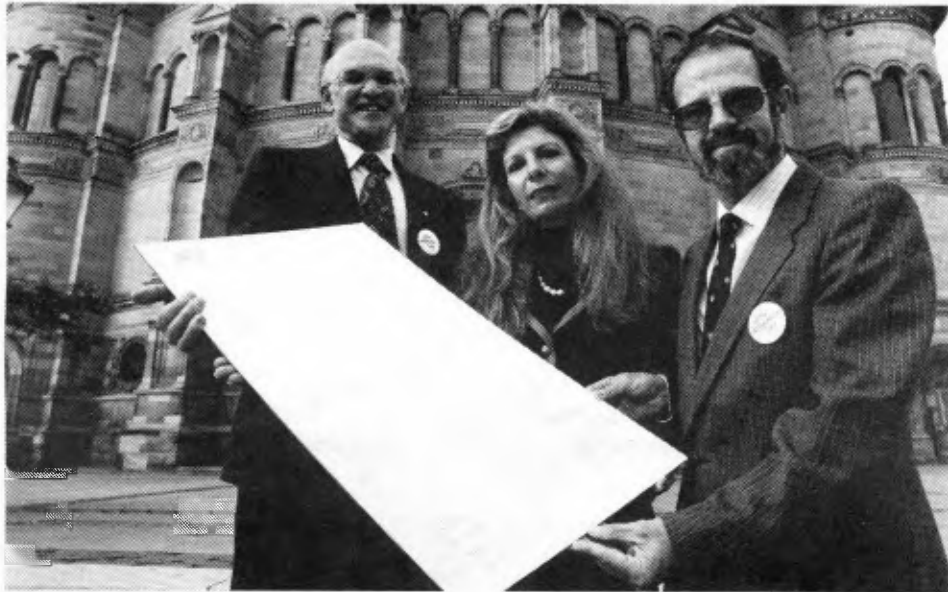
"Our patroness, Mrs. Marike de Klerk, delivered a most warm and touching message, and since the booklet *Caring for the person with dementia* was translated for ARDA by Miss Rina van Wyk, Miss van Wyk was asked to give the first copy, bound in beautiful leather, to Mrs. De Klerk. (This was a very special moment). It marked the first time Afrikaans members could be offered literature in their own language).

"Mr. Cobus Gauche, a star of the TV program *Tekkies*, gave an overview of the morning's mini seminar.

"Most memorable part of the entire evening was the intense feeling of being together as ARDA's family, participants reported."

When ADI Members actively join in observation of World Alzheimer's Day, it sends a message worldwide about the unified global movement dedicated toward conquering Alzheimer's disease and supporting development of systems to provide relief of the enormous burden placed on caregivers. This offers help and hope to over 15 million persons with Alzheimer's disease and their families around the world.

ADI Joined by WHO to Declare World Alzheimer's Day



L to R: Brian Moss, ADI Chairperson, Princess Yasmin Aga Khan, ADI President, and Dr. Jose Manoel Bertolotte, Sr. Medical Officer, World Health Organization display World Alzheimer's Day proclamation.

It was an exciting milestone event when Alzheimer's Disease International (ADI) joined by the World Health Organization declared the first ever World Alzheimer's Day on September 21, 1994. With television cameras rolling and journalists' cameras popping, Princess Yasmin Aga Khan, ADI President; Dr. José Bertolote of the World Health Organization; and ADI Chairman, Brian Moss signed the declaration and challenged everyone to learn the symptoms of Alzheimer's disease and to help caregivers, families and friends cope with its devastation.

"World Alzheimer's Day marks a monumental step toward the day when this insidious disease no longer wreaks havoc on the lives of families worldwide," said Princess Yasmin Aga Khan. "We hope this global observance will not only heighten awareness of the severity of this illness, but that it will also lead to understanding and support among those whose lives have not been touched by the disease."

Alzheimer's disease afflicts more than 15 million individuals worldwide, and cost the United States, England and France a combined estimate of \$75 to \$95 billion. The debilitating and degenerative illness knows no social, economic, ethnic or geographic boundaries and affects all populations equally.

"Alzheimer's disease has reached glo-

bal proportions," said Dr. Bertolote, Senior Medical Officer, World Health Organization. "The financial and social impact we have experienced from this disease thus far represents the tip of the iceberg. As the 65+ global population continues to increase exponentially, so will the devastation of this illness as it leaves its victims in the hands of family members and professional care providers."

Scientists and families are hopeful that recent research advances may lead to the day when Alzheimer's disease no longer threatens the lives of individuals worldwide. Extensive studies are currently being conducted internationally into the diagnosis, treatment, cure, prevention and management of the illness.

"Unless a cure is discovered, Alzheimer's disease and other dementia-related illnesses will continue to threaten the global community well into the 21st century," said Bertolote. "The burdens this illness places on families and health care systems worldwide are immeasurable. Organizations such as ADI and its member societies, leading researchers and health care providers must continue to work together to end the suffering caused by this terrible disease."

ADI will observe World Alzheimer's Day on September 21 in 1995 and each year into the foreseeable future.

Wanderers Registry Organizing in Canada

The Alzheimer Society of Canada and the Royal Canadian Mounted Police (RCMP) have joined forces to create a national database on individuals with Alzheimer's Disease. The Nation-Wide Alzheimer Wandering Person Registry is designed to aid the safe and timely return of people with Alzheimer Disease to their loved ones following an episode of wandering.

"Wandering is one of the worst fears and anxieties Alzheimer families live with," says Steve Rudin, Executive Director of Alzheimer Canada. Individuals with the disease commonly wander away in a disoriented state. They may be searching for a previous home, an old work place or a person from their past. In most instances, the individuals become so confused that they can no longer find home. The results are sometimes tragic.

The new program would enable families to register descriptive information about their loved one. Police forces across Canada would then have access to this information in the event of a disappearance. The program's first priority will be to prevent wandering through training and education. The Society will work with community groups like Block Parents, Med Alert and police forces across the country to increase awareness of Alzheimer disease and wandering.

The program is currently awaiting final approval from the government for funding. Mr. Rudin remains optimistic however, stating that, "with such a great need and the assurance that this program will save lives and money, we remain hopeful that funding will be approved for 1995."

Already inundated with requests from families and professionals to start the program, Alzheimer Canada and the RCMP hope to have the entire program up and running early in 1995. For further information, contact Lisa Dower, Debbie Krulicki +(1 416) 925-3552 at the Alzheimer Society of Canada.

ADI Conference Sites

Over 800 persons were registered for the ADI Annual Meeting & Conference held in Edinburgh, Scotland, in 1994.

Each year the Conference is held in a different country. The ADI Member in that country serves as Host, and works with the Secretariat to plan and organize the event.

ADI Members apply to Host an ADI International Conference three years in advance. ADI's Conference Committee reviews applications and makes its recommendation to Council for approval. Every effort is made to distribute the event around the globe for the convenience of participants.

Globally Speaking

By the year 2025, the number of seniors worldwide is expected to increase to 1.2 billion—or 14 per cent of the total population. If current trends continue, almost three-quarters of the world's older inhabitants will live in developing countries.

Rapid global aging has enormous economic and social implications. Recognizing this, in 1982, the United Nations (UN) World Assembly on Ageing introduced the International Plan of Action on Ageing. Endorsed by the UN General Assembly the same year, the Plan has helped to keep aging issues high on the international agenda for more than a decade.

—Source: Seniors Info Exchange, Canada

Volunteers Promote a "Good Practice"

Alzheimer's Association (Australia) has developed a strong volunteer-run Speakers Bureau program. The bureaus are groups of carers and ex-carers who are trained to be public speakers on behalf of their state Associations

They provide not only a most effective way of getting the Association's message to the public on a low-key, cost-effective and continuous basis, but also provide a welcome way for some carers to give something back to the Association which helped them so much.

Calendar of Events

MARCH 30-APRIL 1, 1995

Neuroimaging in Dementia, Nice France. Contact: Scientific Secretariat, International Conference on Neuroimaging in Dementia; Centre Antoine-Lacassagne-Bibliothèque; 36 Vole Romaine; 06050 Nice Cedex 1, France. Tel: +(33 9) 381-7133 Ext. 2514.

APRIL 8-11, 1995

"Alzheimer Advocacy: Don't Stop Now," Alzheimer's Association (USA) 7th Annual Public Policy Forum. Hyatt Regency Hotel, Capitol, Washington, D. C. Contact: Alzheimer's Association Public Policy Forum; P. O. Box 10571; Fort Dearborn Post Office Station; Chicago, Illinois 60610-0571.

APRIL 23-27, 1995

Assisted Living: Putting People First. Assisted Living Facilities Association of America's Spring '95 National Conference & Trade Show & Institute. Contact: Assisted Living Facilities Association of America; Circle Towers Plaza; 9411 Lee Highway, Suite 1; Fairfax, Virginia 22031. Tel: +(1 703) 691-8100. Fax: +(1 703) 691-8106.

APRIL 27-29, 1995

Reaching New Heights, the 17th Annual General Meeting and Conference, of Alzheimer Canada. Fantasyland Hotel & Resort; Edmonton, Alberta, Canada. Contact: Alzheimer Society of Canada, 1320 Yonge Street, Suite 201, Toronto, Ontario M4T 1X2, Canada.

APRIL 28-29, 1995

Dementia Specific Care Units: Winning Strategies for Success, sponsored by J. A. Haley Veteran's Hospital, Menorah

Manor, Alzheimer's Association Tampa Bay Chapter. Trade Winds Resort, St. Petersburg Beach, Florida. Contact: Mary Kaplan/Menorah Manor; 255-59th St. North, St. Petersburg, Florida 33710. Tel: +(813) 345-2776.

MAY 7-10, 1995

"Practical Solutions in Dementia Care" 5th National Conference, Alzheimer's Association Australia. Sheraton Brisbane Hotel & Towers. Conference Secretariat; 5th National Conference; Alzheimer's Association Australia; P.O. Box 1280; Milton QLD 4064; Australia.

JULY 21-24, 1995

"The Changing Face of Alzheimer Care", The Fourth National Alzheimer's Disease Education Conference of the Alzheimer's Association (USA). Sheraton Hotel and Tower, City Front Center, Chicago, Illinois. Contact: Rita Freeman; Alzheimer's Association; 919 N. Michigan Avenue; Chicago, Illinois 60601. Tel: +(1 312) 335-5722. Fax: +(1 312) 335-1110.

AUGUST 20-25, 1995

XVII World Conference of the International Union for Health Promotion and Education. Japan, Makuhari Messe. Contact: IUHPE World Conference Secretariat, c/o KIKKO Co.; Nagata-cho TBR Building 9804, 2-10-2 Nagata-cho; Chiyoda-ku, Tokyo 100, Japan.

SEPTEMBER 12-15, 1995

"An Interdisciplinary Focus on Dementia Care," The 11th International Conference of Alzheimer's Disease International

Buenos Aires, Argentina. Contact: Organización M.C. Congressos; Av. Pte. Roque Saenz Peña 720-2 Piso "B" (1035); Buenos Aires, Argentina. Tel: +(54 1) 328-0890/1358. Fax: +(54 1) 328-8640.

OCTOBER 29-NOVEMBER 3, 1995

Spirit in Ageing, 7th International Congress of the International Psychogeriatric Association. Park Grand Hotel, Sydney, Australia. Contact: Wyeth Clinical Meetings Service; 7th IPA Congress, P.O. Box 148, Parramatta NSW 2124, Australia. Tel: +(61 2) 843-6406 Fax: +(61 2) 687-2501.

NOVEMBER 19-23, 1995

"Total Care of the Elderly," 5th Asia/Oceania Regional Congress of Gerontology, Hong Kong Convention and Exhibition Centre. Contact: Gardiner-Caldwell Communications Ltd., 2403, Tung Wai Commercial Building, 109-111 Gloucester Road, Wanchai, Hong Kong. Tel: +(852) 519-3083, Fax: +(852) 519-8072.

OCTOBER 8-11, 1996

12th International Conference of Alzheimer's Disease International, Jerusalem, Israel. Contact: Sharon Barnett; Kenes; Tel: +(972 3) 514-0014. Fax: +(972 3) 517-5674.

SEPTEMBER 1997

13th International Conference of Alzheimer's Disease International. Turku, Finland.