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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.)

Researchers Announce Breakthrough Theory on AD

New findings have led Duke University Medical Center researchers to propose a novel theory on how the most common forms of Alzheimer's disease work. If confirmed, it suggests a way to prevent the deadly disease in susceptible people.

In a report prepared for a symposium on, November 7, 1993, sponsored by the U.S. National Institute on Aging, Dr. Allen Roses and Dr. Warren Strittmatter suggested that the disease develops as the result of failure of an inherited form of protein called apolipoprotein-E4 (apo-E4) to maintain nerve cells' interior pathways along which nutrients and protein are shuttled.

This represents a sharply contrasting approach to the disease mechanism proposed by conventional theories. Other theories have focused on the role of another protein, called beta-amyloid, which forms plaque outside nerve cells in the brains of persons with AD.

Other scientists contributing to the research include Michel Goedert and Ross Jakes, from the Medical Research Council Laboratory of Molecular Biology, Cambridge; Li-Ming Dong and Karl H. Weisgraber, from the University of California, San Francisco; and from Duke: Ann Saunders, Margaret Pericak-Vance, Dr. Donald Schmechel and David Huang.

Last year, Duke researchers found that apo-E4, one of three variants of the apolipoprotein-E gene that shuttles cholesterol in the bloodstream, is associated with an increased risk of developing the most common forms of Alzheimer's disease. Apo-E4 has only previously been linked to heart disease.

The scientists later found that in the

groups sampled people who inherited two apo-E4 genes, one from each of their parents, were eight times as likely to get the disease as people who inherited two normal apo-E3 genes. Patients with two apo-E4 genes got the disease by an average age of 68. Apo-E4 is an inherited factor in approximately two-thirds of all Alzheimer's patients studied so far.

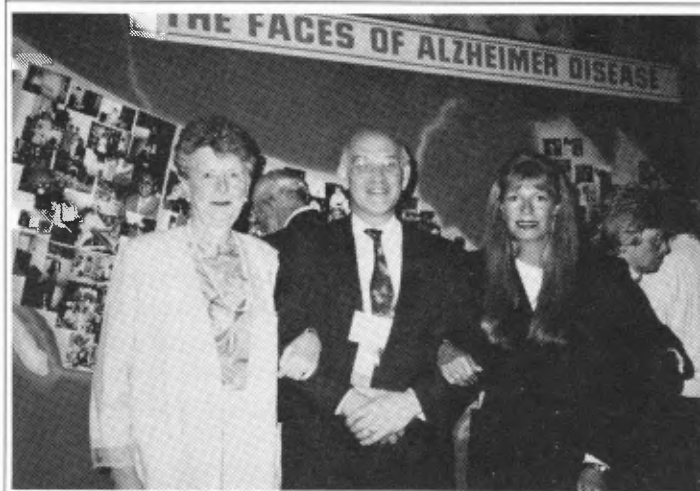
Now, the Duke scientists, working with investigators from California and Great Britain, have developed a theory to explain why apo-E4 promotes the development of Alzheimer's and apo-E3 does not. (The third apo-E gene variant, E2, is rare and has been shown to be involved in high cholesterol disease).

Simply stated, nerve cells use railroad-like transportation systems, known as microtubules, to move molecules to sites where they are needed in the cell. Apo-E3, the *good* apolipoprotein, keeps the railroad's *ties*, arm-like projections made up of a protein called tau, in place on the track. However, apo-E4 does not bind tau, and the *ties* of tau may then tend to stick together.

The researchers believe that in Alzheimer's disease, *tau* aggregates to form thread like *neurofibrillary tangles*.

"The disease mechanism we favor is that Apo-E3 binds to tau to protect it from forming neurofibrillary tangles. Apo-E4

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ADI's 9th
International
Conference
an Over-
whelming
Success

(L-R) Jeanne Bentley, Brian Moss, Princess Yasmin Aga Khan unveiled "Faces of Alzheimer Canada" at the Conference opening session

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Annual Meeting 1993 Marks ADI's Growth & Development

ADI's 9th International Conference held in Toronto, Ontario, Canada, was an unqualified success. We thank Jeanne Bentley, President of the Alzheimer Society of Canada, and her volunteer committee, and the excellent staff at the ASC headquarters offices for a superbly well-



Brian Moss

planned and executed event. An unprecedented 700 plus people from over 30 countries attended the Conference.

ADI's Annual Meeting preceded the Conference (September 17-19). ADI's

AGM, comprising meetings of Council and its committees, marked a period of considerable growth for the ADI Federation. Following are some highlights.

We were pleased to welcome Dr. Jos. Bertolotte, Senior Medical Officer, World Health Organization (WHO). Dr. Bertolotte, is the Designated Technical Officer in the Official Working Relationship ADI has entered into with WHO. His discussions with committee and Council members reaffirmed the potential for raising worldwide Alzheimer awareness and increasing support for families through the collaborative relationship.

Also, we were delighted to welcome as our guests Dr. Katalina Tudose of Romania and Dr. Tadeusz Pamowski of Poland to attend the AGM and Conference, made possible through Project Global Outreach.

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PRESIDENT
Yasmin Aga Khan, USA

CHAIRPERSON
Brian Moss, Australia

SECRETARY GENERAL
Rachel G. Billington

EDITORIAL ASSISTANT
Amy Shirar

Clearly, the 1993 AGM was a very positive event as the Standing Committees met to advance the agenda of ADI.

The **Education and Family Services Committees** met together to move forward the WHO/ADI Caregivers Booklet which is planned for publication in 1994.

The **Public Policy Committee** rolled out the results of its survey, which offers important data on the prevalence of Alzheimer's disease, and gives detailed information on Members' programs. The report, provided in handsome binders (to be updated from time to time) will be a fine addition to Members' libraries.

The **Membership Development Committee** reviewed a membership application from Austria, and reviewed the status of Provisional Members. Congratulations are in order for our new Provisional Member headquartered in Vienna, Austria, the Selbsthilfgruppe, Angehörige der Alzheimerkranken (SAA). Estimating 60,000 persons with Alzheimer's in that country, SAA operates a Helpline, holds Alzheimer awareness programs and provides Support Groups for families.

Congratulations, too, to the Alzheimer's & Related Disorders Society of India (ARDSI); Alzheimer's Association of Israel (AAI); and Federated Associations of Family Alzheimer Associations (FFAA), approved for Full Membership status by the ADI Council.

The **Conference Committee** reviewed four most attractive Future Conference proposals from country members. After lengthy deliberation, they recommended Israel as the site for the 1996 Conference. The Council approved the recommendation. New Guidelines & Standards for future Conference Hosts are now available.

The **Public Relations Committee** announced that the ADI brochure and Me-

dia Guide are now available to members and, heard a presentation on the feasibility and potential of holding a World Alzheimer's Day in cooperation with the World Health Organization. More information on this is forthcoming.

The **Medical & Scientific Advisory Committee's (MSAC) Steering Committee** met to discuss direction for its future programs. In addition, planning and program support was given to Alzheimer's Scotland, host for the 1994 Conference; a task force was appointed to study the level of teaching about dementia provided for general practitioners; and, a plan offering Members Alzheimer's updates and articles for the *Global Perspective*. Congratulations to **Dr. Henry Brodaty**, elected Chair of the MSAC.

We are also pleased to congratulate **Dr. Nori Graham**, Chair, Alzheimer's Disease Society, United Kingdom, who was elected Vice Chair of ADI, at this meeting. And congratulations to **Rachel Billington** appointed Secretary General, succeeding **Edward Truschke** who held that position since 1987. Our thanks and appreciation go to Ed and the U.S. Alzheimer's Association for their generous support in bringing ADI to this point in its development.

As we approach 1994, there is excitement and hope in the air. ADI is reaching more people in more countries and helping them to form new Alzheimer societies. Promising new research findings seem to be announced nearly every week. Scientists are saying we may have a treatment for Alzheimer's within five to ten years. Until then ADI will strive to raise worldwide Alzheimer awareness and shed light on the plight of persons with AD and their families. We are strong in our belief that we can do it together. —Brian Moss

*Best Wishes for a Healthy,
Happy and Prosperous
New Year—1994*



AFCDE Impacts Availability of Dementia Care in Japan

(AFCDE) Association of Families Caring for the Demented Elderly of Japan, was established in 1980. At the beginning, our focus was entirely on older persons with dementia and their families. However, over time, we saw the number of families requesting care advice for younger patients increase, and we found that in many respects, providing care for these sufferers was more difficult than for older dementia sufferers.

To gain a better understanding, our Association conducted a survey among our members in March, 1991. This survey revealed several problem areas in providing care for younger persons with Alzheimer's. These included income decrease after forced retirement, affects on their children, and age discrimination by medical-social services which provided mainly for older patients.

After we analyzed the survey data, we conducted a second survey, comparing younger dementia patients with older dementia patients, to confirm that specific social care issues exist for younger patients. In September, 1991, questionnaires were sent to 1,000 Association members; 337 questionnaires were returned.

Patient Characteristics: Concerning age of patients, 26 were under 65 years and 311 were 65 years and over. In Japan, we have several surveys of morbidity of dementia among the elderly. According to the surveys, it is estimated that there are about one million demented elderly in Japan. Therefore, I can make a rough estimate of the number of younger demented patients in our country, which is 80,000, and a morbidity rate of about 0.5% among the age group between 40 and 64.

Regarding sex of the patients, the rate of male to female was 50/50 in the younger dementia group, and 26/73 in the older dementia group.

As far as causes of dementia were concerned, Alzheimer's disease was more prevalent than cerebrovascular dementia in the younger group. All of the patients in this group had been seen by doctors. Also, in the older group, Alzheimer's was more prevalent than cerebrovascular de-

mentia. About 86% of the patients in this group had been seen by doctors. In our country, it has been said that cerebrovascular dementia is more prevalent than Alzheimer's among the elderly. The result of our survey was different from results of several former reports. However, a recent etiological survey reported that Alzheimer's disease was increasing among the elderly in a community of Japan.

Physical condition of patients was not significantly different between the two groups. But living circumstances of patients was different. For example, about 58% of younger patients and 71% of elderly patients lived in their own home. This may mean that care for the younger person was more difficult than for the older. Another aspect of living circumstances was that more younger patients were admitted to psychiatric hospitals (11.5% to 2.6% in senile dementia patients). In Japan, a psychiatric hospital was one type of facility which readily accepted younger dementia patients, especially if they were in their fifties.

Family Caregiver Characteristics: In relationships between family caregivers and dementia patients, a remarkable difference was found between the two groups. For younger patients, most caregivers were spouses (85%). However, for the older group, about half of the caregivers were daughters-in-law and daughters; only 25% were spouses. The number of family members of caregivers was small in the younger dementia group. Its number was two, including a patient, in half of the families caring for younger persons. However, the number was five in 33% of families caring for the demented elderly.

On the questionnaire many family caregivers wrote about their daily living experiences, their problems, their distress, their hope. From this we found care conditions that were specific to providing care for younger dementia patients. For example, with the early onset of AD, a husband was forced to retire, this resulted in a decrease in income. In the case where a wife was the sufferer, the husband was forced to retire to care for his

wife at home; again, loss of income.

In another case, a younger sufferer and his caregiver had children who went to school, or worked, and were living at home. Care for the younger dementia patient at home impacted every aspect of their daily living. The caregiver had the burden of care not only for a patient, but also for their children.

(We)...made demands for abolition of age discrimination... Now, social programs for younger patients and their family caregivers are improving little by little in our country.

Recently, in Japan, medical and social services for the demented elderly have been improved. The number of home helpers, day service centers, and facilities of short stay service is increasing in the community. However, young persons with Alzheimer's and their families are not able to utilize these services only because they are younger. In our country many social programs for dementia are discriminated by age, that is, they are available only for persons age 60, 65 or 70. This places younger patients and their caregivers in difficult care conditions.

Finally, I report that in August 1992, our Association made demands for abolition of age discrimination for social service programs and financial support to family of a young dementia patients to the Ministry of Health and Welfare. As a result, the Ministry established a special committee and began to study a policy for younger persons with AD. A national board member of our Association became a member of the committee. Now, social programs for younger dementia patients and their family caregivers are improving little by little in our country.

—Author Yoshio Miyake, M.D., Vice President of AFCDE in Japan, is Chief of Geriatric Medicine, Ohta Memorial Hospital, Koriyama, Fukushima, Japan.

European Tour Sheds Light on Exemplary Alzheimer Programs & Facilities

The manifestation of Alzheimer's can be as individual as the persons who contract the disease, so there is no single easy formula for best practices in Alzheimer care. When Beverly Sanborn informed us that she was planning to visit Europe to study exemplary programs recommended to her by Members and others, we asked her to write about her findings. Following is her report.

During July, 1993, I visited Europe to meet with the people who made special programs happen; I wanted to glean their philosophy, to literally experience their facility environments. I wanted to see beyond the obvious—to grasp the intangible ingredients that produce facilities that provide care of exceptional merit.

This quest was inspired by my decade of planning, designing and working in residential Alzheimer's facilities and day care programs. Over the years, my colleagues and I have noticed that as good programs mature, they all begin to look alike—as though responding to some underlying principle of quality.

At the beginning of July, I set forth on my journey. Along the way, I corresponded and met with Alzheimer's societies in Germany, England, Ireland, and Scotland. I also corresponded with Professor Mary Marshall, Director of University of Stirling's Dementia Services Development Center in Scotland. With their combined help, I was able to visit an outstanding group of facilities and service systems.

Highlights of the Journey

Ipf Hof, in Bopfingen, Germany

Ipf Hof, a respite hotel for the physically disabled and Alzheimer's patients, it is located in the Franconian region of north Bavaria (the famous castle area of Germany). Originally a tourist hotel, Ipf Hof was purchased by Frau Dr. Frosen-Putz, a gerontology trained psychology professor whose clinical and community experience suggested a need for a respite-oriented residential facility that could be used for a variety of short-term purposes. Dr. Frosen-Putz maintains a 1 to 2.5 staff

to resident ratio. Residents are treated like guests in an elegant resort with the unobtrusive addition of very professional and attentive care for their special needs. Dr. Frosen-Putz's many innovations includes a two-week October retreat for Alzheimer patients and their families. While the patient is enjoying stimulating activities, the families meet together for mutual support, education, and fun.

Sophiansanatorium, in Thambach, Germany

In the small village of Thambach, about one hour's drive west of Munich, the Collegium Augustinum Corporation (a large, nationwide organization which operates universities, hospitals, clinics, homes for the aged and nursing homes) has established Sophiansanatorium as it's first of two residential Alzheimer's facilities. Housed in a beautiful mansion, this facility can accommodate 25 dementia residents in all stages of the disease. The ambiance of Sophiansanatorium is that of a large, loving family which is energetically engaged in a variety of interesting life experiences. One gets the feeling that the *business of living* is fun here, a feeling that is in no small measure due to the management style of Herr Schiller, the nurse/director and Frau Linn, the program director. Staff ratios are about 1 to 3. All staff have specific roles (most are

nurses) but everyone is expected to join in with therapeutic activities. And, even though front and back doors are locked, residents do not feel locked in because staff is immediately responsive to residents desires and will take them outside whenever they wish.

Die Staatlichen Pflegeheime of Hamburg, Germany

Hamburg has 13 state-run homes for the elderly health impaired, accommodating 4,700 residents, 90% receive state subsidies for care. Facilities range from 30% to 90% dementia. Under the direction of two psychiatrists, Dr. Jens Bruder and Dr. Wojner, seven special care units for dementia have been established. Several of those are experimental and reflect the physicians' ongoing quest to establish the highest quality possible. Dr. Bruder and Dr. Wojner have done a remarkable job transforming these facilities into home-like, non institutional environments for about 20 residents in any given unit. Innovative designs have transformed hospital corridors into cozy spaces. Units are staffed in a 1 to 2 ratio by exceptionally skilled people who have been trained in the nursing school operated by the two psychiatrists. The staff are obviously inspired by the immense dedication of these two physicians. In Hamburg, institutional care wears a very human face.



Sophiansanatorium, the mansion and estate for a residential Alzheimer facility in Bavaria.

Sanborn's Observations on Elements of Good Care

WORK=MISSION. Outstanding programs are managed by people who see their work as a mission to honor and respect people with dementia, and to provide them with an environment in which life is still celebrated, limitations and all.

BALANCE. Managers are able to balance the seriousness of their work (health, safety, and quality assurance) with a wholesome sense of the assured so that life within the facilities is energetic, lively and fun. When talking or interacting with these managers, one feels an affirmation of the value of life.

QUALITY CARE. Managers have exceptionally high standards for quality care.

They make sure that this standard is met at all times. To insure quality, the managers:

- Set up on-going training programs designed to provide staff with knowledge and the ability to become problem solvers.
- Mentor, and role-model responses
- Rely on participatory management practices: these managers hold regular meetings with staff in an active interchange. Problem-solving and evaluation is a mutual exchange experience.

•Use a care plan method that sets goals and objectives for residents. These are monitored on a regular basis.

INSPIRATION. Managers have a gift for inspiring others. They instill in their staff a passion to do the best job possible.

DYNAMIC PROGRAMS. Programs are all dynamic, always being fine-tuned. Every manager described on-going experiments in their constant search for improving

quality. Evaluations are on-going as well. These programs invite evaluation from outside professional and community groups, family members and the residents.

OPEN SYSTEMS. Programs are open-systems with constant interchange and coordination with the larger community. Facilities welcome visitors, are open to critique.

CARING COMMUNITY. The facilities become a caring community. Staff and residents are part of the community. Both are equally valued and nurtured. Residents are selected with an admission policy which looks at the best fit for community, because the programs recognize that every new person will change a group environment.

NORMALCY. Life is kept as normal as possible, with emphasis on an activity-based strategy to manage behavior problems.

LARGE STAFF. Staff to resident ratios are high, never less than one staff to three residents. All consider one-to four marginal and anything less to be substandard.

SMALL UNITS. Units are small with between 15 and 25 residents considered to be the optimum range. Large, more institutional facilities can become more intimate by dividing the spaces into smaller units.

TAILORED CARE. Strong emphasis on knowing the life history of each resident, current capabilities, and then tailoring the care to each person's life experiences.

INDIVIDUALITY. Equally strong emphasis on respecting the individuality of each resident (e.g., introverts do not like prolonged exposure to groups and should be given time alone or one-on-one with staff).

maintain a patient in the home. Families are given a wide range of home care support plus respite options such as adult day care and over night respite beds. Through Dr. Graham's chairmanship of the Alzheimer's Disease Society, she has encouraged growth in volunteer programs such as family support groups and educational sessions. When home care is not appropriate, Dr. Graham can place patients at two separate community-based sites: Queen Mary's, a remodeled unit, dedicated recently by Prince Charles, and the HOO, a stand-alone unit with 24 beds in the former Lipton Tea family mansion. The genius of this system is that a very large number of patients can be successfully treated with a personalized approach that is pleasing to providers and receivers.

Rosebank, Kilmarnock, Ayrshire, Scotland

Rosebank is located about an hour south of Glasgow in the town of Kilmarnock. It is an assisted living residence which has a dementia unit that accommodates four permanent residents, four respite residents and sixteen day care participants. Mary Cullinane, Officer in Charge, operates Rosebank as a community, a place where people gather together to live, socialize, work and play. Although functional limitations are honored, every effort is made to integrate both the persons with dementia and the more independent residents in appropriate, and very interesting activities. Rosebank is in continual communication and interaction with outside community people and professionals. Family members of residents are encouraged to find their niche within the Rosebank community as well. Staff and outside professionals receive on-going training at Rosebank in techniques of dementia care. As a group, they are constantly evaluating and experimenting with new ideas. They have found, for example, that confused residents can find their rooms if the entire space, from top to bottom, is decorated in one distinguishing color. Rosebank is another example of a residential facility that is an integral part of a comprehensive system of continuing care services.

—To be continued.

In the next issue, Ms. Sanborn will discuss Day Care programs she observed on her tour.

Acomb Gables, York England

Acomb Gables is the first of York's Community Units for the Elderly (CUE). Under the direction of Consulting Psychiatrist, Dr. Christine Kirk, a multidisciplinary and multi-service system committee developed a master plan to close a mental health facility and replace it with eight community units. The CUE's consist of a building which offers day care and residential care with several respite beds, all in a setting that is as home-like as possible.

The CUE offers assessments and supportive services designed to maintain elderly mental patients (primarily depression and Alzheimer's) in their own homes. The units have a high degree of inter-agency cooperation, and are a resource center for the community as well—offering support groups for families, training and education for professionals and a community coffee shop staffed by volunteers.

Families and professionals are very happy with the new system. CUE's also offer a financial bonus. The old hospital absorbed 40% of the budget for overhead and maintenance; the CUE's need only 20%.

Hampstead Health District, London, England

Under the direction of Consulting Psychiatrist, Dr. Nori Graham, the Hampstead Health District in London serves a population of 8,000 elderly persons. There are approximately 1,000 persons with dementia and mental illness. Dr. Graham coordinates a system of services using geropsychiatric multidisciplinary teams, which work together amazingly well with the general practitioners and the social services departments. Since many hospital beds have been closed, the emphasis is on marshaling the supportive services and in-home assessments needed to

You Can Make a Difference—Approaches to Effecting Change

Welcome to *Public Policy Pages*, a new feature which will appear regularly in **Global Perspective**, provided by ADI's Public Policy Committee. Following is an introductory overview on aspects of developing a public policy program. Future articles will deal in depth on public policy issues that ADI Members have identified as being of particular interest.

ORGANIZATION—THE KEY TO SUCCESS

On a personal level, when you're organized, you have a special power. You walk with a sure sense of purpose. Your priorities are clear in your mind. Things fall into place when you review your plan. People believe your promises because you always follow through. When you enter a meeting, you're prepared for whatever they throw at you. When you present your position, you're a winner.

As an ADI Member society—to get organized—you may need to look at your case and determine your specific interests—variety of concerns, i.e., funding for programs, changes in government laws, etc. Consider a needs and preference study, which should be neutral, thorough and objective.

PLANNING AND RESEARCH

In the planning process, your society's leadership will want to ask...Who are we lobbying? What are the issues? Why? In responding to these questions, it is important to be clear and objective.

Timing is critical. Establishment of an ad hoc committee may be required. This, too, is a vital part of the planning process.

WHO TO LOBBY—POTENTIAL TARGETS

Government Ministers; other elected officials, members of federal/provincial governments; opposition members; appointed government officials; professional associations, i.e., medical, legal, etc., are all good targets. In preparing your message, you must put yourself in the target's "shoes," arrange your arguments toward his/her concerns or interests.

Your success or failure will depend a great deal on your ability to communicate your concerns, and to meet the needs of the politician to whom you are speaking.

You will not achieve success by treating politicians as enemies.

Politicians often listen to local constituents rather than to organizations.

In influencing politicians, your research must be thorough and accurate. You need to know your governmental structure, and who funds what. Know the personalities of your politicians, their attitudes and voting tendencies.

Seek advice from experts in the field. Look for alternatives—in case your first action may not achieve the results you seek.

YOUR ACTION PLAN—IT SHOULD HELP YOU TO:

- Determine what message you want to get across
- Define your goals
- Research your subject
- Identify your targets (who has the power to change legislation/policy, or fund your project)
- Identify resource organizations/individuals that might help
- Identify possible opposition
- Identify & select the most effective lobbying methods
- Develop a Media Strategy

DEVELOPING A MEDIA STRATEGY

Following are some questions to ask and concerns to be reviewed when planning to work with the news media:

Who comprises "the media" for us?

Who from your organization—or without—should speak with the media?

How do we develop a positive relationship with the media?

How do we prepare for meeting with the media?

How do we deliver our message and handle the questions?

What is our need for media coverage, what do we wish to accomplish?

What is our message?

Planning and preparation are a must before you approach the media for help in telling your story. It can be useful to target specific media and then work to establish trust and a cooperative relationship with your media contacts.

Look for someone in the media who reflects fairly a position—not necessarily an individual who supports your cause.

Select a spokesperson (It is helpful to have an alternate). Your spokesperson should have the full support of your organization—be conversant on all the issues and have available updates for the media on short notice. S/he should be articulate, able to get to the point quickly, and be passionate, but not emotional.

It is important to maintain credibility with the media—always be forthright and truthful. News releases and news conferences should contain new information in order to raise awareness on Alzheimer issues. Take advantage of every opportunity.

—Continued, next page

INTRODUCTORY GLOSSARY IN PUBLIC POLICY/ADVOCACY

Advocacy – The act of pleading for, supporting, or recommending a cause or course of action.

Advocate – to support or urge by argument; recommend publicly; a person who speaks or writes in support of a cause.

Lobby – to try to influence legislation or administrative decisions.

Lobbyist – one who tries to influence legislation or administrative decisions on behalf of a special interest; member of a lobby.

Lobbying – is the pursuit of the beliefs of your organization. It serves two functions, to obtain funding support and regulatory

or legislative change. Lobbying does not just involve influencing politicians. The public have to be influenced as well. "Lobbying" is not a dirty word. It's a very positive word, although many people infer a negative connotation when you say "We're going to lobby for changes." The first requirement for being successful is to be positive.

Public Policy – the basic policy or set of policies forming the foundation of public laws, especially such policy not yet formally enunciated.

Strategy – a plan or method for achieving a specific goal.

Committee Rolls Out Results of 1993 Survey

This year, during the 9th International Conference of ADI in Toronto, the ADI Public Policy Committee distributed to members a remarkable document which for the first time gathers vital information about ADI Members, their societies and the environments in which they function.

Twenty-two of ADI's 27 member Federation responded to the survey sent out early in 1993. A key statistic surfaced when 21 members gave us the estimated number of persons with AD in their countries—14,370,000. Total population for those countries—1,767,491,983.

Preparation and circulation of the survey was part of the 1993 action program of ADI's Public Policy Committee. Com-

pilation and production of ADI data binders to hold the resulting groundbreaking body of information was provided by the Alzheimer Society of Canada, 9th International Conference host.

"Each country is asked to keep its information updated on a regular basis by sending new information directly to Rachel Billington, in the ADI Secretariat office in Chicago," says Jeanne Bentley, Public Policy Committee Chair. She also asks that those members that have not yet provided information about their societies, kindly do so by completing their surveys and sending them to Rachel. Interesting Survey Factoids appear in this issue of *Global Perspective*.

PUBLIC POLICY/ADVOCACY ASSISTANCE TO BE MADE AVAILABLE

As a followup to the 1993 Survey, the Public Policy Committee (PPC) plans to contact ADI Members to learn about their current efforts and future plans for public policy/advocacy activities, and what information Members may wish to have to help with their advocacy programs. PPC contacts were planned to be made by the end of 1993. Members who have not been contacted and wish to provide input and/or request assistance should advise Rachel or contact Jeanne Bentley.

Survey Factoid: In Japan AFCDE's National and local social dementia programs serve 3,265 communities throughout the country.

Approaches to Effecting Change—Continued from previous page

nity to use the media effectively, but don't manipulate.

THE PRESENTATION

Your society's spokesperson will be invited to represent the Society in a variety of settings. Presentations will be verbal as at media conferences and public hearings; or, they may be written as a brief.

Presentations are meant to convince, persuade, sell, and inform! Your spokesperson must convince your audience that your issues, your organization and s/he are all credible.

An effective presentation will discuss existing conditions and why changes must be made. It will recommend changes and outline the process by which these changes would occur.

Include all the well-researched factual material necessary to support your argument. Use easily understood words, and good, concise, sentence structure. Avoid phrases and flowery adjectives. Briefs should be accurately typewritten.

Experts recommend the following presentation format:

OPENING: Be brief, purposeful, energetic
BODY: Develop argument/justification
CLOSING: Be brief, purposeful, energetic

DELIVERING YOUR MESSAGE

Suggested guidelines for making presentations are as follows:

Have a positive attitude and believe in your presentation

Be well-groomed, grooming is indicative of your respect for yourself, your audience, and your subject.

Be enthusiastic and show interest for your subject through voice and body.

Be in a position to see your audience. You know you are not getting through when members frown, look puzzled, doodle, fall asleep or leave the room.

Maintain eye contact with the audience as much as possible.

POINTERS ON ACTION PLANS

1—Monitor the government for bills that could have an effect on your society.

2—Write your politician

3—Send letters to the editor of your local newspaper. They are widely read and help guide public opinion. Politicians often read the letters in their local constituency papers

4—Letter writing campaigns work well. Letter campaigns key in on the issues and ask for support from elected officials. Handwritten, legible letters are better than form letters

5—Individual letters work well too

6—Be assertive not aggressive in letters and presentations

7—Schedule letter mailings over a set period of time

8—Telephone your politician

9—Meet with your politician when s/he is back in home constituency

10—Collect business cards of those you meet. Write the date, place and event at which you meet each individual on the back of the card, how they might help. Have cards of your own to give in return.

—Jeanne Bentley, Public Policy Committee Chair

HOW IT WORKS

The Public Policy Committee is studying the needs of ADI Members in accordance with ADI's Bylaws as set forth in Article 7, Section 3: "...The Public Policy Committee shall identify, develop, and analyze information about existing national programs of support designed to meet the needs of patients and families and make recommendation to the Council for improved public policy needed for patients and families affected by Alzheimer's disease and related disorders."

After it gathers information, the Committee works on developing programs in response to ADI Members' requests. In doing so, it consults with other ADI Committees as appropriate. When the Committee settles on a feasible and affordable plan of action, it makes its recommendation to the Executive Committee of the ADI Council. This body reviews the recommendation and can suggest the plan of action to Council for approval.

What (in the World) We're Doing

Alzheimer's Association, Australia, Inc. (AAA) introduced a Community Education Kit aimed at service providers. It includes basic educational information about dementia, as well as additional information. The kit was launched at the kick-off of National Alzheimer's Week on September, 5th.

Australia also released two Policy Issue Papers: *Education and Training in Dementia Care*, and *Residential Care and Dementia*. The publications are the outcome of the National Association's Policy Research Project.

The Association received notification of funding for a new Policy Research project. The project will investigate the special needs of people with early onset dementia and people with dementia living in rural and remote areas. The families needs will also be investigated.

At the local level, plans for a new Family Resource Center are progressing for the Alzheimer's Association (NSW). The new center will allow the Association to provide the range of services and depth of support needed to accommodate the increase in membership.

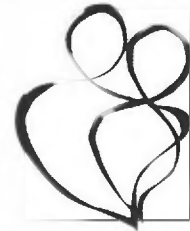
Alzheimer Society of Canada (ASC) in partnership with Home Support Canada offers a training package entitled *Alzheimer's Disease: Care at Home*. The package aims to assist in training home support workers to care for people with Alzheimer's disease. The package includes: a Participant's Workbook, Instructor's Workbook, seven videos corresponding to the topics in the manuals, and reinforcement materials such as games and puzzles.

Alzheimer Society of Ireland (ASI) marked its 10th Anniversary in 1993. Members also note it will be the 4th year the society will promote Irish Charity Christmas Cards. The proceeds from the sale of these cards benefit the Alzheimer Society plus seven other leading charities.

The Society's North Cork Branch had a busy Awareness Week. Fundraising festivities included a Pitch & Putt Competition, a Supper Social and an Annual Church Gate Collection. The North Cork Branch's goal of creating awareness was

The 10th International Conference of

Alzheimer's Disease International



Looking Forward



Looking Back

**A
Decade
of
Change**

Edinburgh — Scotland

21st - 23rd September 1994

Alzheimer Scotland will host ADI's 10th International Conference as indicated above. Planning and preparations are well

underway for an outstanding event that will attract representatives from more new countries than ever before