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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.)

In Ireland, Alzheimer Families Need Not Stand Alone

An estimated 25,000+ men and women in the Republic of Ireland have Alzheimer's disease. Fortunately, they and their carers do not have to face this dread disease alone. They have the support of the Alzheimer's Society of Ireland (ASI).

CARERS TAKE CHARGE

Ten years ago in Dublin, a handful of family members formed a support group to share experiences—and their coping strategies as carers. The group expanded rapidly: members held press receptions and lobbied politicians and various state agencies to raise awareness about the disease. They demanded that Alzheimer's be recognized as a serious and special problem.

That was the beginning of the Alzheimer's Society of Ireland. Now, the Society is a strong national organization represented throughout Ireland's 26 counties.

Last year the Society celebrated its 10th anniversary. During its first decade, it saw Alzheimer's disease go from being a little understood problem—to one of science's highest research priorities. ASI played a major role in bringing about this change.

The story of the Society's expansion nationwide is inspiring. Early on, its leadership established a national develop-

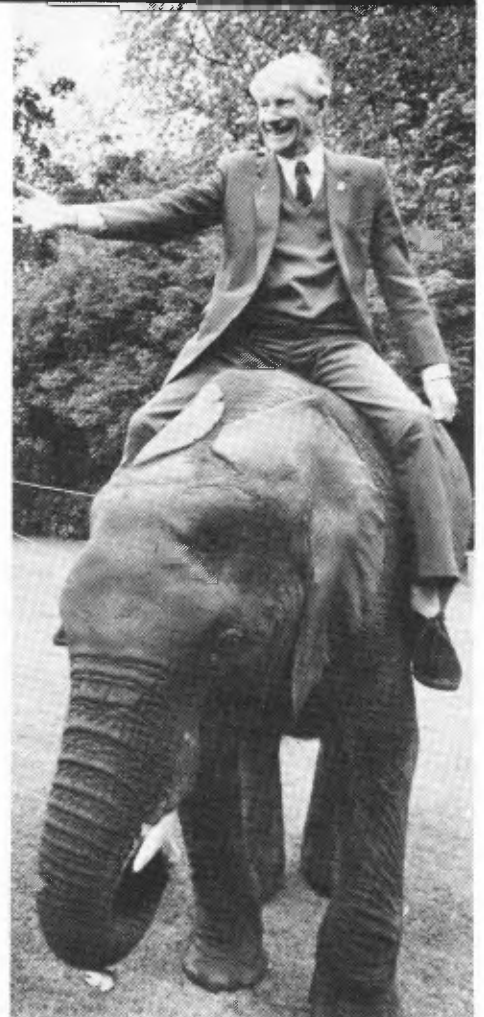
ment plan which included setting up support groups, branches and regional offices throughout the country with at least one day care center in each of the eight Health Board Regions. The fulfillment of this plan has been made possible by a strong network of loyal members and volunteers. This will ensure that help is available for Carers and individuals countrywide.

However, you can't have growth without funds and the Society is in constant pursuit of sufficient funding to make sure its growth plan moves forward. It takes at least £50,000 to establish a Day Care Center. Statutory funding has been less than 10% of the total ASI budget, so the Society relies heavily on funds contributed by many generous individuals, firms, banks, other institutions and a variety of fundraising activities by members, groups, and individuals countrywide.

PROGRAMS

Contributing to its success, the Society surrounds itself with quality programs and dedicated individuals running them. Eight care Centers have been established, and one of them has eight beds for overnight stay four nights per week.

A joint development project *Caring for Carers* was established with the Irish branches of Soroptimist International. The



Michael Coote, ASI's Chairman, couldn't resist a dare for publicity and fundraising

results of a national research program into the needs of Carers was published entitled *Caring Without Limits*, Continued, Page 3

ADI's 10th International Conference

"A Decade of Change
Looking back...Looking Forward"

September 21-23, 1994
Edinburgh, Scotland

In This Issue. . .

European Tour of Alzheimer Care, Part II ... Page 4

Public Policy Page ... Page 6

Research Update ... Page 7

What in the World We're Doing ... Page 8

The Story of ARDSI ...Page 10

ADI 1994—FOCUS ON MEMBER SOCIETIES

Much of the important work of the Alzheimer's movement is done at the national, chapter and support group levels where families can obtain information, help and in some places, services. This issue of *Global Perspective*, focuses on ADI Members' roles and activities. The over-



Brian Moss

view offers exciting information and recognizes that the Alzheimer cause is addressed by more and more national societies around the world. We regret that space limitations allow us to cast

the spotlight on only a few, we hope to highlight other societies in the future.

As you may know, individually, Members of ADI are national societies that represent persons with Alzheimer's and their families within their countries. All ADI societies provide Helplines, support groups and chapters across their countries, they offer educational programs for affected families and the general public. These are all required under ADI Membership Criteria. Some members also provide counseling, day centers, home care, and other types of respite care programs. Collectively, the societies are Alzheimer's Disease International (ADI). As such, they are concerned about the desperate need for information, education and support that exists in non-member countries around the world—where there are no Alzheimer societies to help.

Members understand and feel deeply about this tragic lack, because only a few short years ago, they experienced the

same situation in their own countries. In fact, raising global awareness and providing support to families were major issues on the agenda when (with only six countries then) ADI was formed in 1984.

Today, ADI has twenty-eight Members, all national societies in as many countries. Additionally, ADI's Secretariat is in contact with Alzheimer societies that are in various stages of development in a number of other countries, including Luxemburg, Poland, Romania, Hungary, Ecuador, Korea, Costa Rica, and Uruguay.

Because Alzheimer's does not discriminate, we hear from families around the world. Rachel Billington, ADI's Secretary General, advises that letters, phone calls and faxes, come in daily, verifying that when Alzheimer's strikes, the shock, pain and burden experienced by families, is the same the world over. No matter the culture, geographic location or economic circumstances, families desperately need information, understanding support, and qualified, informed, medical help.

It is gratifying to make a referral with the confidence that in an ADI Member nation there is good information and help available, and persons in need will re-

ceive basic Alzheimer's information and the opportunity to participate in Alzheimer Support Groups at no charge.

Globally, ADI maintains an outreach program and on-going effort to stimulate and encourage development of new Alzheimer societies. In 1993, ADI received a two-year grant from the Helen Bader Foundation in support of Project Global Outreach. In its collaborative work with the World Health Organization, the grant helps ADI support training of physicians from under-developed countries to diagnose, treat and care for persons with AD.

This is responding to needs recognized by ADI's founders ten years ago. However, while we note progress made to date, it is only a beginning. With the commitment and support of its Members and friends, ADI will continue its outreach and support efforts to non-Member countries.

Along with compassionate goals, there is the potential for an interesting circular effect in all this...as the network of ADI members grows, it will have a strengthening effect on the Alzheimer's movement, worldwide, ultimately contributing to the credibility and strength of each individual Member society.

—Brian Moss

"Jonathan Swift Had Alzheimer's Disease," doctor says.

Jonathan Swift, author of *Gulliver's Travels* and Dean of St. Patrick's Cathedral, may have been one of the first recorded victims of Alzheimer's disease, according to an American doctor.

Writing in the influential British medical magazine, the *Lancet*, Dr. John Lewis, an anesthetist from North Carolina, who is a specialist in dementia conditions, says Swift is vividly describing the symptoms of his disease in his tale of the Immortals of Luggnagg in *Gulliver's Travels*. "Anyone acquainted with Alzheimer's will recognize a familiar ring in the words written over two centuries ago," he writes. In Swift's tale, the Immortals "have no remembrance of anything but what they learned and observed in their youth and middle age, and even that is very imperfect. In talking they forget the common appellation of things, and the names of persons, even those who are their nearest friends and relations.

"For the same reason they can never amuse themselves with reading, because their memory will not serve to carry them from the beginning of a sentence to the end...neither are they able to hold any conversation (farther than a few general words) with their neighbours."

Dr. Lewis writes: "Since it seems unlikely such a picture could have been drawn other than from reality, it is probable that Swift was describing in 1726, what we know now as Alzheimer's disease."

Although doctors agree that Swift suffered from a variety of neurological problems, including memory loss and speech difficulties, they previously believed these were symptoms of involuntional melancholia or cerebral arteriosclerosis. Swift, 78 when he died, began writing about his condition 10 years before his death. In 1738, he wrote: "I have entirely lost my memory." Two years later he stated: "I hardly understand one word I write."

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ASSOCIATION ADDRESSES ALZHEIMER'S ON FIVE FRONTS

The Alzheimer's Association (USA) strategic plan to conquer Alzheimer's is best described under the acronym RECAP:

- R—Research
- E—Education
- C—Chapter Development
- A—Advocacy
- P—Patient & Family Services

RESEARCH. Through 1993, the Alzheimer's Association (USA) has committed \$32 Million in its support of research into the cause, treatment and cure of AD. Its 1994 Research Grant Program will include awarding: Investigator-initiated Research Grants; Faculty Scholar Awards; Pilot Research Grants; and the Zenith Awards. Decisions in awarding grants are made on a competitive, peer-review basis by the Association's MSAC.

EDUCATION. The Association holds a national Education Conference, in July.

In addition, it has developed a wealth of information and educational materials in the form of pamphlets, manuals, books, audio tapes and videos. A fine library is located at the national headquarters.

CHAPTER DEVELOPMENT. With 221 Chapters and over 2,500± support Groups, the Alzheimer's Association (USA) is in all 50 United States. Association Chapters are currently undergoing a self-assessment process utilizing the Association's Standards & Guidelines. Chapters participated in developing the Standards & Guidelines to help assure chapter strength, and provision of a high quality and consistent level of services to Alzheimer families.

ADVOCACY. An annual Public Policy Forum on Capitol Hill, Washington D. C., offers Chapter members an opportunity to learn techniques in advocacy, at the State and Federal levels. Members seek an improved level of services and care for

persons with AD. Opportunities to meet and talk with legislators also are included in the week-long Forum program.

PATIENT & FAMILY SERVICES. The Association has developed a number of programs, including: A National Respite Care Demonstration program with 74 respite programs across the country; the *Guidelines for Dignity and Taking Care*, developed for care providers and family members; Safe Return—the national Wanderers Registry; and, a national community services survey.

To help make all these elements viable, the Association conducts an aggressive fundraising program which includes the Rita Hayworth galas; the annual national Memory Walk and other special events; a direct mail campaign; and a major gifts program. The Association conducts an on-going awareness campaign including Alzheimer's Disease Awareness Month.

ASI...Families Need Not Stand Alone—Continued from Page 1

a video of the same name was commissioned for introducing the general problems of Alzheimer's disease and the Society's activities to help the Carers.

OTHER ACTIVITIES

To promote its cause, the Society produces AD literature, organizes events, including an Annual Public Lecture.

A quarterly newsletter, Carer's Handbook and Dementia Information Packet for the medical profession are among its widely disseminated publications.

The Society generates a number of creative fundraising activities, an annual Alzheimer's Awareness Week—with a range of national and regional events—was originated in '92.

ORGANIZATION

Individual subscribers are known as Friends of the Alzheimer's Society of Ireland and are members of a local branch convenient to their home or place of work. Membership is open to anyone. And, there is no fixed subscription but a minimum contribution of £5 is suggested. Currently, 1500+ Society members are rep-

resented by 70 Support Groups, 20 Branches and eight Regional Committees.

Branch members hold an annual meeting at which a committee is elected to run the activities of the branch and two of its members to the Regional Committee. The boundaries of the Regional Committees are coterminous with the boundaries of the eight Irish Health Board

Regions in which they are located.

The Regional Committee co-ordinates the activities of the branches in its area and at its annual meeting, two members are elected to the National Council.

The National Council meets quarterly to implement policy. Activities of the National Council, Regional Committees and Branches are in accordance with the aims and constitution of the Society and are inspired, encouraged and co-ordinated by the National administrative team consisting of Norman Stuart, chief executive, Winifred Bligh, national co-ordinator for respite care; Michael Neville, national development officer; Barbara Scully, public relations officer; secretaries Nurala Dunphy & Myrtle Sullivan and two honorary counselors Joe Rowe and Muriel Banks.

HOW ASI RECRUITS OTHERS TO HELP

The Society encourages people to become involved in its programs, and suggests that the best ways to help are to:

- Become a member of the Society
- Persuade friends, relatives, others to join
- Offer help with day care, support groups
- Organize/support fundraising activities

ASI AIMS

The Society intends to fulfill and maintain the following goals:

- Arouse maximum awareness of Alzheimer's disease;
- Supply information and help to affected families;
- Inform the medical profession and all ancillary services about the disease and the carers' problems;
- Provide carer assistance by establishing Support Groups and organizing respite and other caring facilities;
- Campaign for statutory Day Care, Short Term Respite, and Long Term Residential Care for persons with AD;
- Obtain practical and financial support for carers who are caring for an Alzheimer sufferer in their home;
- Support medical and statistical research into the cause, diagnosis, incidence and treatment of AD.

European Tour of Alzheimer's Care—Part II

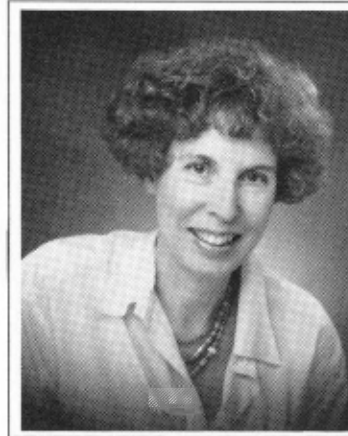
In the last issue of *Global Perspective*, Beverly Sanborn, a Clinical Social Worker in California, wrote of her 1993 tour of Alzheimer care facilities in Europe—focusing on long term care. As promised, following are her reflections on Day Care programs she visited.

Ten years ago, I participated in a California State Demonstration pilot project which tested the concept that adult day care, if properly staffed and funded, could provide a therapeutic program for people with moderate to severe levels of Alzheimer's disease. Working in eight sites, selected because each embraced a different model of care, our mission was to provide service for the people who were rejected by all other day care programs. We actively recruited the wanderers, the combative, the incontinent persons who had no place else to go and were at risk of institutionalization. Our eight programs were housed in senior centers, a converted house, a former warehouse, and an old classroom. They were sponsored or cosponsored by hospitals, day health programs, Alzheimer Association Chapters, adult education and community foundations.

We were essentially novices when we began work in this untested area, but we were highly experimental, willing to try new strategies and vigilant about our evaluation of the results. At the end of three years, both the State and the participants pronounced our project a rousing success. (Since then, 26 similar programs have been added to the mix.) Yet, what surprised all of us the most was not our mutual success, but the way that all the programs had come to resemble each other. It was this observation that sparked my curiosity about exemplary practices. Were there universal themes, essential elements, that high-quality programs must possess? Since my work had been confined to the U. S., I took advantage of a European trip in the summer of 1993 to follow my curiosity, and I visited four outstanding dementia day care programs.

It seemed particularly fitting to begin the quest in Europe, specifically England, where the adult day care movement originated. Day hospitals and psychiatric

day treatment had been in existence since 1942. Day care for the frail elderly came ten years later when Dr. Lionel Z.



Beverly Sanborn

Cosin set up the first Geriatric day care at Cowley Road Hospital, United Oxford Hospitals, England. This program completed the missing piece in his comprehensive array of supportive home health and home health services designed to allow elderly people to *age in place*. Nearly two decades later, Dr. Cosin brought the concept to the United States. The decade of the 1980s and 90s has seen the greatest proliferation of the concept worldwide as health care systems de-emphasize institutionalization in favor of aging in place. Adding dementia-capable programs has been a natural extension of this world-wide movement. Although many day care programs are free-standing single services, my interest was in the model established by Dr. Cosin in which day care is an integral part of a larger system of long term care. My search for exemplary programs led me to seek out day care that was not only excellent programmatically, but was innovative from a systems point of view.

In the United Kingdom I visited two examples of dementia-capable programs in which day care is the linchpin of a service system that aims to maintain the elderly in their own home: Acomb Gables in York, England and Rosebank, in Kilmarnock Ayrshire Scotland. In both programs, the *client* is the whole family.

Acomb Gables: York, England

Acomb Gables has an interesting history. It is actually a creative response to budget cuts. Confronted with shrinking

funds for the elderly mental health and dementia services, consulting psychiatrist Dr. Christine Kirk brought together the health and social service providers plus a larger representation of local residents and consumer groups. This task force explored the fiscal problems and options. Months of study, research and planning produced the CUE (or Community Unit for the Elderly) concept, of which Acomb Gables is the first example. The purpose of Acomb Gables, indeed all subsequent CUE's, is to maintain people in their own home as long as possible.

Acomb Gables is a center which is designed to be homelike, where participants do normal activities such as laundry and cooking. It reflects the local culture in architecture and in program, with committee members, not bureaucrats having the last word. Much to the dismay of the architect, the Acomb Gables planning committee insisted that the lovely interior courtyard have a clothesline planted in the middle of the patio "because our patients expect to see one."

Acomb Gables is meant to be and forever remain an important part of the York community. Besides caring for local older adults, the facility offers training, internship and community education programs. To further insure its integration into the community as a whole, the planning committee established the Acomb Gables Coffee Shop, run by volunteers, where local townspeople can enjoy the ambience, meet participants, and be enticed to volunteer.

The financial and programmatic success of Acomb Gables is due in part to the way the service is structured. The focal point is the adult day health center. Here, participants can enjoy an enriched social and cognitive program while receiving the medical monitoring and assessment which allow them to continue living at home safely. Providing the medical services at the center is more efficient and costs a fraction of a medical-team home visit. Meanwhile, families receive the benefit of support groups, medical education, instructions in self-care and respite services. Staff work in partnership

with families to prevent burnout and exhaustion. Respite beds and some long term beds are available, but home care supports are always encouraged. Acomb Gables is similar in many respects to the United State's On Lok day care programs which have very successfully used day care for both social and medical management purposes.

Rosebank: Kilmarnock, Ayrshire Scotland

Rosebank, Kilmarnock, Ayrshire Scotland (about one hour south of Glasgow), envisions itself as an extension of the larger Kilmarnock community. Every effort is made to be small, intimate and

resource to the community through its outreach and educational services. Unlike the CUE's, the volunteers are able to manage all levels of dementia. One gentleman who is in the severe stages of the disease, unable to speak and prone to combativeness, is gently guided in and out of groups according to his ability to handle stimulation. Volunteers are always respectful to him, even when he threatens them with his fists. Their calm manner defuses his agitation. When he settles down, they give him a kiss and hug. Later, when participants sing old Irish folk songs, this same gentleman joins the group and begins to hum a prolonged almost weeping melodic line.

"There were several themes..."

My visit to the four day care programs revealed a wide range of program structure and program purposes. There were several unifying themes, however, that contributed to the high quality of these programs.

1. All view the family as the client. Support, respite and education for family caregivers is a high priority.
2. Self-care and autonomy is fostered to the degree possible. Staff give prompts and cues to enhance functioning.
3. Programs are directed to stimulating remaining strengths and are adult-oriented, offering activities that are meaningful to residents (e.g. observing coffee time in Ger-

- many; singing Irish folk songs in Ireland)
4. Programs are integrated into larger community-not just the health and social service sector-but the whole community, particularly evident in the strength of volunteer involvement.
5. Staff are highly interactive with participants.
6. There is respect, indeed, almost a reverence, for the elderly participants who are viewed as being special people because they are valiant survivors of wars and social upheavals, and have lived a very long time.
7. Social climate is light and fun.

homelike, with activities that are adult-oriented, creative, appropriately challenging and *normal*. Mary Cullinane, Officer in Charge, proudly displays the participant's handcrafts, and photos of festivals and gala events that punctuate the typical week. Rosebank is dedicated to helping each participant maintain a sense of self. Staff take great delight in giving prompts sufficient to help lower functioning participants respond at surprisingly high levels.

Rosebank divides groups into functional levels for some activities, but whenever possible, all groups are integrated into the daily events. Staff display a remarkable skill in finessing the integration of participants functioning at different levels so that dignity and self-esteem are preserved.

Like Acomb Gables, Rosebank is a

The volunteers explained that he is very moved by the folk songs. "This is his favorite part of the day—Day Care is so important for him and for his wife," they tell me. "She would never make it without us."

At the end of the day, six participants remain to spend the night in the much-coveted respite beds. The night nurse who supervises the overnight program is the only paid position. Stillorgan's level of volunteer commitment and skill is outstanding and demonstrates how a program can succeed without grants in aid from the government.

Die Staatlichen Pflegeheime Hamburg, Germany

On the continent, Hamburg Germany's Die Staatlichen Pflegeheime is experimenting with using a day care model to solve the special care dementia needs in

a large skilled nursing facility. Rather than build a special facility or set up a dementia floor, the dementia residents are placed during the day in a large, beautifully decorated penthouse-style room. Residents enjoy an enriched program of therapeutic activities, with space to wander and pace if necessary, and beds for resting. All three meals are taken in this day care environment. Meanwhile, the cognitively normal residents are provided with the activity program (and privacy) that is commensurable with their interests and needs. Families and residents have been highly satisfied with the experiment, which is currently being evaluated for possible replication.

The Alzheimer programs in Hamburg are under the direction of two psychiatrists: Dr. Bruder and his colleague, Dr. Wojner. Amazingly they have taken large institutional facilities and transformed them into homelike, cozy, intimate environments. They and their staff are constantly experimenting with therapeutic programs and seeking new uses for existing resources. Designs for the facilities, for example, come from contests they hold with University design students.

The staff are exceptionally skilled and interactive with participants. Staff are trained in nursing programs run by Dr. Bruder and Wojner. The staff are obviously inspired by the immense dedication of these two physicians. Dr. Wojner gave me a tour of the day care and three other facilities. I saw him model a type of interaction which can be described as *loving care* for the dignity and uniqueness of each participant and resident. Dr. Wojner not only knew every resident by name (he oversees 4,700 residents in his total program), but he inquired about their family members or other seemingly small though significant details of their lives. Restraints of all types are virtually non-existent in this caring community.

Looking back on my journey, I am deeply impressed by the people of good will and imagination who are drawn to this work. Important issues such as location of program, funding for services, size of facility all appear to be far less important than two central factors: commitment to dignity and quality of staff. Probably the single theme which unifies all the exemplary programs I visited is the joining of staff, families and elderly people who, together, celebrate life.

PUBLIC POLICY PAGE

At its meeting in Toronto, September 1993, the Public Policy Committee received a paper written by Jim D'Arcangelis, Policy Analyst. The paper helped set the tone for future Committee activity. Following is his executive summary of the paper. Jim is an ADI volunteer. Many thanks, Jim!

The ADI Public Policy Committee has a significant role to play in providing information and advice to national Alzheimer's societies. ADI and its member nations share an interest in developing good information which can help change public policies for the benefit of persons with Alzheimer's and their families.

Success is the best educator. However, no systematic mechanism exists for collecting and transferring information about successful advocacy and public policies. The Public Policy Committee can assume this role and begin to identify, analyze, and report information which advocates can use to campaign for change.

The Public Policy Committee can provide information on topics of concern to national Alzheimer's societies: education and public awareness; improved caregiver standards; and patient and family services, which include improved respite, home, and nursing home care, as well as long-term health care insurance and finance. For national Alzheimer's

societies to succeed in these areas, they need comprehensive information on the following factors: the ways to conceptualize policy issues; the parameters of national health policies; the costs of Alzheimer's; various advocacy techniques; the structure of advocacy; and the political context of each nation. The Public Policy Committee can provide comparative in-

“Success is the best educator”

formation on these topics, which national Alzheimer's societies can use to craft campaigns for change.

The Public Policy Committee can produce information for the global policy making community and for nations interested in developing a national Alzheimer's society. The committee can release an

annual state of Alzheimer's policy around the world for the global policy making community. The report would feature an Index of Alzheimer's Indicators, which shows comparative government efforts to address Alzheimer's issues.

For members of ADI, the Public Policy Committee can produce:

- quarterly newsletters with information about advocacy and public policy in member nations.
- policy and advocacy briefs which describe successful campaigns to change government policies on respite, home, and nursing home care; long-term health care insurance and financing; and improved caregiver standards.
- a public policy manual which provides how-to information on advocacy techniques and methods, model legislation, etc.
- videos for motivating and educating Alzheimer's advocates as they lobby for change.
- a clipping service that collects and summarizes news about Alzheimer's public policy around the world.

SOME ADI MEMBERS' PUBLIC POLICY EFFORTS IN REVIEW

Alzheimer's societies can make a significant difference. Even in light of political differences from country to country, similarities in Alzheimer issues exist, and ADI Members' purposes are the same world-wide—to make life better for persons with AD and their families.

Alzheimer's Association (Australia) introduced Policy Papers on Education/Training and Residential Care, to work with governments and interested organizations to develop programs to better serve the needs of people with dementia and their carers. Now, service providers are using the statements to ensure that their services are compatible with the Association's guidelines.

The National Action Plan for Dementia *Putting the Pieces Together*, was the first step towards comprehensive care for persons with dementia in Australia. The plan was a result of a 21-month campaign. Local members lobbied key politicians, and allied organizations provided support by writing letters to relevant politicians. The Association produced a paper calling for a

National Task force on Dementia. These efforts led to a governmental review of Aged Care Reform Strategy. A National Action Plan for Dementia for Australia followed and an additional \$31 million allocated over five years.

Alzheimer Society of Canada will hold a breakfast meeting on Ottawa's Parliament Hill with Federal members. This will be an awareness and educational activity, with the support of Canadians who have personal experience with Alzheimer's disease telling their story to representatives in Ottawa.

Association of Families Caring for the Demented Elderly, Japan (AFCDE) identified problems in providing care to younger persons with AD and took action to solve them. AFCDE called for abolition of age discrimination for social services programs and financial support to families of young persons with dementia from the Ministry of Health and Welfare. As a result, the ministry established a special committee to study a policy for young persons with AD. A national board

member of AFCDE became a member of the committee. Now, social programs for younger persons with dementia and their caregivers are improving in Japan.

Alzheimer's Association (USA) will hold its 6th Annual Public Policy Forum: *Alzheimer Advocacy: Families in Action*, in Washington D.C., April 9-13, 1994.

The event will bring together people from the Association's chapters to advocate for long term care and federal funding for Alzheimer's research.

With a significant educational component, the four-day Forum helps participants learn how to address members of Congress on Alzheimer issues, and prepares them for effective advocacy when they return home. On the last day members will visit Capitol Hill to utilize what they have learned. On the Forum agenda are: an opportunity for children of Alzheimer families to share their personal stories with the Nation's leaders; a Congressional Hearing on Alzheimer's; a Congressional Reception; and, the first National Candlelight Vigil.

Interpreting News Headlines on Alzheimer Research

“U. S. Scientists Find a Test of Early-Stage Alzheimer’s...”

“Vitamin E Called a Boon for Alzheimer patients...”

“Heart Disease Gene, Alzheimer’s Linked...”

“Tea...aspirin...etc...”

These headlines appeared over the last year in newspapers around the world. Of course, not every research report covered in the media will be significant. True scientific breakthroughs occur infrequently. Families reading research articles or seeing television coverage of a “breakthrough” may be unable to judge the significance and may seek guidance. Here are some tips on how to handle newspaper headlines and television medical updates:

- Get as much information as possible. Ask, was a particular researcher or institution mentioned? Was the story about a new therapy, diagnostic procedure, or discovery of a possible cause for AD?
- If an article or report is about a new drug for AD, contact your physician or the national Alzheimer society in your country for the latest information available.
- Ask if the study was performed with animal or human subjects, or in cells grown in the laboratory. A change in nerve cells grown in the laboratory under controlled conditions (in vitro) does not mean that such a change would happen in a living animal (in vivo). In addition, the results of studies using laboratory animals can not be generalized to humans (e.g., if vitamin E shows a benefit in animal studies, that does not mean it will also benefit patients with Alzheimer’s disease). Studies using either cells or laboratory animals will require additional research before they will be of practical use in medical treatment or diagnosis.
- If the subjects were human, how many were studied? Have the findings been repeated at more than one site? Small numbers of participants in a single study suggest that any conclusions are preliminary

and will need to be confirmed in larger numbers of people and by independent groups of researchers. Good studies are those that can be repeated by other investigators and produce similar results.

- Remember that conservative claims by scientists reporting their own work are in general more plausible than are very enthusiastic statements.
- Evaluate the gains reported. Ask what they mean for Alzheimer patients. A test

that can definitely and consistently indicate that a person has AD can be a major step forward. One that can only rule out other causes may not be an improvement upon what is currently available.

- If you have any questions, or need more information, call your physician or your national Alzheimer society.

—From the U. S. Alzheimer’s Association’s 1993 Research Update Summary: *Predicting the Development of Alzheimer’s Disease.*

MORE ON THE APOE GENE & AD

The APOE gene is found on chromosome 19. This gene contains the instructions that enable the body to make a protein called apolipoprotein E (apoE). The most well-known function of apoE is to transport cholesterol into cells. ApoE has other functions throughout the body, some of which are just beginning to be discovered. ApoE is made in the liver, brain, spleen, kidneys, and other organs. In the brain, apoE is made by astrocytes, cells that perform important supportive roles for nerve cells, such as maintaining a structural framework and regulating the environment around the nerve cells.

Researchers know that the APOE gene has three slightly different variations: ε2, ε3, and ε4. Every human has two copies of the APOE gene. The proteins (ε2, ε3, and ε4) produced from these different variants also differ slightly in their chemical makeup. Though these differences may seem small, they cause major differences in the way these proteins function. For example, researchers studying heart disease have learned that the apoE4 protein is more effective than the other forms at moving cholesterol into cells. To protect itself from cholesterol overload, the cell limits the amount of cholesterol it lets inside using a receptor on its surface. Eventually, cholesterol in the bloodstream will build up, making a person with the E4 variant more susceptible to coronary heart disease.

DUKE TEAM’S RESEARCH

For years, Dr. Roses and his colleagues

have been studying families with multiple members who have AD. They focused primarily on families with the common “late onset” form of AD, which arises after age 65. In 1991, Dr. Roses’ team reported that some families with late-onset AD show evidence for the presence of a genetic factor on chromosome 19. Subsequently, several independent research teams around the world confirmed this finding in other families.

In late 1992 and early 1993, Dr. Roses’ team announced that the APOE-ε4 gene is more than three times as common in patients with late-onset familial AD than in people without the disease. A more important aspect of this work was revealed when the prevalence of the gene was examined in cases of apparently sporadic AD—cases with no family history.

“We found basically the same numbers for the sporadic cases as for the familial cases, which suggests that at least some of what has been divided into familial and sporadic Alzheimer’s disease is the same thing,” says Dr. Roses. “Our evidence points to the ε4 gene variant as the first concrete biological risk factor for late-onset Alzheimer’s disease”.

“Having this gene does not necessarily mean that a person will develop Alzheimer’s disease in his or her lifetime. Not having it doesn’t mean that they won’t.”

A genetic risk factor (susceptibility gene) is different from a disease gene: If a disease gene is inherited, the person will develop the disease (an example is Huntington’s disease). *Continued on Page 12*