

Vol. 3, No. 1 May, 1992

Global Perspective

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

ADI to Join in Historic European Community Event

ADI will meet in Brussels from September 24-28, 1992 for its 8th International Conference, and its Annual Meeting. Early this year, Dr. Franz Baro wrote us about plans for the Conference. Until then, few of us fully realized the extent to which ADI would have an opportunity to participate in a most significant historical event. Excerpts from his letter follow:

"ADI's Eighth International Conference will be held in Brussels, September 25-27, 1992. The Conference is situated within the 'Year of Europe' programme, a most important event not only for the member states of the European Community, but also for all other countries. In 1992, the economic borders within the European community will be lifted. But until now, the European Community has paid little attention to health and social issues, in general, nor to Alzheimer's Disease's and Related Disorders in particular (except for 'Eurodem'--an epidemiological study on prevalence, incidence, and risk factors of Alzheimer Disease and Related Disorders in Europe). Therefore, it is essential for ADI to build up advocacy concerning ADRD-related issues and to take profit of increased European awareness in 1992.

"Conference dates given in the First Announcement (September 27-30, 1992) had to be changed to September 25-27, 1992 because of recent changes in the meeting agenda of the European Community.

"On Friday, September 25, the opening address of the Conference will be held at the Headquarters of the European Community in Brussels. Members of the European Parliament and the European Commission will attend this meeting on "Priority Issues and Actions Related to Alzheimer's Disease and Related Disorders in Europe."

"On Friday morning, September 25, the opening address of the Conference will be held at the Headquarters of the European Community in Brussels."

"Of course the attention will not only be focused on the EC Member States, but also on the other European countries. This opening session is organized in close cooperation with Alzheimer Europe. Friday Afternoon is devoted to the ADI member country reports. We choose for a dynamic event, with use of audiovisual aids (overheads, slides, videos), discussion panels, and informal talks, European snacks and drinks. All national Alzheimer Associations will be involved in the organization of this afternoon. This day of hard work will be followed by a well-deserved outing in Brussels at night.

"On Saturday morning, September 26, a series of parallel workshops are planned on topics as *Family Coping in Home Care of*

Patients with ADRD; The Architecture of Alzheimer Units, and others. We expect members suggestions and wishes for these Saturday morning workshops. We also hope to get response from volunteers to participate in the organizational workshops.

"Saturday afternoon is reserved for a plenary session with reknown guest-speakers. This session will be co-sponsored by the Belgian Alzheimer Association.

"On Saturday evening, we are planning a sparkling get-together in the old university town of Leuven. Don't miss it!

"On Sunday, September 27, participants have a wide choice of guided visits to Belgian facilities for care of ADRD patients, followed by a planned visit to a culturally interesting site."

"Also planned are a scientific colloquium on Recent Advances in the Neuro-psycho-pharmacological treatment of ADRD, and an exhibition on Artists Confronting ADRD. "The Closing Session (of the Conference)...is scheduled for Sunday, September 27, 1992."

ADI MEMBERS PLEASE NOTE

The ADI Council will meet briefly in the evening on September 24, and in full session for its Annual Meeting on September 28, 1992.

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Message from the Chair

I am indeed honoured to have been formally elected as Chairman of Alzheimer's Disease International and look forward to working with all member countries as we pursue our common goals. I am committed to working closely with our President, Princess Yasmin Aga Khan, the Executive Committee and Council, and will maintain close liaison with Ed Truschke and Rachel Billington, our Secretary General and Deputy Secretary General.

As an inaugural member of the Executive Committee of ADI, and having attended the first meeting held in Washington, D.C., in 1984, I have been amazed and excited by the growth of the organization since those early days, yet in a sense saddened that the growth we have experienced is evidence of the widespread effect of Alzheimer's disease and related disorders. The excitement and challenge of the task facing ADI is indeed tempered by the knowledge that so many people worldwide are afflicted by this insidious disease.

But rise to the challenge we must. The goals of ADI have been clearly spelled out for all to see. It is now up to the members and ADI leadership to ensure that we get on with the task. If the meetings of the

Executive Committee and Council held during September this year in Amsterdam are any indication, I am sure we are well on the way. I was most impressed with the spirit of cooperation and mutual support, not to mention the camaraderie which is developing between the various representatives of member countries. It augers well for the future.

The appointment of several Standing Committees will do much to enhance our work. It will be impossible for us to make any progress without adopting the procedures of Standing Committees. I am sure you will agree that we will achieve little if we simply waited until our meetings were held each year and it would be a task too demanding for staff to do on their own. We are fortunate that a number of people have agreed to chair the respective committees and even though there would be little opportunity to meet face to face between annual meetings, I am sure progress will be made utilizing fax machines and telephones.

After leaving Amsterdam, I was pleased to have an opportunity to visit the office of Alzheimer's Scotland in Edinburgh and spending some time with Evelyn McPake

and her husband, Alan. I indeed appreciated their generous hospitality. I also visited the Alzheimer's Disease Society's London office. While there, my wife and I enjoyed the hospitality of the President of the Society, Dr. Nori Graham, and her husband Phillip. A profitable day was also spent visiting the national office of the Alzheimer's Association in the United States (Chicago), where I was able to spend some time with Ed Truschke and Rachel Billington going over matters arising from our meeting in Amsterdam.

As a result of a recent Reader's Digest article, the ADI office in Chicago is seeing an increase in queries from family members and caring professionals from around the world. Providing information about Alzheimer's disease and ADI, the article was published in several languages and widely distributed, in Asia, the middle eastern countries, and South America. There is the possibility of some new groups forming around the world.

The year past was a productive one for ADI. I trust that 1992 will be a fulfilling year for all Alzheimer groups where ever they may be.

—Brian Moss, Chairman

CALL FOR PAPERS

ADI's 8th Conference proposes an exciting list of topics in its Call for Papers. The deadline for submitting papers is August 15, 1992. For more information, and to submit papers, write or call:

ADI Brussels 1992
c/o Professor Franz Baro
Krijkelberg 1
B - 3360 Bierbeek, Belgium

Tel: 32/16/45 26 31
Fax: 32/16/46 3209

When Alzheimer's Strikes a Younger Person

In most available literature, Alzheimer's disease is dealt with in the context of care of older persons, generally those over age 65. Yet, Alzheimer's disease does strike younger persons, devastating families—particularly, spouses and young children.

Alzheimer's disease can strike those in their 50s, 40s, (and—rarely—30s and even 20s). Some researchers believe that such cases, identified as "early onset," are more likely to have a family history of AD.

Frequently there are young children who require help in understanding and dealing with the new and unusual behaviors of a loved and respected adult. Participating in caregiving can be a confusing and even traumatic experience. Adult children of Alzheimer victims also often have difficulty with their new parent/child relationships.

Regardless of the similarity in behavior and care required, the younger AD patient

is different from the older patient, and his or her care needs are different as well—as may be the needs of his or her carer.

In 1990, a group of concerned carers met in Liverpool, England, to initiate action on behalf of young people with Alzheimer's disease.

A Declaration of Rights was developed demanding provision of specialist services, automatic access to all benefits, and recognition of this disease as a terminal illness.

The statement was presented by the Merseyside Group at a National Study Day held by the Alzheimer's Disease Society (UK), and the Junior League of London in July at St. Mary's Hospital, London. It was obvious from the reaction that a great need had been identified. The Merseyside Group is now intent on raising the issue at the 8th International Conference & Meeting of ADI.

The *Global Perspective* is published by Alzheimer's Disease International (The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.) 919 N. Michigan Avenue, Chicago, Illinois 60611. Tel: (312) 335-5777. FAX: (312) 335-1110.

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Princess Yasmin Aga Khan Jeffries

SECRETARY GENERAL
Edward F. Truschke

EDITOR
Rachel G. Billington

New Alzheimer's Resource Announced

Richard Gehring, Chairman of the Alzheimer's Association in the U. S., spoke of the soon-to-be opened Benjamin B. Green-Field National Alzheimer's Library and Resource Center, at the ADI Council Meeting, held before the 7th International Conference in Amsterdam. Now opened, the Library and Resource Center is located at the Association's headquarters in Chicago, Illinois. Gehring offered it as a potential resource for ADI Committees in accomplishing some of their goals, and as a resource for ADI Members.

From anywhere in the world, persons who use a personal computer, and have a modem and the right software, can access the Center's catalog.

Following is an article written by Librarian Pat Pinkowski, describing the resources and services available:

A Library and Resource Center

The U. S. Alzheimer's Association national headquarters in Chicago dedicated the Benjamin B. Green-Field National Alzheimer's Library and Resource Center on December 10, 1991. The mission of this Resource Center is to increase knowledge of the biomedical, clinical, and social aspects of Alzheimer's Disease and related disorders. The Center is a source of accurate information for those involved in patient care, policy development, research, or those who simply want to know more about the disease.

The Resource Center collects materials related to Alzheimer's Disease, the related disorders, and a variety of other subjects important to those working and coping with Alzheimer's Disease. These materials are collected in a variety of formats including books, pamphlets, journals, newsletters, videocassettes, audiocassettes, CD-ROM (Compact Disc-Read Only Memory), slides, and memorabilia. Collection access is facilitated by a computerized catalog. Those having a personal computer with a modem can access the Resource Center's computerized catalog themselves. An instruction sheet with specific information on accessing the catalog database is available by contacting the Resource Center.

The Green-Field Resource Center offers a variety of services:



Top: Members of the Green-Field Foundation Board cut the ribbon at the dedication ceremony for the Benjamin B. Green-Field Library & Resource Center. Bottom (L to R): A study corner of the facility; Librarian Pat Pinkowski; and visitors touring the library.

- Two professional librarians provide assistance in locating materials, finding statistical information, addresses & telephone numbers, biographical information, bibliographic information, dates, and referral to other appropriate resources within or outside the Alzheimer's Association.

- Tailored bibliographies are prepared on desired topics using local sources. These sources currently include the catalog, print indexes, and periodical indexes in CD-ROM format (MEDLINE, Health Planning, and Administration, Reader's Guide to Periodical Literature). This service is provided without charge. If additional online databases are accessed, database charges and other costs will be passed on to the requestor. The Resource Center has access to over 400 online databases on a variety of special topics.

- Bibliographic verification, indexing, data compilation, etc., are offered dependent on staff workload. Patrons may be

charged depending on the time involved.

- Books, slides, tapes from the Resource Center collection are lent. Individuals should make requests through their local hospital, university, or public library. Libraries are charged \$7.00 USD an item for this service. Each library has policies about passing this charge on to the requestor.

- Photocopies of articles or chapters in books may be requested directly from the Green-Field Library, there is a charge of \$7.00 USD per item.

- A special section of the Library is set aside for literature contributed by ADI members. This is currently being catalogued.

The facility is open during Alzheimer's Association business hours, 8:30 am to 5:00 pm CT, Monday through Friday. Requests may be made in person, over the telephone, or by mail. For additional information, please contact Patricia Pinkowski, or Vicki Bakowski, Associate Director, at (312) 335-9602.

IPA Announces 1993 Research Awards in Psychogeriatrics

The International Psychogeriatric Association (IPA) recently announced its Third Biennial Research Awards in Psychogeriatrics. These awards which are sponsored by Miles, Inc., Pharmaceutical Division, West Haven, Connecticut, are offered every two years for presentation and recognition at each IPA International Congress.

Awards will be given best submitted original research papers in the field of psychogeriatrics. Unpublished original research papers in English will be considered.

The 1993 Research Awards are expanded to include a Third Prize. The Awards consist of: (1). Cash awards: First Place—\$7,500; Second Place—\$5,000; and Third Place—\$2,500; (2). Travel and accommodation expenses for presentation of each paper at

the Sixth Congress of the International Psychogeriatric Association in Berlin, Germany, September 5-10, 1993; (3). A medallion to each winner; (4). Publication of each winning paper in IPA's journal, *International Psychogeriatrics*.

Review and selection of the award winning contributions will be by an international committee consisting of eleven IPA members and a representative from the sponsoring company.

For further details about submitting entries, write Barry Reisberg, M.D., c/o IPA Secretariat; 3127 Greenleaf Avenue; Wilmette, Illinois 60091 USA. Entries must be submitted no later than December 1, 1992, Awardees will be notified by May 1, 1993.

Speakers Bureaus Serve Educational and Promotional Function

In many member countries, Alzheimer society Speakers Bureaus help "spread the word" about the disease. In the U. S., Speakers are relatives of persons with Alzheimer's. Some are professionals in their own right, in health care, education, law, etc. Their primary goal is to inform and educate family and professional carers. In Australia, Speaker's Bureau members are 'relinquished carers' who visit service organizations (Rotary, Lions, Police Units, etc.).

Speakers help to inform the media and government officials about specific issues and what Alzheimer's families seek as a group confronting a terrible disease. Speakers Bureaus also help increase public understanding, thereby enhancing the climate in which societies can raise funds.

Most successful Speakers Bureaus offer speaking courses, guidance and ongoing support for their volunteer speakers.

Gene Mutation Linked to Hereditary Alzheimer's Disease

By studying three successive generations of a family with Alzheimer's Disease (AD), researchers supported by the National Institute on Aging (NIA), in the United States, have found a gene mutation that may be responsible for the nerve cell death and resulting dementia characteristic of one form of Alzheimer's. The study, reported in the October 4, 1991 issue of *Science*, demonstrates direct transmission from one generation to the next of a genetic mutation associated with the disease.

Dr. Merrill D. Benson and his colleagues at Indiana University School of Medicine & Veterans Affairs Richard L. Roudebush Medical Center have identified a single alteration in a gene, which instructs the synthesis of a common brain protein called amyloid precursor protein (APP), that they believe could trigger the disease. "Dr. Benson's group has provided a new clue to help unravel the complex pathology of this disease, says Dr. Zaven Khachaturian, associate director, Neuroscience and Neuropsychology of Aging Program at NIA. "Discovering that the family members with the altered gene have AD and those with the unchanged gene do not, confirms our suspicions

about hereditary Alzheimer's. Finding such a clear-cut example is very exciting news."

Dr. Benson's research team, Drs. Bernardino Ghetti, Martin Farlow, and Jill Murrell, looked at the DNA of 31 family members spanning three generations, including six individuals affected with early-onset familial AD. Early-onset AD usually occurs between ages of 45 and 55. All six people with AD demonstrated the same abnormal variation in a fragment of the APP gene, located on Chromosome 21. Characteristic lesions of Alzheimer's were found at autopsy in the brain tissues of three members of the family, confirming the diagnosis made by DNA analysis. "The occurrence of the same mutation in the APP gene in several generations with AD certainly implicates it as a cause of dementia in this family," says Dr. Benson.

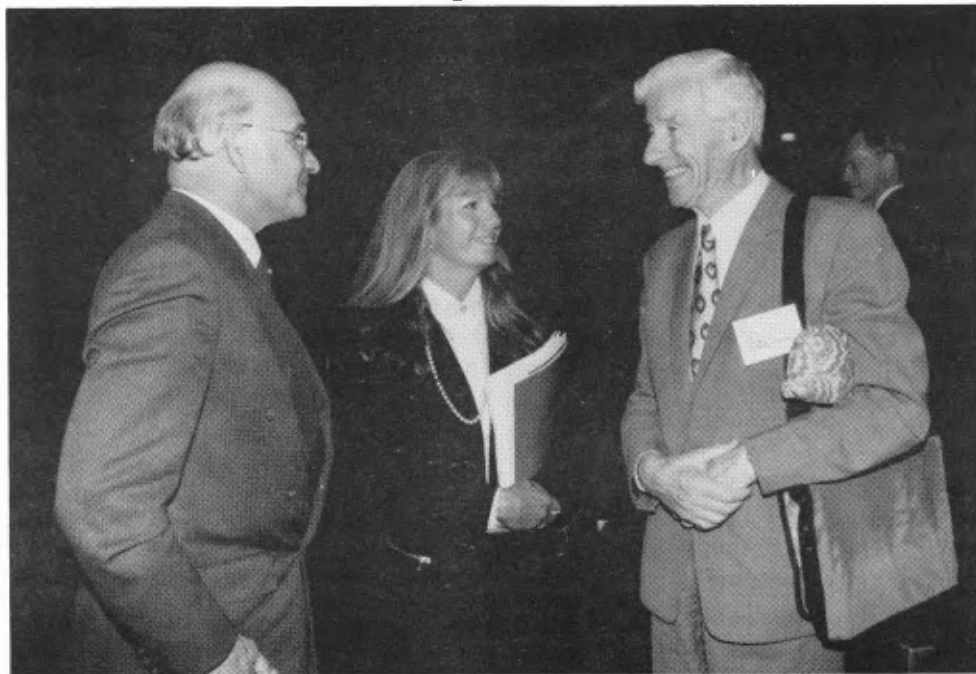
The amyloid protein produced by the APP gene is made up of a long string of amino acids. In this form of familial AD, one amino acid in the chain is improperly substituted by another, which may change the properties of the entire protein and prevent its normal functioning. The faulty portion breaks away from the chain, resulting in the abnormal accumulation of beta amyloid in surrounding tissue.

To learn the effect of this accumulation, scientists in other NIA-supported studies added beta amyloid to mature nerve cells in culture and found that in high concentrations it caused an almost complete collapse of nerve cell growth and function. Scientists recently confirmed this in adult rats, where excess amyloid caused selective nerve cell death. However, in immature nerve cells in culture, beta amyloid had a growth-enhancing effect. Thus, researchers remain unsure of the role of beta amyloid in the normal brain.

"The search for causes of this devastating disease, with particular attention to the genetic component, has been a priority in research on aging," says Dr. Gene Cohen, Acting Director of the National Institute on Aging. While the majority of Alzheimer's cases appear to be sporadic, or unrelated to hereditary factors, up to 20 percent of all AD cases are believed to be familial. In many familial cases, symptoms appear early in life. Sporadic AD appears randomly, usually after age 65.

Alzheimer's disease affects about 4 million persons in the United States, with approximately 250,000 new cases diagnosed each year.

ADI's 7th International Conference Spurs Lively Information Exchange



Seen here taking a break between sessions are: (L to R) Brian Moss, ADI Chairman, Princess Yasmin Aga Khan Jeffries, ADI President, and Michael H. Coote, Honorable Secretary of ADI.

Amsterdam and the RAI Conference Center provided an excellent setting for ADI's 7th International Conference and Annual Meeting. Approximately 400 persons registered for the Conference. ADI President, Princess Yasmin Aga Khan Jeffries participated in the opening ceremonies along with Dr. D. H. Sipsma, Co-chair of the Conference, Dr. Koopman-Iwema, President of the Dutch Alzheimer Foundation, and Ms. H. d'Ancona, Minister of Welfare, Health and Cultural Affairs.

Attendance swelled to nearly 1,000 on the second day, when a joint meeting was held with the Dutch Society of Psychogeriatrics on *The measurement of burden and ways of relieving the burden of caregivers at home*.

The over all Conference focus was on care of the Alzheimer patient in the home and support of the caregiving network. The interdependence of all persons concerned with caring for a patient was emphasized. To quote Dr. Ilenk ter Haar, President of Alzheimer Stichting (hosts for the Conference), "As long as neither the cause nor an effective therapy have been found, the exchange of experiences and learning how others solve everyday problems can be especially helpful."

The Conference comprised an international range of perspectives on caring. Sessions and their chairs included: Svante Svahnstrom, France: *Respite Houses*; Mr. J. Houweling, Geriatrician & Project Leader, Anton Pieck Hofje, Haarlem: *Adjusted Living*; Brian Moss, ADI Chairman and Director, Moorfields Community for Adult Care, Australia: *Environmental Design*; Dr. Nori Graham, Psychiatrist and Vice President of ADI, U.K.: *How to get the G. P. Involved in Dementia Problems*. Free Papers were also included.

Attending to the scientific perspective, in a plenary session, an eminent panel of scientists discussed key topics: Dr. A Kruse, PhD, Institute for Gerontology, Heidelberg, *Psychological Intervention Therapy*; Prof. A. Hofman, MD, PhD, Epidemiologist, Erasmus University, Rotterdam: *Risk Factors for Alzheimer's Disease*; Prof. W. van Tilburg, Psychiatrist, Valeriuskliniek, Amsterdam: *Psychiatric Factors in Dementia*; Prof. Dr. H van Crevel, Neurologist, Academisch Medisch Centrum, Amsterdam: *Diagnostic Assessment in Dementia*; H F. A. Diesfeldt, PhD, Psychologist and Director, Department of Psychogeriatrics, Laren; *The Role of Neuropsychological Assessment; Markers for Alzheimer's Disease*;

Prof. J. Jolles, Professor of Neuropsychology and psychobiology, Limburg University, Maastricht: *Intervention Therapy in AD: Possibilities of Drugs and Memory Training*.

The Conference allowed time for each country member to report on its progress and programs, as well as for dealing with some business aspects of operating a national organization, such as fundraising, volunteerism, and policy making.

Six excursions to Dutch long term care facilities offered participants the opportunity to visit and talk with staff in a broad range of Alzheimer programs in and around Amsterdam. In addition, the gracious Dutch hosts planned social events into the program including a canal boat tour, a visit to the National Maritime Museum, and a sparkling, lively, and memorable Dutch Evening.

1991 ADI Annual Meeting Moves Federation A Giant Step Forward

Alzheimer's Disease International (ADI), is the International Federation of Alzheimer's Disease and Related Disorders Societies, Inc. It has 23 members, national Alzheimer societies, in as many countries around the world. Each year, ADI holds its Annual Meeting in conjunction with its International Conference. Combined into one major event held in September, it is hosted by a different ADI member each year.

In 1991, at its Annual Meeting, ADI took significant steps to promote its own growth by formalizing its Standing Committees. The Committees and their Chairs are as follows: Education Committee, Chair: Dr. Henry Brodaty; Patient & Family Services Committee, Chair: Dr. Nori Graham; Membership Development Committee, Chair: Henry McIntyre; Conference Committee, Chair: Lilia Mendoza; Public Policy Committee, Chair: Jeanne Bentley; Canada; Public Information/Public Relations Committee, Chair: Laurence d'Aramon, France; Bylaws Committee, Chair Evelyn McPake, Scotland; Finance Committee, Chair: Jerome H. Stone, U.S. Each Committee had an opportunity to meet prior to the Annual Meeting and Conference in September to discuss goals and objectives. Notes on Committees' plans will appear in the next issue of *Global Perspective*.

What (In the World) We're Doing...

FUND RAISING

Alzheimer's Disease Society (ADS), in the UK, each year holds a highly successful London Marathon. In 1991, they raised £59,181.75 in sponsorships solicited by 135 runners who "sped, ran, jogged, walked or limped the 26 mile 385 yard course."

ADS also has for sale a line of promotional goods which are available through its branches and support groups. New additions to the line are: quality sweaters, bookmarks, new style mugs, jumbo paper clips, ties and tin badges.

They sell the Cookery Book, and hold a variety of fund raising events throughout the year, including Flag Day and a Holiday Card program.

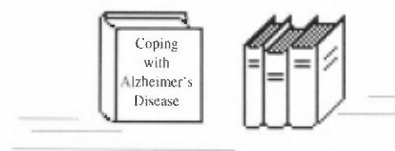
The Alzheimer Society of Canada has its own fund development program that includes individual, corporate and foundation relations, as well as direct mail, special events, etc. However, it recently highlighted two of its affiliates in its newsletter *Esprit de Corps*:

The Alzheimer Society of Nova Scotia enjoyed great success this summer raising both awareness and funds through a Vacation Lottery. The pilot project raised over \$7,000 selling tickets to employees of Camp Hill Medical Centre. The winner received a trip for two to Florida, including air-fare, accommodation, and a rental car, along with an extra week of vacation.

The Alzheimer Society of Toronto claims a little "Horsing Around..." doesn't hurt a bit, especially when it involves their 4th Annual "Racing for Research" program at Woodbine Race Track. The Organizing Committee has set a goal of \$80,000 for the event in 1992.

Alzheimer's Scotland combines enthusiastic volunteer and staff efforts to produce a broad spectrum of snappy fund-raising events that prove successful at two levels: They usually exceed their original goals in raising funds; and, participants have fun in the process! Just a few of their events in 1991 included: Galas, Garden Fetes, a Valentines Day Musical event, Jumble Sales, Walks, a Charity Christmas Card Shop, Street Collections, a Halloween Night Dance, Charity Football Match, Whisky Draws and a Disco/Karaoke Night.

Alzheimer's Association, U. S., also conducts broad-based fund raising which includes, individual donor solicitation, memorials & tributes, direct mail, corporate and foundation solicitation, special events (golf tournaments, galas and other special fund raising events such as Memory Walk, and holiday card sales). Not unlike some other ADI members, the Association has a Marketing and Development Department in its national office, and most of its Chapters have fund raising specialists on staff or as volunteers.



EDUCATION

The Alzheimer's Disease Society in London headquarters office has available excellent educational materials for those who are confronted with Alzheimer's disease. Included are: a booklet titled *Caring for the Person with Dementia. A guide for families and other carers*; a packet of thirteen *Information Sheets*, and a packet of ten *Advice Sheets*. Single *Sheets* may be purchased, or the entire packet, in each case. The Society also offers a comprehensive Starter Pack for those who want to start a Support Group.

The Society has also sent to the ADI library in Chicago, samples of materials that can be most helpful to ADI Members. Included are copies of their: Memorandum and Articles of Association; Rules and Regulation of Membership; Job Descriptions and Employment Contract; Forms used for Society Membership Application and Application for Start up Grants.

PATIENT & FAMILY SERVICES

The U. S. Alzheimer's Association recently completed a phase of its National Respite Care Demonstration Program (NRCDP) which was co-funded by the Association, the Robert Wood Johnson Foundation and the Administration on Aging. The Program comprises a range of

service programs provided to persons with Alzheimer's and their families by some Association Chapters. The programs include Day Center programs, In-home Respite, Financial Assistance, etc. Some are direct services offered by Chapters, others are external programs that are stimulated, encouraged and supported by Chapters. A report on the NRCDP program may be obtained by writing: T. Kirk; Alzheimer's Association; 919 N. Michigan Avenue; Chicago, Illinois 60611 USA.

AWARENESS RAISING

Most ADI members are quite sophisticated in getting the Alzheimer's story out to the public. Some are even evaluating their own effectiveness. Recently, the Worthing Branch of the Alzheimer's Disease Society in the U.K., released its findings from a survey carried out during the Society's 1991 Public Awareness Week:

- 2 out of 3 people questioned had a good idea of what Alzheimer's disease is, but few younger people were aware.
- 7 out of 10 people underestimated the number of sufferers in the District (6,000) and were shocked to hear the true figure.
- 9 out of 10 people said they would approach their GP initially if they were concerned for a relative.

The Alzheimer's Association in the U. S. last year used a "Focus Group" system to study the public's awareness and understanding of Alzheimer's disease. Information showed results not unlike Worthing's.

PUBLIC POLICY ADVOCACY

Public policy will be high on the agenda at the 8th ADI Conference in Brussels.

Australia, New Zealand and the U. S. Alzheimer societies are among ADI members who have written programs recommending changes in public policy to their legislators. Members who are interested in developing their own programs are encouraged to contact them for information.



Please note: Members are invited to send information about 'what we are doing' for inclusion in this column.

Calendar of International Events

MAY 27-JUNE 1, 1992

3rd Meeting of the European Neurological Society; Lusanne, Switzerland. Contact: AKM Congress Service; Clarastrasse 57; CH-4005 Basel, Switzerland. Tel: 41 61 691 51 11, Fax: 44 51 794-507.

JUNE 27-JULY 1, 1992

11th Nordic Congress of Gerontology, Odense, Denmark. Contact: Professor Marianne Schroll Amtssygehuset, P. O. B. 247, DK-4000, Roskilde, Denmark. Tel: 45+63-23-200.

JULY 8-10, 1992

Treatment and Care in Old Age Psychiatry, London, UK. Contact: Mrs. Lee Wilding, Conference Office, Institute of Psychiatry; De Crespigny Park, London SE5 8AF, UK. Tel: 44-71-703-5411, Ext. 3170.

JULY 12-15, 1992

Alzheimer Care Strategies: Practical Approaches, Professional Alliances, Alzheimer's Association, USA, Chicago, IL. Contact: Alzheimer Care Strategies Conference Registration; 500 North Michigan Avenue, Suite 1400; Chicago, Illinois 60611-3796. Tel: (312) 861-1700. Fax: (312) 661-0769.

JULY 12-16, 1992

4th International Symposium on Neural Transplantation. George Washington University; Washington, D. C. Contact: William J. Freed, Neuropsychiatry Branch, NIMH Neurosciences Center; St. Elizabeths; Washington, D. C.

JULY 12-17, 1992

3rd International Conference on Alzheimer's Disease and Related disorders. Padua, Italy. Permanent Secretariat: Dr. Al Snider; Institute for Basic Research in Developmental Disabilities; 1050 Forest Hill Road; Staten Island, New York 10314 USA. Tel: (718) 494-5299. Fax: (718) 494-5360/5269

JULY 19-24, 1992

1st International Symposium on Neurobiology and Neuroendocrinology of Aging, Bregenz, Austria. Topics: Changes in neurotransmission related to aging & Alzheimer's disease, Hypothalamic mechanisms of reproductive aging, and changes of growth hormone release during aging. Contact:

Andrezj Bartke, Dept of Physiology, Southern Illinois University, School of Medicine, Carbondale, Illinois 62901, USA.

JULY 19-24, 1992

25th International congress of Psychology, Brussels, Belgium. Contact: Joan Buchanan, American Psychological Association, 1200 Seventh Street, NW, Washington, D.S. 20036, USA. Tel: (202) 955-7600.

AUGUST 30-SEPTEMBER 3, 1992

Changing Status and Emerging Roles of the Elderly in the 21st Century, Bombay and Pune, India. Sponsor: International Federation on Ageing and the Indian Federation on Ageing. Contact: IFA, Attn: S. D. Gokhale, c/o Kesari, 568 Narayan Peth, Pune 41 1030, India. Fax: 91+212-441667.

SEPTEMBER 2-4, 1992

International Conference on Self-Help/Mutual Aid. Government Conference Centre, Ottawa, Ontario, Canada. For info: Golden Planners, 126 York Street, Suite 404, Ottawa, Ontario K1N 5T5.

SEPTEMBER 22-25, 1992

First International Symposium on Brain Death. Contact: Dr. Calixto Machado, Instituto de Neurologia y Neurocirugia; Zona Postal 4, Apartado 4268 Ciudad de La Habana 10400 Cuba. TEL: Non-dial, 511609.

SEPTEMBER 25-27, 1992

8th International Conference of ADI, Brussels, Belgium. Contact: Belgium Alzheimer Liga; % Dr. Franz Baro, Krijkelberg 1; B-3360 Bierbeek, Belgium, Tel: 32-16-46-0496.

OCTOBER 11-14, 1992

International Symposium on Stereotactic Neuro-Radio-Surgery. Vienna, Austria. Palais Ferstel. Contact: Medizinische Austellungs & Werbegesellschaft; Freyung 6, A-1014 Vienna, Austria. Tel: +43/222/533 2935.

OCTOBER 14-19, 1992

Alzheimer's Association Annual Conference & Meeting, Chicago, Illinois. Contact: Al Williams, Alzheimer's Association, 919 N. Michigan Ave., Chicago, Illinois 60611. Tel: (312) 335-8700.

JANUARY 22-23, 1992

6th Annual Symposium: Genetic counseling & Predictive Testing in Alzheimer's Disease, Huntington's disease & Other Adult-Onset Neurodegenerative Disorders: A discussion of Legal, Ethical and Technological Issues. Queen Elizabeth Hospital, Toronto, Ontario, Canada. For more information, call: (416) 597-3029. Fax: (416) 597-6202.

JULY 4-9, 1993

15th International Congress of Gerontology, *Science for Healthy Aging* in Budapest, Hungary. Topics in aging, including biology; clinical medicine, geriatrics, behavioral and social sciences; practice, planning and policy; multidisciplinary approaches to selected issues. Contact: Gerontology World Congress Secretariat, Budapest Convention Centre; Budapest P. O. Box 233; H-1444, Hungary. FAX: (361) 185-2127. Scientific Information: Tel: (361) 113-5411.

SEPTEMBER 5-10, 1993

6th Congress of International Psychogeriatric Association (IPA), Berlin, Germany. Topics: Neurobiology, neuropsychology, neuroendocrinology; Clinical topics: Services for elderly; Interface between psychogeriatrics, neurology, and other disciplines; rehabilitation in psychogeriatrics, multidisciplinary aspects of diagnostics & treatment strategies. Contact: Congress Secretariat, Gerocon GmbH, Schwalgen-gasse 38-40, 5000 Cologne 1, Germany. Tel: 49-221-219047. Fax: 49-221-231131.

SEPTEMBER 20-23, 1993

ADI's 9th International Conference, *Global Challenge, Local Action*. Alzheimer Society of Canada, Toronto, Ontario, Canada. Contact: Conference Secretariat (416) 925-3552.

SEPTEMBER 1994

10th Annual Meeting and Conference, Alzheimer's Disease International, Edinburgh, Scotland. Contact: Ewan Davidson, Executive Director, Alzheimer's Scotland; 33 Castle Street; Edinburgh EH2 3DN Scotland. Tel: 44-031-226-3762. Fax: 44-31-225-8748.

The Burden on Family Members of People Suffering from Dementia

The following article by Mrs. Mia S. H. Duijnste, Psychologist at Netherlands Institute for Care and Welfare, summarizes the results of her doctoral research as reported at the 8th ADI Conference in Amsterdam.

THE DEMENTED PERSON AND THE PRIMARY CARE GIVER

Usually, the partner or one of the children of a person becoming demented play the key role in care provided at home. They are therefore termed "primary care givers." In this study, the burden on these family members plays the central role.

RESEARCH SUBJECT AND APPROACH

When comparing the subjective burden on primary care givers, the differences can be based in part on the actual differences in the care situation. Thus far, these differences in burden can be understood by an outsider. However, there are primary care givers who perceive more or less identical situations very differently. When something is a problem for one care giver and not for another, there are apparently more factors which influence the subjective burden.

The underlying principle of our study is the difference between objective burden (facts) and subjective burden (the perception of these facts). By establishing the same factual situational aspects of the objective burden for all primary care givers and subsequently investigating how these are perceived, some understanding can be gained of the similarities and differences which occur. This comparison was not, however, our primary objective. Our objective was to find an answer as to why differences arise.

SUBJECT OF THE STUDY

To find what causes the difference between subjective and objective burden, a method is required to access the individual's personal perception of the primary care givers. A qualitative investigation offers the best opportunities for this. We opted for case studies.

In order to develop a concept framework of the intervening factors based on information in the case studies, we combined the analytic induction method and the constant comparative method. The case studies were undertaken as a "relay

TAXONOMY OF OBJECTIVE BURDEN

A guideline was developed to classify, equally, the objective burden on all primary care givers

GUIDELINES FOR PATIENT CHARACTERISTICS:

- **Functional disturbance of demented persons:** Their physical, mental and social functioning we regard as an objective burden which increases in relation to the degree of seriousness and number.
- **Assistance by the primary care giver:** The request for help is determined by the functional disturbances of the demented person. The scope and diversity of the help provided by the primary care giver determine the objective burden.

GUIDELINES FOR CARE GIVER CHARACTERISTICS:

- **Functional validity of the primary care giver:** Physical handicaps reduce the objective capacity and a good functional validity increases the objective capacity.
- **Competing areas of attention:** Task areas confronting the primary care giver, such as job or family, tend to increase objective burden.

GUIDELINES FOR ENVIRONMENTAL CHARACTERISTICS:

- **Financial situation:** Financial restrictions in acquiring modifications and provisions which

race" in which data collection and data analysis alternate. To increase new information, a deliberate search for variation in primary care givers as regards age, sex, and familial tie to the demented person and duration of care was made. On this basis, we attempted to establish major and minor aspects related to intervening factors. We envisaged an impetus to theory shaping and not to theory testing.

INDICATIONS IN THE LITERATURE FOR DIFFERENCES IN THE BURDEN

We reviewed the literature for indications of differences in the burden of primary care givers. For instance, a good relationship between a primary care giver and a demented person before the latter became ill could reduce the burden on the primary care giver. Others point out that caring for a demented person does not necessarily lead to a "sacrifice" by the care giver. There could be material or emotional compensation. Furthermore, the type of family relationship could also affect the burden. Children may be less emotionally involved with the demented person than partners, enabling them to

could ease the task of providing care are regarded as a reduction of the objective capacity.

- **Living conditions:** A living situation aligned to changing and decreasing functioning of the patient increases the objective capacity as does living with the demented person. Where this is not the case, we note a reduction in objective capacity.

- **Social network:** Attention, visits or help from the social network increase the primary care giver's objective capacity to bear pressure. Primary care givers expect more of this from family members than from friends and acquaintances. When expectations are not met and attention, visits or assistance decrease or do not take place, we assume this leads to a reduction in the objective capacity.

- **Professional care:** Assistance provided by district nursing, home help, etc., increases the objective capacity. Absence of professional care, which from the point of view of an outsider is necessary with regard to the remaining characteristics of the objective burden, will make inroads on the objective capacity.

distance themselves more. It is also assumed that duration of care has some influence. As the primary care giver adapts to the situation over time, the burden will be gradually reduced. Other sources suggest a negative effect as over time the burden increases. The literature also notes differences between men and women. Women appear to feel more ensnared by the caring role than men, although men are less familiar with it. Finally, differences in the burden are highlighted as often one care giver can adapt better than another.

INTERVENING FACTORS

The core of our study shows that in addition to objective burden, intervening factors are an important component of subjective burden. Manifested in a wide ranging area, they are often of surprising and varied influence. Coping, acceptance and motivation are common denominators of these intervening factors. These terms represent dimensions. Acceptance, for instance, refers to both the effects of surrender as well as resistance. Further analysis of our research material shows that coping, acceptance and motivation