

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFAREThe meeting was called to order by Senator Roy M. Ehrlich at
Chairperson10:00 a.m./~~p.m.~~ on April 2, 1985 in room 526-S of the Capitol.

All members were present except:

Committee staff present:

Conferees appearing before the committee:

Secretary Sylvia Hougland, Kansas Department on Aging
Dick Hummel, Kansas Health Care Association
Robert Guthrie
Evelyn Sidner
Virginia Burns
Norma Smith
Robert Foster, Alzheimer's and Similar Diseases, Kansas State Association
Linda Wright, R.N.
Marilyn Bradt, Kansans for Improvement of Nursing Homes, written testimony

Senator Reilly made the motion to approve the minutes of March 25, 26, 27, 28, and 29, 1985. Senator Anderson seconded the motion and the motion carried.

SCR-1618 - A concurrent resolution directing the Secretary on Aging to establish a state task force and issue a report concerning the welfare of victims of Alzheimer's disease and related disorders and those who care for them.

Secretary Sylvia Hougland testified briefly and presented written testimony requesting that the Senate Concurrent Resolution 1618 be passed. Attachment I

Dick Hummel testified and presented written testimony supporting SCR-1618. Mr. Hummel stated that the Health Care Association would work cooperatively with the Department on Aging to examine the disease, its impact upon the elderly, and their families, the institution and the State. Attachment II

Robert C. Guthrie testified and presented written testimony supporting SCR-1618. Mr. Guthrie stated the internists and neurologists he has consulted refer to Alzheimer's Disease in the same sense as cancer, cardio-vascular disease, arthritis, emphysema or many other maladies as diseases. Attachment III

Evelyn Sidner testified and presented written testimony supporting SCR-1618. Ms. Sidner's testimony stated that Medicare offers no reimbursement for care, Medicaid is available only after the family has depleted financial resources and reached "poverty level" (which will involve subsidizing caregiver as well as patient care expenses, a few Private Carriers offer very limited and inadequate coverage, Social Security Disability is difficult to qualify for because of existing definitions of retraining and employability, Veterans' Care for veterans under age 65 is not assured because it is a "non-service" related illness and also many veterans' medical centers do not have the facilities nor staff for long term extended care. Attachment IV

Virginia L. Burns testified and presented written testimony supporting SCR-1618. Ms. Burns spoke of her personal situation since her husband was diagnosed as having Alzheimers" in 1974. Attachment V

Norma Smith testified and presented written testimony in support of SCR-1618. Ms. Smith testified as to the difficulties experienced by the persons who care for victims of Alzheimers' disease. Attachment VI

CONTINUATION SHEET

MINUTES OF THE SENATE COMMITTEE ON PUBLIC HEALTH AND WELFARE,
room 526-S, Statehouse, at 10:00 a.m./~~pm~~ on April 2, 1985

Robert E. Foster testified and presented written testimony in support of SCR-1618. Mr. Foster related some of the problems the Alzheimers' Disease patient and their families face. Attachment VII

Linda Wright, RN, testified and presented written testimony in support of SCR-1618. Ms. Wright stated that the state can anticipate an increase in Alzheimers' Disease patients and other related disorders, proportionate to the increase in older persons and that this makes apparent the real and immediate need to address this problem in the state. Attachment VIII

Marilyn Bradt presented written testimony supporting SCR-1618. Attachment IX

Senator Francisco made the motion to pass out SCR-1618 favorable with a second by Senator Mulich. The motion carried.

Meeting adjourned.

SENATE
PUBLIC HEALTH AND WELFARE COMMITTEE
DATE 4-2-85

(PLEASE PRINT)
NAME AND ADDRESS

ORGANIZATION

DICK HUMMEL	KHCA
Robert C. GUTHRIE	ADRDA
Ethel May Miller	QRC/KS.
Robert E. Foster	KASDA
Joy Luffman	ADRDA
Virginia Burns	ADRDA
Eudora Sinner	ADRDA
Norma Smith	ADRDA
JOAN SINGER	Sen Walker office
Tracie Mattini	Sen. Walker office
HAROLD PITTS	TAKTA
Glenn L. Knouse	ADRDA
Lester W. Griffith	ADRDA
John W. Briery	ADRDA
Marcella Bruery	ADRDA
Regina Aldine	ADRDA
Mary Haug	ADRDA
Linda Wright	ADRDA

TESTIMONY ON SCR 1618
TO SENATE PUBLIC HEALTH AND WELFARE COMMITTEE
BY KANSAS DEPARTMENT ON AGING
APRIL 2, 1985

Resolution Summary:

Directs the Secretary of Aging to establish the Kansas Alzheimer's and Related Diseases Task Force and to issue a report of its findings.

Summary Provisions:

1. A task force of 19 members appointed by the Secretary of Aging representative of Alzheimer's victims and their families, and public and private organizations which assist such persons.
2. Report submitted to the Governor and Legislature by January 10, 1986.
 - a. Determine the incidence, prevalence and mortality associated with Alzheimer's and related disorders in Kansas.
 - b. Identify health and social resources which are available to Alzheimer's victims in Kansas. Identify barriers to treatment of the disease.
 - c. Examine problems faced by both victims and families.
 - d. Recommend a course of action for families of Alzheimer's victims.

Testimony:

Alzheimer's disease is a pervasive, degenerative condition that gradually destroys the brain's ability to function. The disease is probably the major cause of severe confusion in the aging population. There are estimates that it may be the fourth leading cause of death in the elderly, exceeded only by cancer, heart disease and stroke.

Alzheimer's victims forget how to perform everyday routine tasks. They forget how to use the language they have always known, and they can not interpret sights and sounds. In the final stages of the disease they are no longer able to perform any purposeful movement. On the average the decline occurs in six to eight years, although the suffering may continue for as long as 20 years. Once the disease strikes, life expectancy is cut in half. There is no known treatment or cure for Alzheimer's disease at this time.

4/2/85
Attachment I

It is important to note that Alzheimer's disease is not only an affliction of the elderly, however. More than 60,000 persons in their late 40's and 50's have been diagnosed as having Alzheimer's. This neurological illness affects between 1.5 to 3 million Americans. Estimates are that 120,000 people die each year as a result of Alzheimer's disease.

The extent of the disease in Kansas is only partially known. One of the responsibilities of the task force would be to assess the number of Kansans afflicted by this disease. More importantly, the task force is needed to study the problems faced by Alzheimer's victims and their families and to identify resources which are available to them, and to somehow support them in their personal tragedies.

Alzheimer's disease can be devastating to the victim's family. Family members are shouldered with an enormous burden as they attempt to render continuous care to their loved one. With few community resources to aid them in their efforts, particularly in rural areas of the state, they are often left alone to provide support and care. Some drive themselves to physical and emotional exhaustion which results in their no longer being able to care for their Alzheimer's victim, thus often necessitating the victim's placement in an adult care facility. SCR 1618 would help provide resources for the families of Alzheimer's victims so fewer people would be forced to place their relatives in institutions.

The Kansas Department on Aging recently released a 30-minute television production entitled, "Living With Alzheimer's." The program was broadcast last Thursday (March 28th) on KTWU-Channel 11. In the film the wife of an Alzheimer's victim stated, "I've accepted ... which is the first thing you have to do ... accepted the condition and accepted that it will get worse and that you can expect that. ... You're doing everthing you can do, everybody else is doing everything they can do. And yet here's this poor person that you knew as a very vital sort of person in more or less a vegetative state, or certainly a childlike state. And you grieve."

Owing to the enormous burden faced by Alzheimer's victims and their families, and to the importance of this issue, the Kansas Department on Aging strongly urges your support of SCR 1618.

SW:mj
4/1/85

A Slow Death of The Mind

Devastating for victims and families, Alzheimer's is now being recognized as 'the disease of the century.'

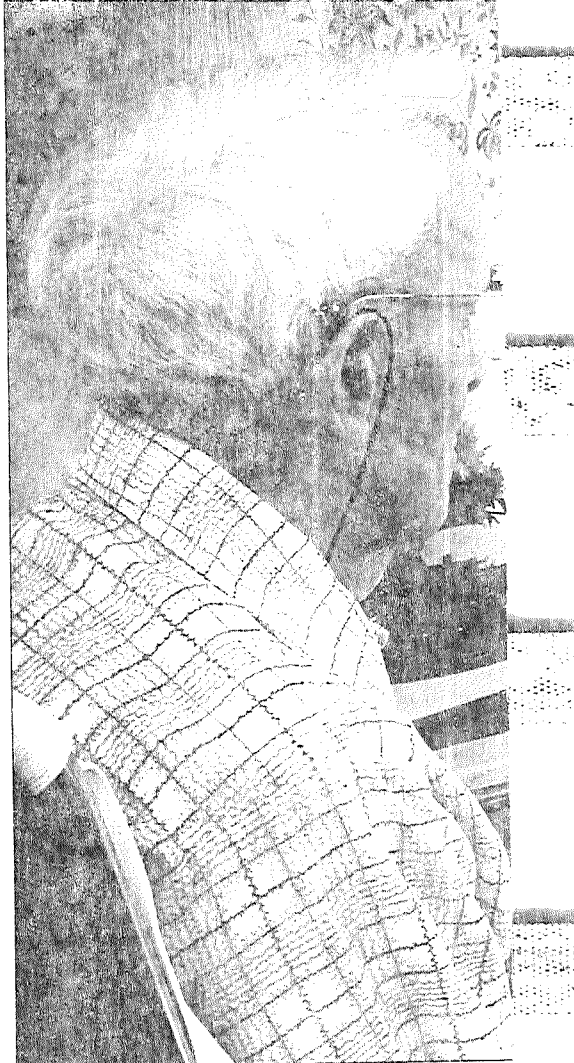
The part where your memory is gone, it's dead. I don't know what's missing. Your thoughts come to a void, and then there's nothing.

—Mildred, a 53-year-old victim of Alzheimer's disease

Of all the incurable diseases, the degenerative brain disorder known as Alzheimer's may be the cruelest, because it kills its victims twice. In Alzheimer's, the mind dies first: names, dates, places—the interior scrapbook of an entire life—fade into mists of nonrecognition. The simplest tasks—tying a shoelace, cutting meat with a knife, telling time—become insurmountable. Then, the body dies. No longer able to walk or control elemental functions, the victim lies curled in a fetal position, gradual-

ly sinking into coma and death. On average, the decline occurs in six to eight years, although some sufferers linger as long as 20. "To lose your mind, your ability to live a constructive life, is worse than cancer," says Elizabeth Reno. "At least cancer is a tangible pain. This disease quietly consumes you." Reno can speak with special insight—she has suffered from cancer, and now has Alzheimer's (box, page 60).

Experts now call Alzheimer's "the disease of the century." It afflicts up to 3 million Americans—about 7 percent of the 27 million people over 65 in the United States are severely disabled by the disease. Actress Rita Hayworth, movie director Otto Preminger and actor Edmond O'Brien all suffer from Alzheimer's, and it has claimed the lives of mystery writer Ross



Memory aids: At Charlwell House, Alzheimer's

MacDonald and artist Norman Rockwell. The causes are unknown. And while medical scientists are beginning to make strides in analyzing the chemical processes of the brain, Alzheimer's remains irreversible. It strikes people of every ethnic and socioeconomic group and the number of cases is expanding apace with the rapid growth of the nation's elderly population. It claims more than 120,000 lives a year, making it the fourth leading cause of death among the old, after heart disease, cancer and stroke.

Anguish: Alzheimer's may be even more devastating for the families of victims. They drive themselves to physical and emotional exhaustion while rendering continuous care, and experience the anguish of seeing a loved one turn into a witless stranger who no longer even remembers who they are. And amid all this, they may see their life savings consumed in the crushing task of caring for a doomed patient. "There's no hope at the end of the tunnel," says Flora Richter, of Palo Alto, Calif., whose 80-year-old husband, Julius, has had Alzheimer's for three years. "It's only going to get worse."

Yet Alzheimer's is a disease that health policymakers somehow overlooked in their grand planning. Neither Medicare nor most private health-insurance programs pay for the "custodial" care its victims need. Before



LESTER SLOVIN—NEWSWEEK

Respite: Patients gather for meeting at Alzheimer's Family Center in San Diego

The following chapters or support groups of ADRDA (Alzheimer's Disease and Related Disorders Association) have indicated their support for SCR 1618:

Arkansas City - Robert Fletcher - Alzheimer's Disease Family Support Group
Chanute - Ella Ranz - Alzheimer's Disease Family Support Group
Coffeyville - Sue Sprague - Alzheimer's Disease Family Support Group
El Dorado - LaNora McAdoo - Alzheimer's Disease Family Support Group
Hays - Mary Brown - Alzheimer's Disease Family Support Group
Lawrence - Judy Dailey - Alzheimer's Disease Family Support Group
McPherson - Lisa Loeffler - Alzheimer's Disease Family Support Group
Manhattan - Kevin McFarland - Alzheimer's Disease Family Support Group
Ottawa - Margaret Hutchins - Alzheimer's Disease Family Support Group
Pratt - Rebecca Harrel - Alzheimer's Disease Family Support Group
Wichita - Robert Foster - Support Group *
Hillsboro/Marion - Jan Eitzen - (Support Group Forming)
Kansas City - Linda Wright - Chapter ADRDA
Topeka - Norma Smith - Chapter ADRDA

* This active group is not associated with ADRDA.



The Organization of
Nonprofit Homes and
Services for the Elderly

Kansas Association of Homes for the Aging
One Townsite Plaza
Fifth and Kansas Avenue
Topeka, Kansas 66603

913-233-7443

TESTIMONY FOR SENATE PUBLIC HEALTH & WELFARE COMMITTEE

SENATE CONCURRENT RESOLUTION REGARDING ALZHEIMERS TASK FORCE

By John Grace, Executive Director
Kansas Association of Homes for the Aging

Thank you Mr. Chairman and Members of the Committee.

The Kansas Association of Homes for the Aging is a non-profit organization that represents the community, religious, and governmental not-for-profit adult care homes, retirement communities and social services for older adults of Kansas.

Our association supports the Senate Concurrent Resolution No. 1618 creating a state task force on Alzheimer's Disease.

The older person entering and residing in adult care homes are increasingly more frail and disabled than ever before. It is estimated that nearly 70% of the adult care home population have significant degrees of mental impairment.

Alzheimer's Disease is a disorder that is receiving widespread attention. More and more residents are being diagnosed with this ailment, for which there is no cure.

We will work cooperatively with the Department on Aging in examining the disease, its impact upon the elderly, their families, the institution, and the state.

Hopefully, we will arrive at some meaningful and constructive methods of addressing the problem of Alzheimer's Disease.

Thank you.

4/2/85
Attachment II

Topeka, Kansas
April 2, 1985

Senate Concurrent Resolution No. 1618

By Senator Ehrlich

Hearing before the Public Health and Welfare Committee on the creation of the Kansas Alzheimer's and Related Diseases Task Force.

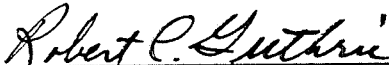
Senator Ehrlich and Committee Members:

My brief remarks are made as a member of the Alzheimer's Disease and Related Disorders Association, Topeka Chapter; as a native Kansan with a deep concern for the tragic problems brought about by this malady; and finally and most sadly, as the husband of a bright, vivacious woman, active in many community, church and civic affairs, who in her sixties has been stricken with Alzheimer's Disease.

Your Concurrent Resolution No. 1618 efficiently covers the wide range of concerns the disease creates. I need not repeat them now.

I do wish to state that my internists and neurologists refer to Alzheimer's as a disease in just the same sense as cancer, cardio-vascular disease, arthritis, emphysema or many other maladies are diseases. Alzheimer's can strike people in their forties or fifties as well as in later years.

Again, as a concerned citizen, who has served on many Boards for the health and welfare of the less fortunate over the years, I urge the passage of the Resolution and the appointment of the Task Force under the direction of the Secretary of Aging at the earliest date possible.



Robert C. Guthrie
3000 W. 19th Street
Topeka, Kansas 66604

4/2/85
Attachment III

April 2, 1985

TESTIMONY TO: Senate Public Health and Welfare Committee

PRESENTED BY: Evelyn Sidner (wife of victim of Dementia/Alzheimer's Type)
10108 W. 96th St. #B
Overland Park, KS 66212
(913) 492-5228

SUBJECT: Senate Concurrent Resolution #1618 introduced by Senator Roy Ehrlich
Re: Establishment of a task force charged with submission of a
report concerning the welfare of victims of Alzheimer's Disease
and related disorders and those who care for them. "

TESTIMONY: The first symptoms of Dementia/Alzheimer's Type presented in 1968, when
my husband was 52 years old.

A presumptive diagnosis was made in 1976, following his retirement as
Assistant Chief of Real Estate, U.S. Postal Service, Kansas City Area.

I cared for him at home until admission to Colmery-O'Neal VA Medical
Center in Topeka in August of 1980, where he still continues to be a
patient.

Since his admission I have been active in ADRDA (Alzheimer's Disease and
Related Disorders Association) at local, state and national levels. I
have had the opportunity to work and share with hundreds of afflicted
families their frustration and discouragement.

Although our researchers are making phenomenal progress in their efforts
to find cause, cure, prevention and treatment of progressive, irreversible
dementias, until answers have been found, the number of affected persons
and their families will increase at an alarming rate, compounding the
problems.

Our needs need to be identified and addressed NOW!

I request and strongly urge your affirmative action on this resolution
which demonstrates your concern and caring about the plight of many
citizens throughout the State of Kansas.

Information relative to a few of the major problems is given in
ATTACHMENT A.

Thank you for your interest and consideration.

Respectfully submitted,



Evelyn Sidner

ATTACHMENTS A and B

4/2/85
Attachment IV

ATTACHMENT A - SPECIFIC ISSUES AFFECTING VICTIMS AND THEIR FAMILIES

- 1) Some physicians need more information about the scope of irreversible, progressive dementias and the precise diagnostic procedures required for a presumptive diagnosis which will identify other kinds of dementia that can be treated.
- 2) Health-care providers, professional and non-professional, need more information and training in understanding and managing neurological-demented persons.
- 3) Services provided by agencies need to be coordinated.
- 4) The entire community needs to be made aware of the responsibilities which, "directly affect all of us through support systems and tax support.
- 5) Financial impact on afflicted families can be devastating and lead to bankruptcy -
 - a) Often the victim is the sole or principal wage-earner of the family. There is no other source of income to meet the expense of patient care and the day-to-day financial needs of the family. This eliminates any possibility of their taking advantage of assistance through home health care, day care and respite care. Many companies do not provide retirement or pension income.
 - b) MEDICARE offers no reimbursement for care, MEDICAID is available only after the family has depleted financial resources and reached "poverty level" (which will involve subsidizing caregiver as well as patient care expenses), a few PRIVATE CARRIERS offer very limited and inadequate coverage, SOCIAL SECURITY DISABILITY is difficult to qualify for because of existing definitions of retraining and employability, VETERAN'S CARE for veterans under age 65 is not assured because it is a "non-service-related" illness and, also, many Veterans' Medical Centers do not have the facilities nor staff for long-term extended care.
 - c) Often the home caregiver cannot seek employment outside of the home because of the confining responsibilities of caregiving.

Some caregivers have, with extreme agony, had to resort to divorce to insure providing care for their loved one and maintain an existence for themselves.

d) Children of victims have had to abandon plans for higher education and go to work to supplement the family income. In many cases, this has caused alienation within the family and the children have "walked out."

Married children, with families, have had to supplement the caregiver's income causing great hardship to themselves.

e) Caregivers, particularly among the elderly - though not exclusively, become ill and must rely on government financial assistance for their care and support.

ATTACHMENT B - EXISTING SUPPORT SERVICE NETWORK IN KANSAS

ADRDA/TOPEKA CHAPTER

ADRDA/GREATER KANSAS CITY AREA CHAPTER

KASDA (Wichita) state organization

Independent Family Support Groups (assisted in facilitation and service by ADRDA)

Arkansas City	Lawrence	"
Chanute	Leavenworth	
Coffeyville	McPherson	
Colby	Ottawa	
El Dorado	Pittsburg	
Great Bend	Pratt	
Hays	Salina	
Junction City	Sterling	

Contact Persons -

Beloit
Hillsboro/Marion
Hutchinson
Newton
Prairie Vie

The National Department of Health and Human Services, through the Administration on Aging has been most helpful in cosponsoring educational workshops, forums and seminars for families and professional health-care providers. Through the Area Agencies on Aging, they have cooperated in facilitating Family Support Groups.

THERE IS AN URGENT NEED TO EXPAND SUPPORT SERVICES TO ALL RURAL COMMUNITIES IN THE STATE OF KANSAS.

April 2, 1985
PUBLIC HEALTH & WELFARE COMMITTEE
SEN. ROY ERLICH - CHAIRMAN

Joe D. Burns
4000 W. 98th Terr.
Overland Park, KS 66207
913-648-2123

Joe and I have lived at this address for almost 25 years. We have been married for 35 years. We have 3 adult children. Joe is an Electrical Engineer, having been employed by AT&T for 28 years before his illness. He is a graduate of Illinois University.

Joe was diagnosed in 1974 at age 50. He is now 61. As we now know more about the disease, we can be reasonably sure that his illness must have begun several years before diagnosis. We began to recognize his forgetfulness, difficulty in doing routine things and general frustrations with life. But we really thought that it was connected with his job which at times could be very stressful and demanding. It wasn't until his employer told him that his performance wasn't up to par that we became concerned. He was admitted to St. Luke's Hospital in KC and after extensive testing was told that he had "presenile dementia". Early retirement was suggested by his doctor but AT&T would not allow him to return to work at all. Of course, at age 50 you plan to continue working for a few years and then enjoy a pleasant retirement. But that was not to be. It wasn't until a year later when I requested a letter of permanent disability for the IRS from the doctor that the term Alzheimer's was applied to his illness. Because of his illness, he was deprived of at least 15 productive and financially rewarding years. At this time he has completely lost his ability to speak, can do nothing for himself and has lost control of all bodily functions. He makes a constant parakeet type noise which we assume is his form of communication. His general health is excellent and his remaining years is a guess.

Not only has he been deprived of working but as the disease has progressed friends and in some cases family have stopped coming. I didn't understand the disease and our doctors gave us no information as to what would happen to him other than it would result in death. We went $6\frac{1}{2}$ years thinking he was the only one in KC suffering from this as we were told that it was extremely rare. There was a time I considered suicide. I know because of my deep religious feeling and my desire to live, that I was really asking for help that was not available to me. It wasn't until 1981 when our ADRDA was organized that I received any information about the disease or that there were others in our area with it. I care for Joe at home but I really don't believe that I could continue to do that if it wasn't for the support and understanding that this organization has given to me. We have grown from a few people at our first meeting to a mailing list of around 3000. Now I know that the disease is not rare and that I did nothing to cause it. The guilt, frustration, loss of self respect and despair that you feel is almost devastating. At this time there is no known cause. Only the symptoms can be treated and you wait for death.

Because Joe can not be left alone it is impossible for me to work. I care for Joe at home because I love him and want to keep him at home. But, also you must realize that nursing home care is most expensive. If I were to place him, it would in all probability be impossible for me to get a job that would pay for his care, because at this time I am 58 years old. I know about age discrimination, but what is written and what is practiced are two different things. Even at age 47 when his illness began, I found it difficult to find a job. I was employed by the Shawnee Mission School District for 5 years

4/2/85
Attachment V

but was forced to quit because of the progression of his disease.

Also, Medicare does not pay for Alzheimer's patients. I am currently asking Medicare for a review of a claim. Because Joe can no longer get up and down I purchased a seat lift chair for him. This is really necessary for him and also for me. He was turned down not for his lack of need, but for having the wrong name applied to his illness. When Medicare doesn't pay our tie in plan also doesn't pay. When he was admitted to St. Luke's Hospital in 1984 for a CAT scan I was told that if I put down the reason as Alzheimer's that Medicare would not pay for it. We put down disoriented and confused and they paid for all of it.

Holidays are no longer a joyous occasion at our home. Even if some of our children are able to be at home, it is very depressing for them to see their father in the condition that he is. They have lost their father. The loving caring father is gone even though the body remains. When our daughter was married in 1979, he walked her down the aisle, crying very loudly. Last May when she married for the second time, he was in a motel with a sitter and our oldest son walked her down the aisle. Another son was recently married in Texas and again he was not able to participate and was cared for at a relative's home.

Socially I am an outcast. I think of myself as a widow with a husband, a social leper. I am not socially acceptable to singles or couples. If it weren't for the friends I have in ADRDA, I wouldn't have many friends. They share and understand my feelings.

It is because I can speak first hand about the help ADRDA has given me that I urge you to pass this bill to appoint a Task Force. By becoming united in a state effort we can determine the number of families affected by this disease, and perhaps attend to their needs more effectively.

Virginia L. Burns

I am Norma Smith the wife of a Alzheimers Victim.

I feel the Resolution #1618 introduced by Senator Ehrlich, states very well some of our problems.

I can only tell you what it's like for the Breadwinner, to become totally disabled at age 45.

What it has done to our family. How very hard it is for our children to accept what has happend to their Father. Some of the children still will say "I know something is wrong with Dad but it can't be Alzheimers. The docters are wrong!"

AS the caregiver it is at least a 36 hour day. I have had help from the children when my husband was at his worse. One of us was at home while the other one worked. The most help of all has been through our support group. You have to make new friends as your old friends quit coming around, they don't know how to handle their old friend has changed.

How do you tell your Grandchildren what is wrong with Grandpa.

The worry about what will happen to our children & grandchildren if this disease is inherited.

At the rate it's being diagnosed I or 2 of our children, by age 65 And 4 of our 16 grandchildren will most likely be victims.

This is without any chance of it being inherited, the chance is much greater if it proves out to be inherited.

How many people fall through the cracks in our present assistant programs.

The breadwinner in our case is on medicare & plan 65.

While i was working i had health insurance.

The past 6 months i have been disabled. I do not qualify for Social Security I am mentally able to work.

I do not qualify for welfare as social security of less than \$500. is to much income. We are not able to get supplement security for my husband gets .60 cents a month to much. Our medicine alone is approx \$100. per month.

*Norma Smith
325 Alkie
Topeka Ks
66607*

*4/2/85
Attachment VI*



ALZHEIMER'S AND SIMILAR DISEASE (THE SILENT EPIDEMIC) KANSAS STATE ASSOCIATION

Phone: (316) 261-9099

P.O. Box 2763
Wichita, Kansas 67201

An Independent Association Meeting Kansas Needs

FACTS ABOUT ALZHEIMER'S DISEASE

1. Approximately 50% of patients with dementia have Alzheimer's type.
2. Affects 2 million Americans.
3. Fourth leading cause of death after heart disease, cancer and strokes.
4. Accounts directly or indirectly for 120,000 deaths per year.
5. The long term care costs were estimated at 26 billion in 1981.
6. By 1990 Health Care Finance Administration projects nursing home care costs to be 78 billion dollars.
7. These costs are expected to increase substantially by year 2000.
8. Dr. Robert Terry, Chairman of Department of Pathology at Albert Einstein College of Medicine said "if we do not control this disease, it will eventually bankrupt us."

SOME OF THE PROBLEMS THE ALZHEIMER'S DISEASE PATIENT AND THEIR FAMILIES FACE ARE:

1. Families not able to find outside support system.
2. No respite care available.
3. Custodial care for patient--not available, too expensive, or inadequate training.
4. Medicare does not cover long term care in nursing home.
5. Private insurance does not cover because Medicare does not cover.
6. Nursing home personnel in many cases not trained to care for Alzheimer's patients.
7. Nursing homes will not accept Alzheimer's patients or will find ways to move them out if they are hard to care for.
8. Some have problems getting an accurate diagnosis of their problem.

We believe an Alzheimer's Disease Task Force is needed in Kansas to gather information on the problems Kansans are facing, numbers of victims and care costs in Kansas. This should help plan a course of action for the State of Kansas to take to help combat the problems that arise from Alzheimer's Disease.

Robert E. Foster
5317 E. Kinkaid
Wichita, KS 67218
1-316-684-2662

4/2/85
Attachment VII

April 2, 1985

Testimony in support of:

Senate Concurrent Resolution #1618

Linda Wright, R.N.

Five percent of Kansans over the age of 65, and 20% over the age of 80 may be so affected by memory loss, confusion, and impaired intellect that they are unable to function as a family member, friend, or community participant. These persons have a physical illness which affects the body's most vital organ - the brain. The illness, Alzheimer's Disease or a related disorder, eventually leads to a totally dependent state, leaving family caregivers drained physically, emotionally, and financially. Most often, the illness will lead to institutional placement and may account for half of the older adults residing in these facilities.

While this illness is not exclusive to the population 65 and older, this is the age group which is most often affected. From 1970-1980, Kansas had an increase in excess of 15% of those persons age 65 and older. In addition, the state reported a remarkable 40% increase in those adults 85 and older. Based on these statistics, Kansas can anticipate an increase in Alzheimer's Disease and related disorders, proportionate to the increase in older persons. This makes apparent the real and immediate need to address this problem in the state.

Through formation of a Kansas Alzheimer's and related disease task force, the first steps can be taken to define the scope of this illness in Kansas. There is a need to assess the resources available for affected persons and their families and to evaluate ways we might better serve these citizens. These are citizens who formerly gave to the community and who now, due to the tragedy of an illness as yet without a treatment, as yet without a cure, can no longer help themselves or others.

I encourage the committee's support of this resolution on behalf of the many Kansans who are affected by this disease and on behalf of their families who must cope with the most difficult realities of this illness.

4/2/85
Attachment U